SOCIETAL HEALTH
NOTEBOOKS

What have we learned from the pandemic?

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Defining Societal Health

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1.

Societal Health: An inclusive approach to health knowledge

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A definition of Societal Health is necessary at the beginning of Iscte-Health, as something that is simultaneously aggregating, provocative, but also points a way forward. Without defining this concept, necessarily under construction, we may lose ourselves - the more than 30 teachers and researchers who have already mobilized at Iscte around health and our stakeholders - in the maze of complexities that a holistic approach to a cross-cutting theme in society always places. It makes no sense, however, to build and define concepts in a void when, in the silence of past years, the Iscte was "doing" Health. In its own way, there was and there is Health at Iscte! Thus, from the collection of dozens of small lights and their alignment a strong lighthouse is made. If we open this text conceptualizing, in an incomplete way, the cut of it, we close to gather, highlight and align the small lights that already gave Iscte visions and actions on health and society.

A CONCEPT IN THE MAKING

Societies have evolved to secure basic needs, created complex human structures of government and control, expanded human presence over the entire planet and beyond the moon, and yet, continue to struggle to successfully deal with common diseases such as the flu or deadly loneliness. Medical science has reached incredible achievements such as brain implants or the removal of kidney stones via the application of ultrasounds, and yet, many members of the human society die from domestic violence, obesity, or only plain sadness. From the start of the 21st century to its first quarter, as we dive through one of the world's largest and deadliest pandemic to hopefully reemerge soon, we begin to acknowledge that the *health of nations* – not just *the wealth of nations* (Smith, 1776) – is of paramount importance to humankind, and to the fulfillment of truly advanced states of civilization. Perhaps, even more importantly, to happiness.

The health landscape is undergoing unprecedented transformations. It is becoming more digital, integrated, global, personalized and focused on citizens' engagement and empowerment. The traditional bio-medical paradigm has increasingly shown its limitations and how unfit it is to address by itself current and future challenges in health. The integration of social and technological sciences will

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bear groundbreaking contributions to addressing such challenges. Drawing upon this multi-level and interdisciplinary approach, merging social and technological sciences while engaging and empowering people and communities (WHO, 2016), it is possible to tackle major societal health challenges. This approach also protects citizens' rights not just to healthcare but to live healthy lives and be actively involved in the development and implementation of health policies and other health decisions that affect them.

The concept of **societal health** – focusing on the external determinants of health – derives partially from the multi-level approach of the social determinants of health framework proposed by WHO (2020). These social determinants are "the non-medical factors that influence health outcomes. They are the conditions in which people are born, grow, work, live, and age, and the wider set of forces and systems shaping the conditions of daily life. These forces and systems include economic policies and systems, development agendas, social norms, social policies and political systems". This perspective stresses the fact that certain populational subgroups, particularly those who are less empowered and have lower socioeconomic status, tend to live and work in more degraded environments and have a higher exposure to risk

factors for disease, as well as to the physiological impacts from chronic stress (Andermann, 2016). For example, in Europe persons with a lower level of education are over 3.12 times at risk for depression and 2.36 times for diabetes than those with a higher level of education (McNamara et al., 2017). These inequalities are the result of multiple levels of determinants that act simultaneously. Population health is linked to - and explained - by a range of societal factors and conditions, from gender, family and social support, neighborhood conditions, work environment, community involvement and social cohesion, availability and access to social services - such as education and health - to the overall class and particular conditions or factors of the political structure that lead to good or ill health. That is why Sir Michael Marmot called them the "causes of the causes" (Marmot, 2005, p. 1102).

The concept of societal health derives from the multi-level approach of the social determinants of health framework proposed by WHO

Taking a societal perspective to health, we intend to stress three other dimensions that are not explicit in the social determinants' perspective. The first is to make unequivocal the **political and structural forces underpinning health choices**. As Birn (2011) puts it "social determinants of health generally refer to interactions among people and communities, whereby public policies and private sector actions shape hierarchies of exposure to factors that determine health. Societal determinants of health, by contrast, refer to the political-economic order and structures of power' (p. 38) It includes the deconstruction of the different public health discourses and policies, and their impact on the persistence of inequalities in the health system. For example, in 2001 a first important step took place in Portugal when innovative legislation was passed to secure the universal access to the National Health Service for documented immigrants, under the same conditions Portuguese citizens enjoy. The same legislation entitled undocumented migrants' free access to healthcare in situations of public health endangerment (Despacho 25360/2001 from the Ministry of Health). More recently, as part of the public response to the COVID-19 pandemic, a significant upgrade to the legislation was passed, with the Portuguese Government granting access to the NHS for all migrants and asylum seekers with pending applications within the Immigration and Borders Service (SEF) to ensure no one was left behind. This pragmatic and clearly inclusive public health policy is opposed to the traditional perspective that positively discriminates access to healthcare and excludes and discriminates against immigrants and it is associated with a strong political statement in favor of human rights. This type of analysis is an overarching political perspective on health choices. If the social determinants of health can be seen as the "cause of the causes",

the societal approach adds one level: 'the causes, of the causes of the causes of health' (Birn, 2011).

Another aspect that a societal health approach addresses is the **digital transition**, a major issue for the next years with huge impact on healthcare. There is a global need for a new healthcare system organisation. The will for transformation was dormant, and the need has become prominent with the COVID-19 pandemic. Digital solutions are shaping eHealth (von der Leyen, 2019) adding value to 20th century-born healthcare systems. Developing and deploying eHealth services that fit into and optimize existing healthcare systems is crucial to improve their performance, accessibility, comfort and efficiency – but it is not the same as a digital-first healthcare (Martins, 2020). A digital-based healthcare system is much more than using sophisticated information systems wisely (Ribeiro 2019) or undergoing digitalisation of healthcare (von Eiff & von Eiff, 2020). It goes further than merely achieving a stage where citizens have full access to their health data and better access to more effective and comfortable care or improving system efficiency and sustainability through digital support. The digital transition is about creating digital solutions, securing inclusion mechanisms, increasing digital literacy, and embedding technologies in urban and domestic settings as socio-technical architectural elements, recognizing its inherently complex social matrix. Only with societies' acceptance and co-creation - elicited through the use of anthropological, sociological and psychological know-how and know-about – will disruptive technologies such as interconnected wireless medical devices, artificial intelligence or full human-computer brain-machine interfaces be useful and not just another gadget or technical innovation without societal health value. First, 'do no (digital) harm'; digital threats to human health and dignity can come from misuse or abuse of digital health technologies, as any other impactful human invention. An increasing number of scientific reports point out the dangers and damaging effects of digital technology to health. In this regard, digital and health literacy can work as a powerful digital vaccine. However, its distribution is limited, its scope is narrow and with respect to incentives and political visibility, it has been surpassed by the glamour of AI in health, or Robotic physiotherapist care. On one side, human dignity may be at risk regarding privacy matters in robotized clinical decisions, because of cybersecurity breaches. On the other side, it is also at risk when waiting times of two years for a dermatological consult are not cut to two months by using simple teledermatological screening. High-quality solutions, adequate regulations and robust oversight strategies are some of the

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ways required to mitigate the risks of the digital health transition and thus achieving a positive benefit-risk relationship in this field.

Around the globe, people's health has never been so at risk. As air travel and globalization peeked, so did the risk of cross-border health threats. At the same time, G5 technology, satellite internet and artificial intelligence are linking us on a **global scale**. Deadly viruses can spread through the world in a matter of hours, leaving behind a trail of death. Similarly, the harmful WannaCry cyber virus in 2017 crippled many sectors, including healthcare. Chained globalization in health today (Hunter & Fineberg, 2014) means to think digitally and to think societally. Because these social and technology chains are both the enablers and restrainers of future human action, there cannot be a global approach to disease and health promotion without a tremendous effort to create links, interoperability of people, processes and information systems. Only through those means, can orchestrated strategies emerge to address common needs and perspectives on health and disease, either at a local, regional or worldwide scale. This is by no means a task for one single disciple – nor should Medicine be left alone do deal with these health challenges.

Lastly, the societal approach to health is based on **collaborative research**. This collaboration is either associated with different scientific fields or with different stakeholders. Promoting interdisciplinary research is a major goal, as health issues benefit from being addressed by different disciplines. Moreover, several authors advocate that innovation in research requires interdisciplinary collaborations (Gohan, et al. 2019; Kivits et al., 2019). Collaborative research is also about co-production of knowledge, i.e., the engagement of researchers with the various healthcare stakeholders – including members of the public – to share their respective knowledge and co-create new ideas, methods and frameworks to address health issues. Co-production has the goal of creating new, jointly generated knowledge that is more relevant and well-suited to inform health decision-making (Rycroft-Malone et al., 2016), and consequently, to better meet people's needs and social preferences (WHO, 2016). ISCTE has a long tradition of working together with patients' associations or specific vulnerable populations (e.g. Portuguese Refugee Council; Portuguese High Commission for Migration; caregivers, persons with disabilities). Some of ISCTE´s work in this domain resulted in the co-creation of specific technological solutions to promote the inclusion and quality of life of vulnerable groups (e.g., OLA FP7, on technological solutions for caregivers; SIFORAGE FP7, on the technological inclusion of older citizens).

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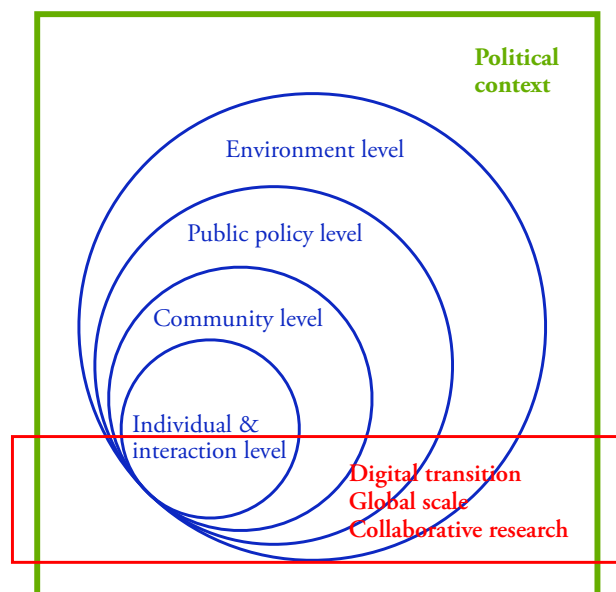
Figure 1. Societal model of health (inspired by Solar and Irwing, 2010)

In summary, from a perspective of social determinants of health, the societal approach to health implies that health is examined at **different levels of analysis**, including individual and group factors, community, public policy and environment levels (Richard et al., 2011). This perspective assumes a complex view of the relationship between individuals and their social context, exploring the interconnection between different cultural, social, economic, political and historical factors (Burke et al., 2009). In addition, there are three key transversal dimensions that introduce change at each level of the proposed model: digital transformation, global scale and collaborative research.

This conceptual frame will guide future ISCTE_Health initiatives. We call this approach the 'societal health', because it enlightens the social factors that frame health, but also includes major challenges facing society today, such as digitalization, globalization and citizen empowerment.

CONTRIBUTIONS AND THOUGHTS FROM ISCTE'S RESEARCH

In the last decades, ISCTE has developed an impressive set of training and research in the domain of societal health with important partnerships within society. Besides having followed about 140 students in the last 5 years in

the postgraduate program for Health Professionals form Indeg, 150 in the Master of Health Services Management, also from Indeg, and 120 in the Master of Health Management from Iscte Business School, the DBA program of Iscte, together with two Chinese Universities, meant the successful conclusion of 45 doctoral dissertations prepared by doctors on themes of Health Care Management, in a fruitful partnership with Southern Medical University in Shengdu (China). A brief analysis of these PhD theses shows that 21 relate to general healthcare themes and 6 focus on digital health problems. Hospital Management topics were worked upon on 29 theses, whereas 16 looked at aspects related to human resources management or clinical workflow. A horizontal analysis shows that 21 theses are somehow relevant to digital and global health issues.

Iscte has developed an impressive set of training and research in the domain of societal health with important partnerships within society

About 20% of all ISCTE scientific production in scientific papers or research projects is on the topic of health. Areas such as Management of Healthcare, Sociology of Health, Public Health Policies, Health Psychology or Technologies in Health have been growing in the last years, with a relevant number of projects and researchers. To face the future challenges of health, fundamental questions need the contributions of social and technological sciences:

› How can the effectiveness, efficiency and sustainability of the health system be promoted in a digital and global world?
› How does communication, education and participation impact health literacy?
› How can consistent behavior change towards healthy lifestyles be promoted, using digital instruments in a collaborative way?
› How can new technologies be used to create more inclusive public health policies and to reduce inequalities in health?
› How can health services be co-designed with the involvement of healthcare users/patients, as well as health professionals', in order to better meet needs and respect social preferences?

The research produced at ISCTE has already delivered many important contributions to answering these questions. In order to collect information on these achievements and the actors that contributed to the development of knowledge in the health domain at ISCTE, an invitation was sent to all ISCTE teachers and researchers to join this initiative. Forty persons from the four Schools at ISCTE – School of Social Sciences and Humanities, School of

Sociology and Public Policies, School of Technologies and Architecture, and Business School – answered this call. They were then asked to briefly describe their research in the domain of health. The following section of this paper summarizes the contributions received and is divided into seven sections:

1. Promoting health and healthy lifestyles
2. Reducing the burden of chronic illnesses and improving health-related quality of life
3. Reducing health inequalities
4. Improving efficiency of health services in the context of societal health
5. Locating the improvement efforts within the hybrid nature of healthcare organizations
6. Actively searching for optimization approaches to the planning of healthcare delivery
7. Preparing health professionals, managers and funders for better decisions

Twenty-eight contributions were received from teachers, researchers and PhD students from ISCTE in the fall of 2020. It is an incomplete sketch of our production, but still an impressive image of our potential and a first attempt to move from discipline-focused writing to integrated research writing-up around Societal Health.

Promoting health and healthy lifestyles

The Societal Health perspective assumes a preventive and health-promoting approach. The research that has been developed at ISCTE is a good example of this broader and socio-ecological perspective of health. Some of the most relevant contributions in this field are precisely at a societal level of explanation, trying to articulate an analysis of public policies with community and social practices in the field of health. Good examples of this work are related to the analysis of the current pandemic situation of COVID-19. In this regard, the work of Maria Antónia Pires de Almeida (2013, 2014) offers an important contribution by analyzing the public policies of the various countries in relation to the multiple pandemics that have occurred throughout history. In this analysis, the author demonstrates how certain patterns in responses to pandemics are repeated over time and places, demonstrating the importance of analyzing these phenomena in the light of a historical framework.

In the *Long-Term Care Homes COVID-19 Crisis* project, Luís Capucha (2020) analyses the public policies followed in this period and their articulation

with the responses to a particularly vulnerable population: older people in residential care homes. In a framework marked by a strong and rapid aging of the population, the report detects important flaws in the coverage rates of the various facilities for older people provided for in Portuguese legislation, as well as important weaknesses in the quality of services provided in much of the network, and especially the large scale presence of illegal residences of increasingly inferior quality. The report concludes that it is necessary to review the political management model of facilities for older people and to clarify the mission of residential structures for aging in relation to the provision of continued healthcare.

The research that has been developed at ISCTE is a good example of this broader and socio-ecological perspective of health

Still on the topic of the COVID-19 pandemic and its impact on older populations, Sibila Marques and collaborators (Filipe, Marques & Cunha, in prep) analyze representations in the main online newspapers in Portugal in relation to this age group. In this analysis, the authors demonstrate how ageist views have become salient during this period, revealing a view of older people as a homogeneous group of sick people, unable to cope with the challenges of the pandemic. Knowing how ageism towards older people (i.e. negative attitudes towards older people due to their age) has relevant implications for their health and well-being (Marques et al., 2014; Marques et al., 2015; Marques et al., 2020) this paper is an important example of how articulation between levels of analysis can be fundamental to understanding health and disease.

The articulation between different levels of analysis in health promotion is also a constant in ISCTE's research when analyzing other subjects. The work of Helena Rodrigues and collaborators (2019) on thermal tourism supply, demonstrates how this activity can be a relevant economic source for Portugal, while promoting the creation of a health focused community, both nationally and internationally. In the same way, Moriconi and de Cima (2020) defend the importance of creating a truly health-promoting community, where the fight against corruption in the sports sphere assumes a central role. In these works, the author has been demonstrating how criminality, illegality and corruption jeopardize the sustainability of sports as a social, cultural and economic activity. The research on the importance of a solid social support network for well-being and health is a traditional line of investigation at ISCTE, where the work by Luisa Lima and collaborators (e.g., Lima et al. 2017, Lima, 2018, Lima et al., 2020) has had wide dissemination.

From a more individual perspective of health behaviors, the research of Marília Prada et al. (2017; 2019) has offered important contributions in the area of healthy consumption and obesity prevention. These studies have

focused on how individuals process the information present in available food packaging and how this processing influences the effective consumption of these foods. From a multi-level perspective, this work has truly relevant implications for the creation of public policies in the area of food and the promotion of healthy consumption.

The behaviors associated with a healthy lifestyle, namely physical activity and sports (Oliveira-Brochado et al., 2017) are influenced by personal, social and environmental factors (Brochado, et al., 2010). Understanding the relationship between the individual and the social, economic, and geographical environment allows identifying barriers and facilitators of adopting healthy habits.

Finally, another example of the research that has been carried out at ISCTE focuses on the area of technologies for health promotion and smart healthcare services. Within a vast set of other initiatives, the research in the field of smart sensing and applied virtual and augmented reality, developed by Octavian Postolache and his group, originated the development of highly motivational remote physical therapy solutions associated with rehabilitation services (Postolache et.al, 2020). The successful research in IoT healthcare and tailored environment are followed by new developments. It can also be mentioned the ongoing PhD research work of Mariana Jacob-Rodrigues and collaborators (2020) that seeks to explore the development, implementation and validation of a plethora of novel assisted living environments (AAL – Ambient Assisted Living) that assures the improvement of quality of life and the wellbeing of older people. The aim of this work will be to allow the assessment of the health status of a user through the monitoring and recognition of activities or tasks that are performed on a daily basis, for an early detection of the emergence of common health problems in the older population related to physical and mental condition. This work is part of extended research of the group that materializes a good articulation between smart environments, wearable sensing solutions, natural interaction with high usability systems and health at the most individual level.

The work by Fernando Batista and Ricardo Ribeiro is also a good example of the application of technology for health promotion. Using natural langue processing of language, text mining and machine learning, these authors (Rosa et al., 2018, 2019) analyze texts from different social media platforms in order to inform health strategies in these domains. The automatic detection of cyberbullying in social networks is an important contribution to this field of study.

Another example of the research that has been carried out at Iscte focuses on the area of technologies for health promotion and smart healthcare services

Another example of successful national research collaboration in the domain of health assessment is the work by João Cordeiro (Cordeiro et al., 2019) on child welfare. Cordeiro addressed neonatal problems, healthy child development and even the detection of cardiovascular diseases using artificial intelligence algorithms and data science.

Sexual, reproductive and maternal health is a growing research topic at ISCTE. In the construction of health knowledge in this domain – and consequently, in the organization of health services and the improvement of healthcare – a biomedical perspective prevails, centered on caregivers, and which generally reduces the experience of health and illness to professional processes of dealing with bodies and minds. The epidemic shows evidence of the deep and inextricable symbiosis between natural, social and institutional phenomena, and, therefore, the need to learn how to deal integrally with everyone at the same time. The intersectionality, focused on building common spaces of synergy and collaboration open to all knowledges, responds to inter and transdisciplinary practical difficulties. In the area of maternal, sexual and reproductive health, social sciences can contribute to improve not only the health conditions of individuals, but also disease prevention and health promotion, namely in the design of public policies of humanization and rationalization of health institutions. The transdisciplinary work of nascer.pt (ISCTE's Laboratory on Social Studies of Birth) is a good example of this type of work.

This area of research encompasses five aspects: (1) analysis of pregnancy and childbirth as social phenomena, by Mário Santos (Santos et al., 2019); (2) sexual health, sexually transmitted infections and the use of contraceptive methods as one of the most effective ways to prevent them, with David Rodrigues (Rodrigues et al., 2020); (3) the role of communication and health literacy in the prevention of disease situations as in the work of Rita Espanha (Espanha & Oliveira, 2019) and, transversally to all researches, (4) the problem of discrimination and violence in the field of maternal, sexual and reproductive health; and (5) the reflection on inter and transdisciplinary ways to mobilize science for health challenges, which imply rethinking the crossroads of social and therapeutic practices by social sciences and medicine.

In a context of low fertility rate, Fernandes et al. (2020) identified gynecologists' and general practitioners' beliefs on female reproductive diseases, namely those more difficult to diagnose and treat and that are more common in their practices. The inductive nature of the study shows that the three most relevant disorders mentioned were polycystic ovary syndrome, endometriosis and vulvodynia; that these diseases have several consequences on the lives of women, because they feel stigmatized and limited in their daily life and sexuality - and the diagnosis takes too much time. Governments should better redistribute the financing of women's health and allocate resources to specialized centers.

Reducing the burden of chronic illnesses and improving health-related quality of life

Life expectancy in Portugal has increased continuously since the year 2000 and so did the number of people living with chronic diseases and disabilities or suffering from work-related stress which increases the pressure on the healthcare system. Technological solutions such as ambient assisted living, personalized self-care and automatic decision tools exist and have been proposed as a way to increase the quality of life of health professionals, patients and their families, but often these systems are not co-produced with the input of end-users. ISCTE researchers have developed important contributions in both these domains: the production of knowledge on chronic illnesses in partnership with patient associations, and the development of technical solutions to investigate and act on these topics.

Chronic pain has a huge prevalence among the Portuguese adult population: 36.7%, with an average duration of 10 years, recurrent or continuous in 85% of cases (Azevedo et al., 2012). The psychological and social aspects of

this condition have been successfully approached by a team coordinated by Sónia Bernardes, with other researchers, like Marta Matos and Inês Oliveira. Their work has provided conceptual and empirical significant contributions to the Social Psychology of Pain, namely on the domain of social disparities in the evaluation processes of pain treatment by health professionals (Brandão et al., 2019; Diniz et al., 2020) and interpersonal dynamics in the processes of adaptation to chronic pain (Bernardes et al., 2017; Matos et al., 2017; Mittinty et al., 2020). Understanding the processes of body awareness in people with chronic pain and examining their relationship with risk factors / pain protectors in the light of contextual factors, allows us to establish guidelines for the development of effective therapeutic interventions, which are easily available to the community and whose effect is lasting. Moreover, deepening this knowledge is essential to guide evidence-based decision-making in the design of health policies.

In line with the WHO Framework on Integrated People-Centred Health Services (WHO, 2016) and the model on co-production of health and knowledge (Kickbusch & Gleicher, 2012) - which establish the involvement of people and communities as a key pillar to co-production of quality health services that meet people's life course needs and respects social preferences, as well as to health systems governance - Crisóstomo and Santos (2018) have developed a research-action, 'MORE PARTICIPATION better health', where patient and consumer representatives were involved from the beginning and in co-production of the various project activities and deliverables. The main aim of the project was to claim the institutionalization of participatory mechanisms in health decision-making, at the both the institutional and political level, which also led to the approval of a new law in the Portuguese Parliament that saw the approval of the Charter for Public Participation (Law no. 109/2019, 9 September). As part of this project, digital communication, internet and social networks were key for social mobilization, collective action and public awareness-raising (Crisóstomo et al., 2017, 2019). Crisóstomo has also conducted a review of the current status and role of public participation in medicine research, regulatory agencies and HTA, and examples of public participation in the field of HIV, cancer and rare diseases, all of which support the essential role of citizens in modelling access to medicines (Crisóstomo & da Costa, 2020).

Mental health is also an important area of research, with contributions from Clinical Psychology (e.g., Moleiro, 2018), Social Work (e.g., Nogueira, 2019) or even Genetics. Diana Prata's work aims to understand the role of oxytocin

Technological solutions have been proposed as a way to increase the quality of life of health professionals, patients and their families

in human social cognition and its relevance to psychosis and autism (Neto et al., 2020; Prata et al., 2019). They are also identifying integrated genetics, neuroimaging and environmental biomarkers of the diagnosis and prognosis of psychosis and treatment response, applying artificial intelligence to neuroimaging data for neurological and psychiatric biomarker development.

Matias and Sousa (2017) conducted a systematic literature review attempting to determine what is happening in the field of kidney disease prevention campaigns, highlighting the use of mobile health as a tool to enhance the campaign's effect on targeting individuals and behaviour change. In the face of the lack of evidence on behavioural change as a result of kidney disease prevention campaigns, the study calls for the need to rethink communication strategies, processes, indicators, and tools in order to improve populational engagement on kidney disease prevention campaigns.

In the field of the sociology of health and illness, Elsa Pegado has done research on Complementary and Alternative Medicine (CAM, Pegado, 2020). Her research contributed to the understanding of how the field is structured in Portugal, the sociography of users and the exploitation of social patterns of demand, the identification of the diversity of social practices in the involvement of users with CAM and the different configurations of its pairing with conventional medicine (Pegado, 2017, 2019).

Another chronic condition that is studied at ISCTE has to do with the impact of work and employment conditions on the health of different professionals

Another chronic condition that is studied by different teams at ISCTE has to do with the impact of work and employment conditions on the health of different professionals, including health professionals. Fatima Suleman's research aims at the employment and working conditions of health professionals. The central argument of this project is that the sustainability and quality of public and private health services depend on the type of contracts, salaries, working time, training opportunities, reconciliation of work and family life - among others - of professionals. The lack of physical and mental conditions related to fatigue certainly compromise the performance of professionals, consequently putting the health of users at risk. Other teams have approached this topic from a psychosocial perspective. Sara Ramos studied work conditions and burnout (e.g., Ramos et al., 2020) and Sílvia Silva focused on the impacts of safety perception and training (Paolillo et al., 2020). It should be noted as an important effort to create and validate instruments adapted to the evaluation of illness or health in specific populations, often in co-production with patients (e.g., Sousa at al., 2018).

There is also significant research on ageing related disabilities and long-term care at ISCTE. The research team of Dália Nogueira and Elizabeth

Reis defined profiles for the functional disabilities of older institutionalized Portuguese persons, attending daycare centers and receiving domiciliary healthcare (Raposo et al., 2017; Lopes et al., forthcoming). A methodology was also proposed to identify costs associated with the healthcare provided for these different profiles (Nogeira et al., 2013), as well as the individual and social impact of the several levels of disability and dependency (Nogueira & Reis, 2012).

There is also significant research on ageing related disabilities and long-term care at ISCTE

In the digital-health area, the work of Isabel Machado-Alexandre addressing an increasingly common problem in the aged population – dementia – should be emphasized. She proposes computer techniques (artificial intelligence algorithms of cognitive stimulation) that can minimize and delay the effects of dementia in the life of the population (Caixinha & Alexandre, 2016). João Carlos Ferreira contributes with a vast experience in national and international projects, in partnership with hospitals. His research applies IoT devices and text and image processing techniques to different problems, from the extraction of the type of disease, electronic medical records, reduction of queues and inefficiency in certain medical services, support services for older persons and Telemedicine (Gonçalves et al., 2018; Helgheim et al., 2019).

Diana Mendes' work also contributed to the optimization, prevention and explanation of healthcare access, using tools from network analysis and machine learning, while having a clinical dimension as well. In a recent study (Laureano et al., 2020), she examined the dynamic characteristics of the pupillary light reflex and provided a contribution towards their explanation based on the non-linear theory of dynamical systems. The results from this research have implications for optic nerve injury, oculomotor nerve damage and brain tumors.

Reducing health inequalities

The analysis of health inequalities is a critical topic for health policy. ISCTE has a long tradition in providing research, training and policy recommendations and solutions from an inclusive perspective. Studies on the evaluation of policies, intervention projects and technical-scientific assistance to policymaking have been conducted. More recently, ISCTE's privileged inter-disciplinary environment has produced research that has included digital solutions and remote interventions to improve the quality of life of all citizens.

ISCTE researchers worked with specific vulnerable populations to include their views, needs and rights in the health agenda. Some projects unfolded the

inequalities on health and healthcare assistance associated with age, gender or social class (e.g., SoS PAIN project on pain treatment, Diniz et al., 2019). The work with persons with disabilities is also quite relevant in ISCTE's research (project YMI, with Associations of Persons with Autism, Nogueira, 2019). ISCTE's collaborative work with vulnerable groups also allowed for the identification of health needs and the health of immigrant communities (e.g. with Portuguese Refugee Council, Padilla et al., 2018), gender minorities (with the with the Commission for Citizenship and Gender Equality, Moleiro & Pinto, 2020), and also to develop and validate instruments to assess the needs of people living with specific diseases (e.g., Multiple Sclerosis patients for Biogen Portugal, Sousa et al., 2018; Chronic pain patients with Angelini Farmacêutica, Bernardes et al., 2020; Disphagic patients, Nogueira et al., 2015). Some of ISCTE's work in this domain allowed for the co-creation of technological solutions to promote the inclusion and quality of life of vulnerable groups (OLA FP7, on technological solutions for caregivers – Eloy et al., 2019; SIFORAGE FP7, on the technological inclusion of older citizens, Marques et al., 2014).

There is now a growing recognition of the global challenge of healthcare delivery, from the increasingly individual and cultural diversity of users

Other ISCTE researchers have also contributed to this line of research. Using data relevant to Portugal, Simões et al. (2016) proposed an algorithm to convert information provided by the official National Health Survey to EuroQol. Results show that there is a remarkable level of health inequality, with significant rates of poverty and wealth. The econometric study reveals that gender, age, education, region of residence and eating habits are among the most critical determinant factors for health.

Ricardo Rodrigues analyzed the social inequalities and how they are perceived by children (race, age, gender social class, Vauclair et al., 2018). This area of research has contributed fundamental knowledge in the development of interventions aimed at reducing social inequalities in education and promoting well-being in children and young people (e.g., Guerra et al., 2019; Marques et al., 2014). As these interventions were developed with a strong link to local stakeholders, they have a high potential to inform other educational programs targeted at vulnerable populations.

There is now a growing recognition of the global challenge of healthcare delivery, from the increasingly individual and cultural diversity of users. Several projects have been developed at ISCTE responding to this societal challenge, considering psychopathology and culture (Moleiro, 2018), and seeking to promote parity in mental health (Moleiro, Freire, Pinto & Roberto, 2018). For more than a decade, we have been investigating the health needs

of migrants (Moleiro et al., 2009; Moleiro, Freire & Tomsic, 2013), ethnic minorities (Moleiro, Marques & Pacheco, 2011), and sexual minorities (Moleiro & Pinto, 2015) – including the intersection with other characteristics such as religion or age (Moleiro, Pinto & Freire, 2013). More recently, we have also focused on the underlying welfare issues of refugees, including unaccompanied minors (Roberto, Moleiro & Lemos, 2020) and refugees, and LGBTQI+ asylum seekers (Moleiro, Solntseva & Aybar, 2020). The results have been involved, not only in academic and professional training (e.g. same-sex domestic violence; Moleiro, Pinto, Oliveira & Santos, 2016), but also in the rationale underlying public health policies (Law of Self-determination of Gender Identity of 2018; Moleiro & Pinto, 2020).

Improving the efficiency of health services in the context of societal health

Healthcare is central to human dignity and having access to quality services makes a fundamental difference in the lives of people and the development of communities. This concern is evident in the United Nations' sustainable development goals for 2030, which hinder on the provision of health services. The improvement of the level of service is also a major imperative for organizations within the healthcare sector, thus joining the effort for a better and more sustainable world for all.

Overall, the health industry has a considerable impact on economies. As estimated by Deloitte (2017), global healthcare expenditures are expected to reach $8.7 trillion in 2020, from $7 trillion in 2015. The percentage of GDP spent on healthcare will also rise, from 10.4% in 2015 to 10.5% in 2020. According to the same source, the tendency for growth will be observed worldwide, but emerging and lower-income countries are expected to show higher growth rates. This growth is explained by the combination of three major factors: the increase in life expectancy and related high demands for services, the rising of healthcare labor costs and the increasing innovation in diagnosis and therapeutic practices which are essential for improvement, but also more expensive. Besides cost containment, the healthcare sector is required to deal effectively with several issues related to the delivery of care, innovation, efficient and safe operations, and an overly complex regulatory environment (Deloitte, 2017). Under these circumstances, it is foreseeable that health services providers will be challenged to deal with the contradictory pressures of delivering better care for more people at lower costs, a circumstance that contributes to the rise of tensions.

In this context, ISCTE's researchers undertook several initiatives aimed at better understanding the organizational dynamics underlying the quest for quality and efficiency, thus contributing to a better care. More precisely, three domains have attracted the attention of researchers at ISCTE: locating the improvement efforts within the hybrid nature of healthcare organizations; actively searching for optimization strategies; preparing managers and funders for better decisions and producing specialized knowledge on specific health issues.

Locating the improvement efforts within the hybrid nature of healthcare organizations

Healthcare organizations operate in a highly institutionalised environment. In fact, to manage tensions arising from external pressures to enact multiple conflicting strategies and, at the same time, address the internal pressures to perform multiple cultures and identities is a core feature of the dynamics of change in pluralistic contexts like healthcare (Burnett *et al.*, 2016; Nunes, Anderson, Martins & Wiig, 2017). It is in this context that organizations strive to improve.

In a study of public hospitals, Major and Clegg (2019) attempted to understand the role of activity-based costing technology (ABC) to support the institutional work of the Portuguese Ministry of Health in introducing a new institutional logic in the sector (managerialism), therefore blurring boundaries between the way public and private hospitals operate. ABC advocates claim that it provides accurate and relevant information about the consumption of clinical resources in hospitals and that it helps clinicians to understand the impact of their medical treatments on patients, within the financial performance of hospitals. This study helped understand the inherent complexity in the implementation of managerial practices of private organizations within public hospitals. ABC implementation in the healthcare sector is a complex issue and, despite its popularity as a method of engaging clinicians in hospital management and of controlling costs, its use is more difficult than portrayed in the normative literature.

In another study, Major, Conceição and Clegg (2018) examined the reasons behind the implementation of a responsibility centre in a unit of a Portuguese public hospital (the cardiothoracic surgery service – CSS), and why the initiative failed, despite its support by legislative action. Empirical findings showed that notwithstanding the efforts of the institutional entrepreneur to implement the initiative in CSS, he was unable to bring about the

change the centres were designed to elicit. From a governmental perspective, responsibility centres empower through the distribution of decision-making while simultaneously tightening power through increasing responsibility for the decisions made (Major, Conceição & Clegg, 2018).

The hybrid nature of healthcare organizations was also highlighted by the research conducted on community pharmacies – often the first stop for patients experiencing symptoms. In this regard, Nunes et al. (2015) developed a model conceptualizing the community pharmacy as playing multiple roles - pharmaceutical supplier, advice provider and community health promoter - to which patients responded and suggested an organizational identity expansion as a mechanism to integrate this multiplicity. Nunes et al. (2017) investigated the hybrid nature and identity orientation (normative and utilitarian) of community pharmacies and the role of organizational identity work undertaken by owners and managers in promoting performance.

Actively searching for optimization approaches for planning healthcare delivery

Healthcare organizations face strong organizing challenges. According to the World Health Organization (WHO, 2017), 400 million people don't have access to health services that could be delivered by primary care providers – 10% out of the 421 million hospitalizations worldwide each year result in patient harm and, importantly, up to 40% of all healthcare spending is wasted through inefficiency. This calls for an increased effort from healthcare managers and decision-makers to improve the service delivered, at least for the sake of efficiency and safety.

Healthcare organizations face strong organizing challenges

The application of microeconomic models, and the corresponding empirical application in various areas of social science, has been developed by Felipa de Mello-Sampayo. De Mello-Sampayo (2014) developed a microeconomic model of decision in the context of uncertainty applied to the treatment of patients with gastrointestinal tumors. When there is irreversibility and uncertainty in the cost of treatment, low-risk patients switch to the second treatment, when it is priced at a lesser amount. As the costs of reversing treatment impacts decrease, it becomes more feasible to switch treatment later for low-risk individuals (de Mello-Sampayo, 2015).

To analyze the utility of spatial interaction models and gravity models as tools to assess accessibility to health services, theoretical interaction models were derived using the entropy approach to deal with the random component

of the utility function (de Mello-Sampayo, 2016; 2018a; 2018b; 2020). The results of the empirical application of the spatial interaction models suggest their use in the analysis of policies on accessibility to health.

In the economic analysis from the patient's point of view of the use of teledermatology in the Portuguese public health system and under specific cost assumptions, the teledermatology used in pre-surgical planning and preparation is the preferred strategy – surpassing the conventional reference system, especially for patients with severe dermatoses (de Mello-Sampayo, 2019). In the Portuguese public health system, assuming several specificities on the part of the health user, cardio protection defined by the assessment of the left ventricular ejection fraction (LVEF) for patients at risk of cardiotoxicity related to chemotherapy provides more QALYs at a cost less than uniform cardio protection (de Mello-Sampayo et al., 2020).

At ISCTE another arm of research is devoted to the development of optimization-based tools to support healthcare planning in general, palliative and long-term care - both at the national and international level. Particularly, several studies have been developed in this area, recognizing that an adequate planning should meet not only patients' needs, but also the concerns of healthcare organizations. Starting with patients' point of view, several models have been built so as to ensure the delivery of quality care, while also promoting patient well-being and equitable access for all patients in need (Cardoso-Grilo et al., 2019; Cardoso-Grilo et al., 2015; Cardoso-Grilo et al, 2016). Concerning healthcare providers, research has taken into account the multiplicity of objectives that often need to be considered at this level (e.g., when one considers private or public provision of care), as well as several key limitations, such as budgetary, material and human resources-related constraints (Cardoso-Grilo et al., 2015; 2016). Simultaneously, it has also been considered that the healthcare sector is characterized by several key uncertainties – such as uncertainty surrounding demand and supply of healthcare in the medium and long-term (Cardoso-Grilo et al., 2020; Cardoso-Grilo et al., 2012; 2015).

In the context of providing better grounds for decision-making, Sousa et al. (2019), reviewed the literature on how big data analytics can use large-scale data sets in order to provide evidence-based support for people management decisions and the cost-effectiveness evaluation of healthcare organizations. This review offers a predictive model for people management processes. In 2020, Pesqueira, Sousa and Rocha explored further the role of sustainable development of Big Data skills in healthcare and pharmaceuticals, to propose a set of skills to increase the capacity building of the health professionals.

At ISCTE another arm of research is devoted to the development of optimization-based tools to support healthcare planning in general

Preparing professionals, managers and funders for better decisions

Delivering healthcare with quality and cost containment has been considered a key policy challenge of most countries, challenging healthcare organizations to make the best decisions regarding the conciliation of these somehow contradictory issues. Preparing managers to handle complex decisions may have a fundamental impact on society. In the same vein, professionals can enhance performance using tangible instruments to facilitate knowledge utilization.

Delivering healthcare with quality and cost containment has been considered a key policy challenge of most countries

Using a multilevel multiple case study design including ten hospitals from five European countries (Robert et al., 2011; Burnett et al., 2013) included in the QUASER project (European Community's Seventh Framework Programme, under grant agreement n. 241724), ISCTE's researchers where involved in developing two guides aimed at preparing top managers in hospitals and funding entities to make decisions informed by a deep knowledge of the organizational challenges involved in the quest for decisions. These guides (Quaser research team, 2014a, 2014b) were developed as reflective tools providing an empirical based comprehensive tool for the effective identification of gaps in quality strategies and a framework and language for understanding and sharing ideas on how to improve (Anderson et al., 2019).

Drawing on data from the same project, Nunes et al. (2020) identified six dualities involved in the quest for improved service in hospitals - plural consensus, distributed connectedness, orchestrated emergence, formalized fluidity, patient coreness, and cautious generativeness - and challenged hospital managers to move from the usual sequential, project-based and systemic thinking on quality improvement, to the development of meta-capabilities to balance the simultaneous operation of opposing ideas or concepts.

Other studies (highlighted the role of user-generated contents to understand the main dimensions of the perceived service quality of specific healthcare services, like thermal and mineral spas (Rodrigues et al., 2019) or medical tourism (Rodrigues et al., 2017). Nascimento, Nunes and Anderson (forthcoming) studied the key role that post-acute care organizations play in maintaining and promoting patient health - a goal that is influenced by their experience and stay in in these facilities and the transition from hospital to post-acute organizations.

Using an emergency room department as a context, Sousa et al. (2020) examined the tensions between dynamic knowledge embedded in individual

workers and static knowledge rooted in documented information, highlighting the relevance of finding the right balance between these two types of knowledge; what can be achieved by the combination of a culture of knowledge translation and sharing; the development of soft skills and the objectivation of this process into practical tangible instruments.

In this regard, several ISCTE academics have been involved in postgraduate training of healthcare managers. An example of this is the Health Economics course (Nuno Crespo). Combining research, teaching, and supervision of several thesis, Nuno Crespo concentrates his effort on the following key topics: (i) economic methods for decision-making in healthcare; (ii) methods for economic evaluation (cost minimization, cost-effectiveness, cost-utility, and cost-benefit; (iii) ageing (key trends and implications, with special focus on the Portuguese case); (iv) health literacy; (v) measurement of health related quality of life.

Several ISCTE academics have been involved in postgraduate training of healthcare managers

Ana Lúcia Martins also leads several projects focused on identifying ways of process improvement in healthcare institutions. These studies aim to improve the quality of health response offered, response time, increasing quality of life for users and reducing costs in the healthcare system response (Bendito & Martins, 2012). The second topic ruling the work of this researcher is the perception of the quality of service provided by healthcare institutions to their professionals. This research has had important consequences for the well-being of health professionals, like nurses and doctors (e.g., Martins et al., 2014; Martins & Concinha 2017).

FINAL NOTES

In this paper we present a new perspective to health research that inspires **ISCTE Health**: Societal Health. It is rooted in the social determinants of health approach, and for this reason it emphasizes the different social and environmental contexts that impact health, while encompassing and articulating different levels of analysis. However, **ISCTE Health's** vision of health research extends further, in several ways. First, as other authors propose, it includes a clear political level of analysis that deconstructs policy options in terms of power. In addition, the societal view of ISCTE_Health also includes the major challenges that society in general and healthcare in particular face today: the digital transition, globalization of threats and solutions and the participation of citizens (both healthcare users and patients, as well as healthcare professionals).

ISCTE Health is built upon the impressive record of training, research and publications in the domain of health, that were produced at ISCTE in the last decades. The description of the different lines of research presented in this paper is a strong portfolio of ISCTE's expertise in different and fundamental dimensions of health. Moreover, ***ISCTE Health*** is built upon a strong belief and will to engage in collaborative and inter-disciplinary research, i.e., to do research in collaboration with stakeholders that represent either healthcare users, persons with chronic illnesses, health professionals, institutions, and enterprises. ISCTE has many partnerships in the domain of health and ***ISCTE Health*** will foster the creation of synergies as well as business value. However, the most innovative aspect of ***ISCTE Health*** will be the strong focus in interdisciplinary articulation and building spaces where collaborative ideas to research questions can arise. ISCTE's outstanding disciplinary expertise in the fields of social sciences – psychology, anthropology, sociology, political science, history, economy, management sciences - together with technological sciences, such as artificial intelligence, data science and computer sciences, provides an opportunity to produce strong and innovative research in this field.

ISCTE Health is built upon the impressive record of training, research and publications in the domain of health, that were produced at ISCTE in the last decades

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PART 2

Promoting health in times of pandemic

2.

A space for age:
healthy and smart cities for aging

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This year's 1st of October International Day of Older Persons was celebrated in a different manner. First of all, it was its 30th anniversary, which highlights the long struggle that has been carried out on the behalf of the rights of older people. Secondly, it took place right in the middle of the COVID'19 pandemic, increasing the visibility of older people's living conditions across the globe. In this context, the United Nations[1] released an important declaration with a clear statement that one of the main aims for 2020 was to "raise awareness of the special health needs of older persons and of their contributions to their own health and to the functioning of the societies in which they live".

On that same day, one the most important news channels in Portugal released a piece on the experiences of older people during the pandemic[2]. In this piece, a 92 year-old woman revealed how the pandemic has changed her daily

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[1] https://www.un.org/en/observances/older-persons-day

[2] https://sicnoticias.pt/especiais/coronavirus/2020-10-01-Medo-solidao-e-falta-de-afetos-como-
-a-pandemia-lhes-mudou-a-vida?fbclid=IwAR2wwJ9kdX8DvXquR1IKGvOmXCXZixb0L6_9VM-
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life and how staying at home for so long, made her lose her walking habits that she is now frightened to walk in the streets again: "I don't want to go vote in the presidential elections. Would I dare to cross the street? I'm afraid of falling". This is a good example of the impacts of the pandemics on older people's daily lives, social participation, and usage of streets and public spaces.

Fear of walking has been linked with negative outcomes for older people's health[3], including less mobility and more social isolation[4]. Some studies[5] have even shown that older people's perceptions of social integration were related with the levels of age discrimination or ageism in their neighborhood[5] , with potential consequences on a range of negative outcomes for them and on their overall levels of health and well-being[6,7].

These negative impacts reinforce the need to invest in inclusive living spaces that take into consideration all age groups. In this context, policies for the creation of Healthy Cities (WHO, 2007) should have a higher priority in the upcoming years.

The need to invest in inclusive living spaces that take into consideration all age groups

It is important to emphasize that cities and urban development are one of the current pillars of the EU agenda. Urban areas in Europe are home to over two-thirds of the EU's population, which makes them a priority for intervention in several dimensions. At the same time, the ageing of the population has impacts on several aspects of the cities' lives and therefore cities must adapt their policies to integrate the needs of older people. The EU Urban agenda includes policies related to health, sustainable development, social inclusion, and digital transition, which are being given priority due to their potential widespread impacts on society and economic growth. European policies will focus on bringing about a smarter, greener, more connected, and

[3] Leite, S., Dias, M. S., Eloy, S., Freitas, J., Marques, S., Pedro, T., & Ourique, L. (2019). Physiological arousal quantifying perception of safe and unsafe virtual environments by older and younger adults. Sensors, 19(11), 2447. DOI: 10.3390/s19112447

[4] Rantakokko, M., Mänty, M., Iwarsson, S., Törmäkangas, T., Leinonen, R., Heikkinen, E., & Rantanen, T. (2009). Fear of moving outdoors and development of outdoor walking difficulty in older people. Journal of the American Geriatrics Society, 57(4), 634-640. DOI: 10.1111/j.1532-5415.2009.02180.x

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[6] Chang, E. S., Kannoth, S., Levy, S., Wang, S. Y., Lee, J. E., & Levy, B. R. (2020). Global reach of ageism on older persons' health: A systematic review. *PloSone*, 15(1), e0220857. DOI: 10.1371/journal.pone.0220857

[7] Levy, B. R. (2003). Mind matters: Cognitive and physical effects of aging self-stereotypes. *The Journals of Gerontology Series B: Psychological Sciences and Social Sciences, 58*(4), P203-P211. DOI: 10.1093/geronb/58.4.P203

social Europe in the upcoming years. Through urban policies and the help of funding programmes such as URBACT,[8] cities are aiming at investing in inclusion, namely of older people, and in the physical and urban development, improving mobility and public space.

For the World Health Organization, the Healthy Cities movement encourages better urban planning to prioritize increased access to safe transport systems and greener public spaces, which together helps reduce road traffic accidents, improve air quality, and promote physical activity. Healthy Cities aim at "tackling inequalities and promoting good governance and leadership for health and well-being."[9]. Concurrently, Smart Cities policies are exploring the potential of advancing ICT, IoT and energy and mobility-related technologies to promote increased connectivity, clean energy and sustainable and efficient services. Both strategies – of healthy and smart cities – contribute to the broader cause of creating inclusive cities for the older population. The EU currently has a host of programmes under this scope, such as the "Active and Healthy Ageing" and the "Smart Healthy Age Friendly Environments" programmes. In Portugal also the "Cidades Sustentáveis 2020" strategy defines policy for more healthy, inclusive, and smart cities via specific actions on the development of ICT smart systems, inclusive urban communities, and healthy urban environments.

Despite the good intentions, much needs yet to be done if we want to create inclusive cities, where older people will not be afraid to walk in the streets

However, despite the good intentions, much needs yet to be done if we want to create inclusive cities, where older people will not be afraid to walk in the streets. At present, we know that although cities are places for everyone, they are not designed in an inclusive way. Both public and private spaces in cities constantly fail to provide an accessible way for older people and people with disabilities to move around.

The legislation regulating the built environment and actual architectural practice respond to several types of needs, from general needs to those of specific stakeholders, and too often inclusive design and the needs of older people and people with disabilities are secondary priorities insufficiently taken in consideration. Hanson[10] refers that "the urban built environment represents

[8] https://urbact.eu/

[9] https://www.euro.who.int/en/health-topics/environment-and-health/urban-health/who-european -healthy-cities-network/healthy-cities-vision

[10] Hanson, J. (2004) 'The Inclusive City : delivering a more accessible urban environment through inclusive design.', in RICS Cobra 2004 International Construction Conference: responding to change. York, UK, pp. 1–39.

the most concrete example of how people with impairments can be disabled by barriers to access". Such situation denies older people the ability to live an independent and safe life and excludes them from participating in the urban social arena.

The main barriers in cities are related to access to buildings, to public space, and to public transports. Besides construction-related physical barriers such as high steps and changes of level, high traffic and bad lighting also can be factors leading to a feeling of lack of safety, which segregates older people. The expression "architectural disability"[11] is used to refer to a physical space suffering from lost functionality due to lack of maintenance or, more commonly, bad design. To design an inclusive built environment, a user-centred design must be used through a participatory, people-oriented process, and therefore analysed and evaluated together with the users.

Moreover, the investment in heavy technology use may also bring important challenges for the older population. In fact, the concept of Smart Cities emerges with the advent of the personal computer, the Internet in general and the ubiquitous use of technologies spread throughout several services of the city (fibre-optic networks, sensors, and actuators). The original concept of wired city suggested a city providing a network for very diverse activities, beginning with the automation of emergency services such as the police, fireman, ambulances, and other city services such as waste disposal and transports[12]. Sensors would collect large amounts of data that would be transmitted, stored, and analysed by systems with massive capability.

To design an inclusive built environment, a user-centred design must be used through a participatory, people-oriented process, and therefore analysed and evaluated together with the users

Besides all the areas where smart cities act, including the environment, home, energy, buildings, transportation, logistic, farming, hospitality, education, and security, for older people smart cities also brought new advantages in healthcare[13]. Indeed, with smart health, older people can take advantages of more efficient services and a constant monitoring and close connection to their caregivers.

Despite these advantages, there are also obstacles to the development of smart cities and adoption of smart health technologies by the less

[11] Goldsmith, S. (1997) Designing for the Disabled: the new paradigm. Oxford: Architectural Press.

[12] Batty, M. (2012) 'Smart cities, big data', Environment and Planning B: Planning and Design, 39(2), pp. 191–193. doi: 10.1068/b3902ed.

[13] Lim, C., Kim, K. J. and Maglio, P. P. (2018) 'Smart cities with big data: Reference models, challenges, and considerations', Cities. Elsevier, 82(February), pp. 86–99. doi: 10.1016/j.cities.2018.04.011.

technologically-able groups in society, including many older people. Often, smart technologies are not developed with user-centred design, with inclusiveness measures in mind, which hinders users' acceptance and satisfaction. Unfortunately, the speed of technological innovation works against carefully tested design of inclusive solutions. This limits their adoption by older users, who are often not used to these types of technological innovations and frequently also perceived as lacking the right technological skills. Also, there is also a widespread stereotypical belief in our societies that older people lack the technological skills needed to adapt to these new circumstances, and this also may influence older people's adoption of these technologies to begin with. In fact, studies have shown that older people feel threatened by these stereotypes and that this influences their use of technologies.[14]

The future is clear: we will live in an ageing world; and mostly in cities

Despite all these difficulties, there is no doubt that change is needed. The future is clear: we will live in an ageing world; and mostly in cities. Any policy to build the cities for the future should adopt the principle of "*leave no one behind*". According to the WHO, the next decade will be the "Decade for healthy aging"[15]. All the 17 Sustainable Development Goals have one thing in common: they all have to be implemented considering people of all age groups. We hope this will be done also through the crucial adaptation of the places where we live so that even during pandemic, older people will not be so afraid to walk the streets as to forego their fundamental right of voting in the presidential elections.

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[14] Mariano, J., Marques, S., Ramos, M. R., Gerardo, F., & de Vries, H. (2020). Too old for computers? The longitudinal relationship between stereotype threat and computer use by older adults. Frontiers in Psychology, 11. DOI: 10.3389/fpsyg.2020.568972

[15] https://www.who.int/initiatives/decade-of-healthy-ageing

3.

Will everything be ok?
The costs of loneliness and telepresence as a social snack

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"Everything will be ok" – it was written everywhere, like a positive mantra, at the beginning of the confinement. Nine months and more lockdown measures later, it's time to ask ourselves if everything is okay. Levels of family stress have increased, particularly among women[1], and complaints of domestic violence have skyrocketed[2]. Data on the sale of psychoactive drugs (anxiolytics, sedatives[3], hypnotics, and antidepressants) show a large increase from

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[1] https://www.publico.pt/2020/10/12/sociedade/noticia/stress-familiar-causa-pandemia-recai-despro-porcionalmente-mulheres-1934952

[2] https://www.publico.pt/2020/06/16/sociedade/noticia/covid19-pandemia-agudizou-situacoes-violen-cia-domestica-ja-existentes-1920817

[3] https://www.dn.pt/edicao-do-dia/09-jun-2020/em-tres-meses-vendidas-mais-de-5-milhoes-de-emba-lagens-de-ansioliticos-e-antidepressivos--12283380.html
https://sicnoticias.pt/especiais/coronavirus/2020-06-11-Consumo-de-ansioliticos-e-antide-pressivos-em-Portugal-aumentou-com-a-pandemia

the pre-pandemic period, especially among young people[4]. Research shows that, although necessary, quarantine situations have negative consequences for mental health, which may remain after those periods[5].

In fact, the main measures to control the pandemic have been physical distancing and the reduction of social contacts. Our face-to-face contacts have been reduced to a minimum and, when they exist, they are marked by uncertainty, fear, masks, gel and distance. We touch each other less, and we are afraid of closeness. Family meetings, friends' dinners, coffee conversations, parties, all the social rituals that were part of our daily life a few months ago are now greatly reduced. In a study conducted in May 2020 with a sample of Portuguese adults, 92% of the persons questioned said that what they miss most is to socialize with people and to touch them[6]. It is therefore natural that research has shown an increase in feelings of loneliness, particularly among young people,[7] whose lifestyle is associated with frequent sociability.

Research shows that, although necessary, quarantine situations have negative consequences for mental health, which may remain after those periods

There is little doubt that the pandemic has caused much suffering and that there are urgent mental health problems that must be addressed. Loneliness, the feeling of not having someone who understands us nor to turn to in a difficult situation is a great source of suffering. Comparative research shows that in Portugal the levels of loneliness were already among the highest in Europe even before this pandemic, especially among older people[8].

Loneliness is a critical public health concern. It increases the risk of mental and physical illness and decreases life expectancy. People who often feel lonely not only feel sadder but also become sicker. They tend to have poorer sleep

[4] https://observador.pt/2020/05/02/jovens-sao-quem-mais-refere-ter-comecado-a-tomar-ansioliticos-e--antidepressivos-durante-a-pandemia/

[5] Brooks, S.K., Webster, R.K., Smith, L.E., Woodland, L., Wessely, S., Greenberg, N., & Rubin, G.J. (2020). The psychological impact of quarantine and how to reduce it: rapid review of the evidence. *Lancet, 395*, 912–920. Doi: 10.1016/ S0140-6736(20)30460-8

[6] Observatório da Solidão (2020). *Estudo sobre sentimentos, atitudes e projetos das pessoas no período de desconfinamento da pandemia COVID 19 (18/05/2020 - 26/05/2020).* Porto: ISCET – Instituto Superior de Ciências Empresariais e do Turismo. Retirado em 11.11.2020 de https://www.iscet.pt/uploads/obSolidao/estudo_iscet_observatorio_da_solidao_-_pos-emergencia.pdf

[7] Groarke, J.M., Berry, E., Graham-Wisener, L., McKenna-Plumley, P.E., McGlinchey, E., & Armour, C. (2020). Loneliness in the UK during the COVID-19 pandemic: Cross-sectional results from the COVID-19 Psychological Wellbeing Study. *PLoS ONE 15(9),* e0239698. Doi: 10.1371/journal.pone.0239698
McGinty E.E., Presskreischer R., Han H., & Barry C.L. (2020). Psychological distress and loneliness reported by US Adults in 2018 and April 2020. *JAMA, 324(1),* 93–94. doi:10.1001/jama.2020.9740

[8] Yang, K., & Victor, C. (2011). Age and loneliness in 25 European nations. *Ageing and Society, 31*(8), 1368-1388. doi:10.1017/S0144686X1000139X

quality and consequently they feel more tired. They have higher blood pressure and due to this their body is under permanent effort and stress. Research also shows that people with chronic loneliness problems live in a permanent situation of hypervigilance and feel constantly threatened, which, besides the permanent activation of the body, makes it difficult for them to approach others. Not surprisingly, longitudinal studies indicate that social isolation causes a worsening of physical health and an increase of mortality risk, and that loneliness is more serious than other recognized public health problems such as obesity or regular tobacco consumption. On the other hand, research consistently reveals that social integration - having people with whom to share intimate matters, having friends, and playing diverse social roles – is linked to happiness, to physical and mental health, and to immunity from physical illnesses as common as the cold. Therefore, the most recent studies of the economic costs of loneliness show that there are heavy costs for health services and that interventions to combat loneliness can both save money and reduce the burden of disease on health services.

Loneliness is a critical public health concern. It increases the risk of mental and physical illness and decreases life expectancy

By applying measures to protect us from contagion, are we making people more vulnerable not only to mental illness but also to physical illness? Are we pondering the costs of social isolation to which we subject citizens?

Along with signs of increased loneliness, there is also evidence of increased social and emotional support during the pandemic[9]. Despite physical distance, most people can remain emotionally attached to others. First of all, because our social connections have not ceased to exist, they only take place differently. We use social networks, teleconferences, and even talk to friends we have not contacted for a long time. We have adjusted by sending virtual hugs and by giving elbow bumps instead of kisses. It is not the same thing, but it helps to break the distance. Pre-pandemic research was skeptical about the psychological value of online relationships, considering them a weak substitute for face-to-face relationships[10]. Even if this is true in contexts where we have options, it is the creativity with which we maintain online relationships that allow us to manage the emptiness left by the physical distance of friends and family.

[9]   Luchetti, M., Lee, J.H., Aschwanden, D., Sesker, A., Strickhouser, J.E., Terracciano, A., Sutin, A.R. (2020). The trajectory of loneliness in response to COVID-19. *American Psychologist, 75(7),* 897-908. doi: 10.1037/amp0000690.

[10] Lima, M. L., Marques, S., Muiños, G., Camilo, C. (2017). All You Need Is Facebook Friends? Associations between online and face-to-face friendships and health. *Frontiers in Psychology, 8*:68. 10.3389/fpsyg.2017.00068

And, also, we find ways of synchronizing with others, despite the distance. Group interaction creates community and identity through synchronization processes. That means doing something simultaneously, such as a walk, a Sunday family lunch, a religious celebration, singing the national anthem or happy birthday, or painting a room together. We can do many of these things together despite the distances. We manage to have dinner together, each in his or her own home. We can do gymnastics at the same time as others, watch the same movie, or have a drink together at the end of the day, each in their own home. These are new forms of synchronization, perhaps not as exciting as face-to-face ones, but which keep families and groups together.

Group interaction creates community and identity through synchronization processes

We can ultimately overcome the loneliness in this pandemic if we feel that we are all in this together. If we don't look at this situation as something that affects 'me', but as something that affects us all. This sense of collective threat enhances a common identity and solidarity and prosocial behaviors[11]: willingness to help neighbors, to contribute to solidarity causes or even to adopt civic behaviors (such as wearing masks, cleaning hands, or staying at home). Viewing these behaviors as solidarity reinforces the feeling of belonging to the group, which is an important buffer against loneliness.

Being alone together is, at least, a palliative for the feeling of isolation and distance. Loneliness is complex. But it is easy to understand that people with physical, visual, or auditory-verbal limitations feel even more lonely. Most of the telepresence tools that have suddenly invaded our social lives, like Zoom, WhatsApp, or Teams, were not designed for blind or for deaf people. It is difficult to navigate in many of the public websites, not to mention private ones, being, for example, a blind person. It is difficult for a deaf person to communicate when the other person wears a mask that prevents them from seeing their lip movements. Another group of doubly lonely people is that of COVID-19 patients admitted to hospitals. Unable to see their family, they suffer – and some die – alone. This decision is imposed on patients' families who, during these months, have lost some rights they had gained within health services: to accompany their relatives. Should family members not have the right to assume the risk of going to the hospital? Or, conversely, does the public administration not have the duty to guarantee the right of the families to a final farewell, even if they have to manage the associated risks? The decision is understandable from a purely biomedical (epidemiological) perspective

[11] Bentley, S.V. Social isolation. In J. Jetten, S.D. Reicher, S. A. Haslam & T. Cruwys (Eds). *Together Apart: The Psychology of COVID-19* (pp. 59-63). London: SAGE.

of health – but from a societal health perspective, it is hard to understand. If physical health is not independent of the social well-being of patients, why should we prevent visits? We know that social contacts have a protective effect on health and that loneliness hinders physical recovery. Promoting interactions, even online, with the support network is a way to help patients recover. The logistical decision to ban visits was understandable during the unorganized beginning of the pandemic, but no longer in November 2020. Incoherence and ambiguity create a feeling of injustice, which results in a lack of comprehension, and anger. These feelings help neither the recovery of patients nor the quality of life of their relatives and friends.

Telepresence stands for physical presence as a snack stands for a meal (it does not feed you, but it takes away hunger). When face-to-face social interaction is unavailable, it is possible to temporarily deceive social needs with relationship substitutes[12] such as photos, letters, or other objects that remind us of good times and good relationships. Telepresence works as a social snack. That is why, at this uncertain time of difficult face-to-face meetings, it would be a good idea to use more of these snacks in health services. Even before the Covid-19 pandemic, there was a lot of talk about telehealth. Portugal is one of the few countries in the EU-27 with a national strategic plan for telehealth[13].

Telepresence stands for physical presence as a snack stands for a meal (it does not feed you, but it takes away hunger)

Telepresence, however, benefits from being conceived differently from telehealth. We can define telehealth as all human activity that uses technologies (currently eminently digital, although the telephone and some analog and radio systems have been, and are in some contexts, still used) for the promotion of health, and the prevention, diagnosis, treatment, and monitoring of illness. Telepresence, on the other hand, refers to the ability to create in people the feeling that someone or something is present, even if they are physically absent. To better understand telepresence, it is good to remember that we all already feel that someone is "absent", even if he or she is in front of us. We have had experiences of watching entire families having lunch at

[12] Gardner, W. L., Pickett, C. L., & Knowles, M. (2005).Social snacking and shielding: Using social symbols, selves, and surrogates in the service of belonging needs. In K. D. Williams, J. P. Forgas, & W. von Hippel (Eds.), *The Social Outcast: Ostracism, Social Exclusion, Rejection, and Bullying* (pp. 227-242). Psychology Press.
Douglas, J. (2012). Societal linkage, self-concept and well-being after severe traumatic brain injury. In J. Jetten, C. Haslam & S.A. Haslam (Eds). *The Social Cure: Identity, Health and well-being* (pp. 235-254). New York: Psychology Press.
[13] https://www.oecd.org/officialdocuments/publicdisplaydocumentpdf/?cote=DELSA/HEA/WD/HWP(2020)1&docLanguage=En

the same table, but each one, by themselves, connected with (physical absent) others through a cell phone. This means that the concept of presence which interests us here implies creating a relationship and it is not just a physical presence. We feel that someone is present when there is a connection with that person, something that we define with difficulty, but which is certainly more than just the physical proximity of their body to ours. The spatial-temporal distancing allowed by information and communication technologies, to which the mobile dimension is associated, nowadays provides a window of opportunities for the creation of relationships. If the physical and mental presence is always more complete, it is also certain that it is more dangerous in these times and never, as nowadays, in the last months of 2020, has telepresence been so important for humanity. It is therefore necessary to embrace the idea of telepresence. Thus, was already the case before the pandemic because telepresence is the basis of telework, telehealth, and some aspects of tele-life. Now it is essential to synchronize with others and avoid the feeling and suffering of loneliness; after this harmful pandemic, it will return to being an option in our lives again.

A few months ago, the Ministry of Health decided to remove the "harmful"[14] snacks from the vending machines, in an unprecedented and controversial public health measure[15], since they only apply to the "National Health Service (NHS) facilities". Without entering into this policy debate, we can remark that the decision implies that there are such things as "healthy" snacks. Use of telepresence in the NHS, in health units and isolation rooms, and the mandatory and urgent development of telehealth, with an urgent promotion of home tele-assistance,

Telepresence is therefore an imperative in these times

are healthy social snacks. Perhaps, more than simply healthy, it is a type of snack which should be urgently and mandatorily made available. The forms of telehealth (tele-consultation, synchronous or deferred, tele-monitoring, tele-assistance) are multiple and the National Strategic Plan for Telehealth[16] approved by the government in October 2019 is in force until 2022. This would be the ideal time to implement it! The many forms of tele-presence can be technically more or less sophisticated: from the traditional phone (although it is not always easy to call an in-patient or a blind person in Portugal), to video calls, emails and message portals, blogs, and emojis. There

[14] https://www.sns.gov.pt/noticias/2017/11/02/maquinas-vending-nos-servicos-do-sns/

[15] https://sol.sapo.pt/artigo/511483/sns-vai-dar-o-exemplo-maquinas-de-vending-vao-deixar-de-ter-alimentos-prejudiciais-a-sa-de

[16] https://www.sns.gov.pt/noticias/2019/11/13/plano-estrategico-para-a-telessaude/

is even augmented reality and tele-olfaction. Technology is not the problem, nor is the cost, since these are increasingly accessible technologies and their cost is easily recouped by avoided costs from mental health decline and unaccompanied chronic patients.

Telepresence is therefore an imperative in these times. It is very important to stay connected and to fight against loneliness. But for families and isolated patients in the hospitals, it is crucial. It works as a snack that nourishes at least the hope of reunion. It maintains a bond that comforts. For the most vulnerable in this locked down digital society, it is also a question of human rights. The sick, the elderly, or simply the most fragile of us cannot, and moreover, have the right to not be left alone.

4.

Overcoming the challenges of Covid-19 pandemic to the self-management of chronic diseases: Contributions of behavioral Sciences and digital technologies

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In 2019, cardiovascular diseases and cancer alone accounted for around half of deaths worldwide.[1] Musculoskeletal pain-related disorders, on the other hand, were the leading cause of Years Lived with Disability, and an increasingly large proportion of worldwide disease burden and health expenditures[1]. Indeed, besides the enormous physical and psychological suffering chronic non-communicable diseases (NCDs) impose on individuals and their

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[1] GBD 2019 Diseases and Injuries collaborators (2020). Global burden of 369 diseases and injuries in 204 countries and territories, 1990–2019: a systematic analysis for the Global Burden of Disease Study 2019. Lancet, 396, 1204-22. https://doi.org/10.1016/S0140-6736(20)30925-9

families, they seriously threaten the sustainability of social and healthcare systems[2]. Therefore, reducing the burden of NCDs is a major health challenge for the 21st century.

In 2020, the Covid-19 (SARS-CoV-2) pandemic has raised these challenges to a whole new level. By bearing several direct and indirect threats to people with NCDs, the Covid-19 pandemic has the potential to greatly increase the burden of chronic diseases. First and foremost, the virus poses a direct physical threat to people with NCDs. Fifty to 80% of the severe cases of Covid-19 present comorbidities, such as cancer, diabetes, cardiovascular and chronic respiratory diseases[3]. Also, the death rate due to Covid-19 among these patients is much higher than among the overall population[4].

The Covid-19 pandemic has the potential to greatly increase the burden of chronic diseases

Second, the pandemic also has indirect effects on the mortality and health status of chronic patients not infected by Covid-19. Among these, a steep rise in acute cardiovascular deaths has been reported[5] and substantial increases in cancer deaths are expected due to diagnostic delays[6]. Moreover, many individuals with chronic diseases (e.g., diabetes, rheumatoid arthritis) have reported worsening physical

[2] OECD (2019). Health at a Glance 2019: OECD indicators. Paris: OECD Publishing. http://www.oecd.org/health/health-systems/health-at-a-glance-19991312.htm

[3] Grasselli, G., Zangrillo, A., Zanella, A., Antonelli, M., Cabrini, L., Castelli, A., Cereda, D., Coluccello, A., Foti, G., Fumagalli, R., Iotti, G., Latronico, N., Lorini, L., Merler, S., Natalini, G., Piatti, A., Ranieri, M. V., Scandroglio, A. M., Storti, E., Cecconi, M., Pesenti, A., COVID-19 Lombardy ICU Network (2020). Baseline characteristics and outcomes of 1591 patients infected with SARS-CoV-2 admitted to ICUs of the Lombardy region, Italy. Journal of the American Medical Association, 323(16), 1574–1581. http://doi.org/10.1001/jama.2020.5394.
Richardson, S., Hirsch, J.S., Narasimhan, M., Crawford, J.M., McGinn, T., Davidson, K., & Northwell Covid-19 Research Consortium (2020). Presenting characteristics, comorbidities, and outcomes among 5700 patients hospitalized with COVID-19 in the New York City area. *Journal of the American Medical Association, 323(20),* 2052–2059. https://doi.org/10.1001/jama.2020.6775

[4] *Saini*, K.S., Tagliamento, M., Lambertini, M., McNally, R., Romano, M., Leone, M., Curigliano, G., & Azambuja, E. (2020). Mortality in patients with cancer and coronavirus disease 2019: A systematic review and pooled analysis of 52 studies. European Journal of Cancer 139(Nov), 43–50. https://doi.org/10.1016/j.ejca.2020.08.011.

[5] Wu, J., Mamas, M., Mohamed, M., Kwok, C.S., Roebuck, C., Humberstone, B., Denwood, T., Luescher, T., Belder, M., Deanfield, J., & Gale, C.P. (2020).Place and causes of acute cardiovascular mortality during the COVID-19 pandemic. Heart, 0, 1-7. *https://doi.org/10.1136/heartjnl-2020-317912.*

[6] Maringe, C., Spicer, J., Morris, M., Purushotham, A., Nolte, E., Sullivan, R., Rachet, B., & Aggarwal, A. (2020). *The impact of the COVID-19 pandemic on cancer deaths due to delays in diagnosis in England, UK: a national, population-based, modelling study. The Lancet Oncology; 21, 1023–1034.* https://doi.org/10.1016/S1470-2045(20)30388-0.

status since the onset of the pandemic[7]. Overall, these findings suggest that the social and systemic changes brought upon by the pandemic are taking an increasing toll on individuals with chronic diseases. Indeed, several social changes have been identified as threats to people with NCDs, namely, social isolation and loneliness for some and increased family/role conflicts and family care burden for others, reduced access to high-quality non-urgent healthcare, and the exacerbation of social inequalities[8].

The pandemic also has indirect effects on the mortality and health status of chronic patients not infected by Covid-19

The mechanisms accounting for the toll these social changes take on the health of people with NCDs might be various. We will first focus on the challenges these changes pose to the self-management of chronic diseases. We will then illustrate how synergies between behavioral sciences and digital technologies may contribute to overcome some of these challenges, while also contributing to the promotion of high-quality healthcare services at optimized costs.

COVID-19 CHALLENGES TO THE SELF-MANAGEMENT OF CHRONIC DISEASES

Chronic disease self-management is an interactive, dynamic, day-to-day, (often) life-long process through which individuals, along with their family, community and health care professionals, are actively engaged in managing

[7] Chudasama, Y.V., Gillies, C.L., Zaccardi, F., Coles, B., Davies, M.J., Seidu, S., & Khunti, K. (2020). Impact of COVID-19 on routine care for chronic diseases: a global survey of views from healthcare professionals. *Diabetes & Metabolic Syndrome: Clinical Research & Reviews*, 14(5), 965-967. https://doi.org/10.1016/j.dsx.2020.06.042.

Saqib, M.A., Siddiqui, S., Qasim, M., Jamil, M.A., Rafique, I., Awan, U.A, Ahmad, H., & Afzal, M.S. (2020). Effect of COVID-19 lockdown on patients with chronic diseases. *Diabetes & Metabolic Syndrome: Clinical Research & Reviews, 14*(6), 1621-1623. https://doi.org/10.1016/j.dsx.2020.08.028

Ziadé, N., Kibbi, L., Hmamouchi, I., Abdulateef, N., Halabi, H., Hamdi, W., Abutiban, F., Rakawi, M., Eissa, M., & Masri, B. (2020). Impact of the COVID-19 pandemic on patients with chronic rheumatic diseases: A study in 15 Arab countries. *International Journal of Rheumatic Diseases, 00*, 1–8. https://doi.org/10.1111/1756-185X.13960.

[8] Karos, K., McParland, J., Bunzli, S., Devan, H., Hirsh, A., Kapos, F., Keogh, E., Moore, D., Tracy, L., & Ashton-James, C. (2020). The social threats of Covid-19 for people with chronic pain. Pain, 161(10), 2229-2235. http://dx.doi.org/10.1097/j.pain.0000000000002004.

their illness[9]. It involves multiple tasks[10], such as (1) recognizing and managing body responses, associated treatments and adoption of health promoting behaviors (*e.g.*, changing diet and physical activity patterns); (2) activating resources, *e.g.*, creating and maintaining relationships with healthcare providers or obtaining and managing social support from significant others, whose actions may help or hinder individuals' adjustment to chronic diseases[11], and (3) processing the emotional and existential challenges posed by the disease so as to integrate it into the self and daily life, achieving a "sense of normalcy".

Social changes brought upon by the pandemic have hampered such self-management processes. First, lockdowns and social distancing restrictions have seriously interfered in chronic patients' daily care routines by reducing physical activity, leading to more imbalanced diets and sleep disturbances, disrupting their symptom monitoring and medication intake[12].

Second, patients have reported increased difficulties in the activation of medical and social support resources. Medical resource reallocation to

Social changes brought upon by the pandemic have hampered such self-management processes

9   Allegrante, J.P., Wells, M.T., & Peterson, J.C. (2019). Interventions to support behavioral self-management of chronic diseases. *Annual Review of Public Health, 40*, 127-146. https://doi.org/10.1146/annurev-publhealth-040218-044008

    Lorig, K.R., & Holman, H.R. (2003). Self-management education: history, definition, outcomes and mechanisms. *Annals of Behavioral Medicine, 26*(1), 1–7. http://doi.org/10.1207/S15324796ABM2601_01

10 Schulman-Green, D., Jaser, S., Martin, F., Alonzo, A., Grey, M., McCorkle, R., Redeker, N.S., Reynolds, N., & Whittemore, R. (2012). Processes of Self-Management in Chronic Illness. Journal of Nursing Scholarship, 44(2), 136-144. https://doi.org/10.1111/j.1547-5069.2012.01444.x.

11 Bernardes, S.F., Forgeron, P., Fournier, K., & Reszel, J. (2017). Beyond solicitousness: A comprehensive review on informal pain-related social support. Pain, 158 (11), 2066-2076. https://doi.org/10.1097/j.pain.0000000000001033

12 Chudasama, Y.V., Gillies, C.L., Zaccardi, F., Coles, B., Davies, M.J., Seidu, S., & Khunti, K. (2020). Impact of COVID-19 on routine care for chronic diseases: a global survey of views from healthcare professionals. *Diabetes & Metabolic Syndrome: Clinical Research & Reviews*, 14(5), 965-967. https://doi.org/10.1016/j.dsx.2020.06.042.

    Cristoforidis, A., Kavoura, E., Nemtsa, A., Pappa, K., & Dimitriadou, M. (2020). Coronavirus lockdown effect on type 1 diabetes management on children wearing insulin pump equipped with continuous glucose monitoring system. *Diabetes Research and Clinical Practice,166*, 108307. https://doi.org/10.1016/j.diabres.2020.108307

    Di Renzo, L., Gualtieri, P., Pivari, F., Soldati, L., Attinà, A., Cinelli, G., Leggeri, C., Caparello, G., Barrea, L., Scerbo, F., Esposito, E., & De Lorenzo, A. (2020). Eating habits and lifestyle changes during COVID-19 lockdown: an Italian survey. Journal of Translational Medicine, 18(1), 229. https://doi.org/10.1186/s12967-020-02399-5

    Saqib, M.A., Siddiqui, S., Qasim, M., Jamil, M.A., Rafique, I., Awan, U.A, Ahmad, H., & Afzal, M.S. (2020). Effect of COVID-19 lockdown on patients with chronic diseases. *Diabetes & Metabolic Syndrome: Clinical Research & Reviews, 14*(6), 1621-1623. https://doi.org/10.1016/j.dsx.2020.08.028

covid-19 patients has negatively influenced chronic patients' continued access to healthcare; many have missed routine medical screening, testing, and check-ups and reported disruption in medical supplies and in access to their health-care provider[13]. The mobilization of social support from significant others is also compromised both in cases of social isolation[14] and of increased exposure to interpersonal conflict in living conditions of enforced proximity, due to stresses associated to juggling multiple roles and responsibilities and/ or increased social vulnerabilities (e.g., job and financial insecurity)[15]. Third, and consequently, chronic patients have reported worse mental health (e.g. anxiety, depression) since the onset of the pandemics[16], suggesting difficulties in managing impending emotional and existential upheavals.

In sum, by deeply interfering with chronic patients' self-management processes, the COVID-19 pandemic has the potential to increase the burden of chronic diseases for the individual, family, and societal levels.

[13] Chudasama, Y.V., Gillies, C.L., Zaccardi, F., Coles, B., Davies, M.J., Seidu, S., & Khunti, K. (2020). Impact of COVID-19 on routine care for chronic diseases: a global survey of views from healthcare professionals. Diabetes & Metabolic Syndrome: Clinical Research & Reviews, 14(5), 965-967. https://doi.org/10.1016/j.dsx.2020.06.042.

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SELF-MANAGEMENT OF CHRONIC DISEASES
IN THE DIGITAL ERA

Digital technologies may contribute to overcome some of the barriers posed by covid-19 to the self-management of chronic diseases. Digital technologies such as smart environments, pervasive computing or Internet of Things (IoT) for healthcare creates new opportunities to increase the effectiveness of chronic patients' self-management processes, protecting their health status. Considering the patient's wellbeing along with the optimization of healthcare system costs, associated with classical clinical intervention, new developments are focusing on digital interventions (DIs). With DIs, patients may better understand their condition and can receive appropriate information about risk behaviors and recommendations of activity for optimal disease self-management through common digital tools such as mobile applications.

In the current pandemic context, the impact of DIs in society becomes more important considering the limited assistance for non-Covid-19 patients. In the particular cases of patients with cardiovascular and musculoskeletal pain-related disorders, DIs can be an integral part of at-home healthcare services. The adherence to digital home health assessment tools are mainly related to their transparency, usability and also their ease of deployment in chronic patients' homes.

Digital technologies may contribute to overcome some of the barriers posed by covid-19 to the self-management of chronic diseases

In this context DIs are supported by common APPs for mobile devices such as smart phones or tablets, which may be suggested by health-care providers. Based on these APPs, disease self-management can be improved by promoting, for instance, medication adherence. The improvement of self-management behavior can also be stimulated by using specific APPs that are known as serious games. Serious games are defined as "a mental contest, played with a computer in accordance with specific rules that uses entertainment to further government or corporate training, education, public policy, and strategic communication objectives."[17]. In health contexts, serious game can be denominated "health games", and serve several goals ranging from training healthcare providers to supporting patients in their self-management tasks, such as, managing body responses and treatments and adopting health

[17] p. 25 of Zyda M. (2005). From virtual simulation to virtual reality to games. Computer.;38(9):25–32. https://doi.org/10.1109/MC.2005.297; p.25

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promotion behaviors[18]. Specific serious games for physical rehabilitation that are also denominated as "exergames", were reported by Reis et al.[19]. These serious games, which are designed for upper and lower limb limbs, or balance rehabilitation[20], are mainly expressed by tailored virtual reality environments, specific user interface (such as Microsoft Kinect) as part of IoT healthcare ecosystem. A serious game for physical rehabilitation can be easily integrated in an innovative healthcare service such as remote physical therapy. This digital solution that puts patients playing their way to recovery are moving from the research laboratory to the rehabilitation clinics. One of the successful examples of "digital physical therapy" in real world is promoted by MIRA[21], which uses external sensors to track patients as they perform their exercises and helps clinicians track progress and compliance. The platform is designed to help therapists better engage with patients in recovery and to provide patients real information that can be used for self-management during the physical rehabilitation period. DIs in physical rehabilitation may combine different technologies of the digital era. Thus, remote sensing for natural user interface combines with virtual reality (VR) technologies for serious games, increasing user motivation, but also extract the information for objective evaluation of patient outcome. The analyzed data is presented to the patient based on mobile APP, to increase the self-management of the physical therapy process by following the prescribed training

A serious game for physical rehabilitation can be easily integrated in an innovative healthcare service such as remote physical therapy

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[21] MIRA (2020), Play your way to recovery:and make physical and cognitive exercises more engaging with MIRA, on-line at: http://www.mirarehab.com/

plan in autonomous way[22]. To materialize the digital solution for physiotherapy, the remote sensing can be replaced by a wearable smart sensing solution that provides interaction capabilities between the patient undergoing rehabilitation and the VR serious game[23]. Indeed, these DI may be particularly useful for chronic musculoskeletal pain rehabilitation, as they may provide the means for ongoing support for functional autonomy, which increases patients' pain-related self-efficacy and reduces pain disability[24].

The wearable sensors can also be used to monitor the cardiac and respiratory conditions of patients affected by cardiovascular diseases while performing their daily activities

The wearable sensors can also be used to monitor the cardiac and respiratory conditions of patients affected by cardiovascular diseases while performing their daily activities. Wearable sensing solutions materialized by smart watches provide information about cardiac activity, such as heart rate, through photoplethysmography[25]. During the COVID-19 pandemic, the smart watch and mobile APP for smart watch data management and analyses may prove to be a useful digital tool for chronic patients' self-management, and also to diminish the psychological pressure over possible contamination with the new virus. Thus, wearable devices that provide blood oxygen saturation (SpO2) information can offer patients the possibility of monitoring if anomalous values of SpO2

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are detected, which can be considered a contamination warning[26]. The measurement of blood oxygen level (SpO2) can also be useful to avoid critical events during the physical rehabilitation sessions and can be used by physiotherapists to establish personalized training plans for their patients.

Finally, it should be noted that the level of interaction between patients and these systems expressed by mobile APPs, serious games or smart wearable solutions is different, leading to different levels of acceptance that may affect the effectiveness of self-management processes. The higher complexity of the interaction between patient and the devices that deliver the data to the clinical site for future analysis and decision has a lower level of acceptance than smart healthcare devices, which can acquire, analyze and provide real-time feedback to the patients on their health status. The human-device interaction associated with tele-monitoring healthcare systems can be also considered a form of self-management[27]. Smart healthcare devices integrated in smart homes will create all the conditions for increased self-management, whereby patients assimilate their own knowledge of their condition with clinical recommendations to adopt a regime of integrated management.

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5.

Communication and organization in primary care in the context of covid19: two stories

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March 2020. Primary health care organizations face the challenge of responding to new requirements arising from the COVID-19 outbreak. The executive directors of two ACES[1], one located in a densely populated urban area (ACES1) and another in a smaller but geographically dispersed community (ACES2), moved to prepare their organizations to deal with an unknown

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[1] Primary health care providers were organized into groups of health centres (*agrupamento de centros de saúde* – ACES) (Decree-Law No. 28/2008). These units include family health units (*unidades de saúde familiar* – USF), community care units (*unidades de cuidados na comunidade* – UCC), personalized health care units (*unidades de cuidados de sauúde personalizados* – UCSP) and public health units (*unidades de saúde pública* – USP). This structure, which has administrative autonomy, aims to promote the participation of the local community and to improve access to health care.

situation. Table 1 describes some of the measures thought up, shared and introduced, for the most part, from one day to the next. Basically, everything happened in three weeks: an intense, fast, and multidimensional organizational change.

The two stories we report are, in essence, collective experiences of change and of learning while changing. They illustrate the recognition that it is not possible to respond to unexpected events through the same work processes that we use to deal with well-known ones. And that the so-called "resistance to change" so often associated with public organizations can be transformed into its opposite: "propensity to change". Very quickly, rigid and placid organizations revealed fluidity and dynamism. In the two stories, one can notice, among other aspects, clearly divergent changes in several domains:

it is not possible to respond to unexpected events through the same work processes that we use to deal with well-known ones

> › Signalling the change in the *modus operandi*: the establishment of a crisis office and design of a contingency plan.
> › Reorganizing spaces, setting up COVID-19 paths for patients.
> › Modifying individual and collective care delivery routines: creating new schedules, but also new tasks, some of which are clearly outside the usual duties.
> › Creating multidisciplinary teams to handle new tasks or initiatives.
> › Improvising professional protection equipment's, a response to the scarcity of resources.
> › Changing communication strategies with patients and the nature of the services provided.
> › Creating new, IT-based forms of communication between professionals.
> › Intensifying the interaction with external entities, such as civil protection, firefighters, schools, or municipalities.

As stated by Weick e Sutcliffe[2], if an aim of organizing is to ensure that different things are where we expect, it is possible to assume that organizations are more prepared for continuity than able to face discontinuity, especially in crises. But the stories we have heard show that crisis situations can prompt initiatives for organizing (*organizing* in the sense used by Weick[3], that is, using

[2] Weick, K. E., & Sutcliffe, K. M. (2015). *Managing the unexpected: sustained performance in a complex world*. New York: John Wiley & Sons.
[3] Weick, K. E. (1979). *The Social Psychology of Organizing*. New York: McGraw-Hill.

TABLE 1. Two stories

ACES 1	ACES 2
The Executive Director had just taken over management of the ACES. She had limited knowledge about her team members (around 150 professionals) when the great challenge arose: to define a strategy for dealing with the COVID-19 outbreak. In addition to responding to the demands of the Directorate-General for Health, she created a crisis management team and developed a contingency plan.	Despite knowing all the team members well, and the apparently good relationships between these professionals, and a good connection between them and the ACES even though the health units are dispersed over an extensive geographical area, being able to change very quickly was far from guaranteed for the Executive Director. One of the first measures he took was the creation of a crisis management team and a "battle plan".
Facing a public health problem, she soon engaged in collaborative strategies with municipal structures, hospitals, higher education institutions, primary and secondary schools, civil protection, firefighters, and other associations.	The interaction between the members of this ACES and other relevant community actors (municipal structures, hospital, schools, firefighters, etc.) has clearly intensified.
Internally, the spaces for handling COVID and non-COVID cases were reorganized.	Internally, the spaces were reorganized and the equipment redistributed according to the new needs.
Some characteristics of the professionals' personal protective equipment had to be improvised, due to its unavailability in the market.	The work of entire teams assigned to some units belonging to this ACES was reorganized in order to create specific areas of service to separately receive COVID-19 and non-COVID patients.
Multi-professional teams were created including healthcare, civil protection and social care professionals.	In view of the heterogeneity of the community, specific action plans were created by specialty or by region. Each operation has been given a name so that professionals and users would be on the same page.
Working hours and schedules were changed and alternative compensation strategies were created. New forms of communication were developed with support for new technologies.	Multidisciplinary home support teams were created.
Added-value initiatives emerged. For example, a group of professionals established contacts with patients who did not have a designated family doctor. There were some professional groups whose activities were postponed and were assigned to other necessary activities, is most of cases by personal initiative. Teleconsultation was implemented, with productivity gains.	A number of different strategies were adopted to guarantee the supply of personal protective equipment to professionals, given their lack in the market.
Intermediate leaders emerged, with gains in team cohesion and initiative and, consequently, in results. This Director had the opportunity, in a short time and during a crisis, to become acquainted with her team, and strengthen the team's spirit, and to nurture its sense of purpose. Satisfied with the response produced, she fears that the sense of mission created in the meantime will be lost.	Care hours were extended, and shifts without contact between teams and rotating schedules were established.
	New forms of communication were developed between the teams (e.g. health professionals' WhatsApp groups, digital meetings, SMS) in order to facilitate the circulation of information.
	The Director was particularly pleased with the results, as they reinforced the sense of purpose within the ACES, as well as its culture of safety and high performance.

of the verb and not the noun, so as to emphasize the dynamic and eventually ephemeral nature of organizational solutions) with a highly adaptive potential. In fact, trying to change almost everything indicates a recognition that the existing organizational solutions are not appropriate, but also that the creation of new solutions, as a continuous process of organizing, can always be initiated, shared and, eventually, institutionalized. In our view, the experience expressed in the two stories can be interpreted around four key ideas:

Idea 1. Contexts of crisis favour the emergence of transformational leaders because they comprehensively activate the normative goals. The role of transformational leaders in initiating change is well known[4]. However, we consider that crisis contexts, especially those involving healthcare, activate the generalized normative goal[5], that is, the proclivity to act appropriately for the benefit of a collective entity, relegating to the background the goals, which are also generalized, of maximizing personal resources (gain goal) and of improving current well-being (hedonic goal). Once the common good becomes a priority, leaders find a context conducive to change according to this purpose, even if it entails experiencing unpleasant situations (hedonic goal) or not obtaining immediate gains (gain goal). In this context, the propensity for organizational change becomes much clearer.

Contexts of crisis favour the emergence of transformational leaders

Idea 2. Crisis contexts encourage systems to create ways to deal with unexpected situations, enhancing the commitment to resilience and the deference to expertise in order to provide the most appropriate responses, that is, to maximize organizational reliability. According to the high-reliability approach[6] reliable organizations are able to deal with unexpected events because they demonstrate commitment to resilience, that is, their members are able to reuse the resources they have to improvise solutions, learn from them and, when necessary, bounce back to the initial state. On the other hand, in emergency situations, highly reliable organizations show deference to expertise, that is, they change their decision-making dynamics and authority structures in order to find flexible solutions. They do this by migrating decision-making to the actors who are more knowledgeable and not necessarily

[4] Yukl, G., & Gardner, W. (2020). *Leadership in organizations* (9th ed). New York: Pearson.

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those who occupy hierarchically higher positions. In both cases, the signs of organizational experimentation and the mobilization of different actors with diverse resources are very evident: in spaces, teams, equipment, and work strategies.

Idea 3. Crisis contexts promote the coordination of work based more on informal relationship between actors, both within and between organizations, promoting more effective responses because they come from higher levels of relational coordination. Relational coordination[7] describes more spontaneous forms of coordination established at the system level, that is, in the articulation between different internal and external actors, based on frequent, timely, accurate problem-solving oriented communication. To be effective, these routines of information flow must be based on a relational infrastructure of shared objectives, mutual knowledge, and mutual respect between actors. This ability promotes effective responses of systems that operate in situations of intense interdependence between actors who face uncertain situations and are required to come up with fast responses. The reported cases illustrate how two systems promoted the circulation of information between internal and external actors.

Crisis contexts promote the coordination of work based more on informal relationship between actors

Idea 4. Situations of crisis prompt changes in communication strategies, as a constitutive element of organizing processes. These stories, as also demonstrated by this crisis in general, highlight the relevance and indispensability of communication at all levels. Communication becomes a key factor in the organization, both internal and external, of the institutions, but also in its consequences for the prevention and provision of health care, both for the population in general and for the population that uses health care services.

More generally, these stories demonstrate changes in behaviour. According to Dutta-Bergman[8], the dominant approach to behavioural change in the field of health care is often found at the individual level. But this focus on health behaviour in the individual can be problematic, as it reflects an individualistic cultural bias, it ignores the role of context and structure, and it is cognitively oriented. It is therefore crucial to consider the socio-cultural contexts and the

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[7] Gittell, J. H. (2016). *Transforming relationships for high performance: The power of relational coordination.* Stanford: Stanford University Press.
Gittell, J. H., Logan, C., Cronenwett, J., Foster, T. C., Freeman, R., Godfrey, M., & Vidal, D. C. (2020). Impact of relational coordination on staff and patient outcomes in outpatient surgical clinics. *Health Care Management Review,* 45(1), 12–20. DOI: 10.1097/HMR.0000000000000192.

[8] Dutta-Bergman, M. J. (2005). Theory and practice in health communication campaigns: a critical interrogation. *Health Communication*, 18(2), 103-122. DOI: 10.1207/ s15327027hc1802_1.

need to develop forms of communication that are not intended only for those considered to be "at-risk groups", but for the population in general, because in health risk situations, such as pandemics, behavioural aspects are critical[9]. Organizations that are close to users thus have increased responsibilities, but also the advantage of that same proximity, which allows them to consider, in these communicative processes, aspects such as individual conditions (how they act), the social and economic situation of the community, environmental factors, and the organization of the health system to which users have access[10].

in crises, systems tend to abandon their habits and routines, simply because new situations require new responses

In a nutshell, in crises, systems, that is, individuals, teams, organizations and communities, tend to abandon their habits and routines, simply because new situations require new responses. As a crisis evolves, key actors become involved and committed to achieve a better understanding of the situation and to devise solutions that have not been tested or learned before. In this sense, crises are also opportunities for deep learning, which opens up opportunities to question the basic assumptions on which the priorities, objectives and organizational models of the systems are based.[11]. Without this deep learning, systems cannot evolve.

But crisis situations do not always pave the way for deep collective learning. In the specific case of health services, learning is a complex process, involving the institutionalization of a large number of routines and practices,[12] and the existence of multiple levels of analysis (individuals, teams, organizations, communities),[13] whose communicating channels may become obstacles to learning, has to be taken in to account. Capturing the knowledge produced

[9] Gillis, D. E. (1999). The "People Assessing Their Health" (PATH) project: Tools for community health impact assessment. *Canadian Journal of Public Health*, 90 (Suppl. 1), 53–56.

[10] Parvanta, C., Nelson, D. E., Parvanta, S. A., & Harner, R. N. (2011). *Essentials of public health communication*. Ontario: Jones & Bartlett Learning.

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[12] Garvin, D., Edmondson, A., & Gino, F. (2019). Is yours a learning organization? *Harvard Business Review, Winter*, 86-93.
     Singer, S. J., Moore, S. C., Meterko, M., & Williams, S. (2012). Development of a short-form learning organization survey: The LOS-27. *Medical Care Research and Review, 69*(4), 432–459. DOI: 10.1177/1077558712448135.

[13] Harrison, M. I., & Shortell, S., M. (2020). Multi-level analysis of the learning health system: Integrating contributions from research on organizations and implementation. *Learning Health Systems*, e10226. DOI: 10.1002/lrh2.10226.
     Crossan M., Lane, H. W., & White, R. E. (1999). An organizational learning framework: from intuition to institution. *Academy of Management Review*, 24(3), 522-537. DOI: 10.5465/amr.1999.2202135

during the crisis and the creation of moments of individual and collective reflection are fundamental processes in order to improve the learning process and its impacts on the strengthening of the NHS, in this case, the ACES. We are not sure that, in the context of overuse of resources and exhaustion of the different actors involved, it is possible to further enhance this collective learning. If so, are we missing the opportunity to retain the essentials?