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Design driven approaches in healthcare:

An action research through European Projects participation

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ABSTRA	ABSTRACT		
PART 1	- SETTING THE SCENE	8	
1 TH	HE BINOMIAL DESIGN-HEALTHCARE	8	
1.1	New services in Healthcare: current status and trends	8	
1.2	Design methods and research		
1.3	THE EUROPEAN POLITICAL AGENDA		
1.3	3.1 European Research: the call for user participation in healthcare	14	
1.4	THE PROMISING ROLE OF DESIGN		
2 AI	M OF THE WORK AND METHODOLOGICAL APPROACH	17	
2.1	Research questions	21	
3 ST	ATE OF THE ART ANALYSIS	24	
3.1	ICT AND THE MARKET OF HEALTHCARE AND WELLBEING		
3.2	PATIENT/CITIZEN CENTRED APPROACHES		
3.3	MHEALTH		
3.3	3.1 The healthcare apps' market	29	
3.3	3.2 Wearable sensors		
3.4	Mobile and Social media		
3.5	Behaviour Change		
	ELD REDICTIVE AND PERSONALISED HEALTHCARE		
5 PF	REVENTIVE AND PARTICIPATORY HEALTHCARE		
6 PE	EGASO AND JUVENILE OBESITY		
6.1	THE GRAND CHALLENGE		
6.2	SPECIFIC OBJECTIVES	50	
6.3	DESIGN APPROACH AND TOOLS	52	
6.4	ANALYSIS OF RESULTS	56	
7 NI	ESTORE AND HEALTHY AGEING	58	
7.1	THE GRAND CHALLENGE		
7.2	SPECIFIC OBJECTIVES	61	
7.3	DESIGN APPROACH AND TOOLS	62	
7.4	Preliminary results		
8 SH	IARP@WORK AND AGEING IN THE WORKPLACE	66	
8.1	THE GRAND CHALLENGE		
8.2	SPECIFIC OBJECTIVES	68	
8.3	DESIGN APPROACH AND TOOLS	70	
8.4	CONSIDERATION ON THE APPROACH	72	
PART 3	- DISCUSSION AND CONCLUSIONS	74	

9	THE	E ROLE OF "DESIGN" IN HEALTHCARE RESEARCH	74
10	TH	E FUTURE OF HEALTHCARE: THE VISION EMPOWERED BY P4	
1	0.1	More than user centred: a multiuser-driven ecosystem	
11	THE	E NEED FOR NEW POLICIES FOR CO-CREATING HEALTH	
12	CON	ICLUDING REMARKS	
13	BIB	LIOGRAPHY	
1	3.1	OTHER RELEVANT WEB SITES	
ANN	IEXES	S	
14		NEX 1 - THE PROJECT PEGASO	
1	4.1	THE RATIONALE BEHIND PEGASO	
	4.2	THE UCD APPROACH	
1	4.3	PROJECT START: REQUIREMENTS DEFINITION PHASE	
	14.3		
14.3.2			
14.3.3			
	14.3		
	14.3		
1	4.1	Along the project duration: Pre-pilot phase and system co-design	
1	4.2	PROJECT END: FINAL PILOT AND OVERALL EVALUATION OF THE PEGASO SYSTEM	
1	4.3	Conclusions and Lessons learned	
	14.3	2.1 Considerations for follow-up "The Life Companion"	145
15	ANN	NEX 2 - THE PROJECT NESTORE	148
1	5.1	RATIONALE BEHIND NESTORE	148
1	5.2	MODEL AND APPROACH	151
1	5.3	FIRST PHASE METHODOLOGY AND FINDINGS	155
1	5.4	Preliminary findings	156
1	5.5	TRANSFER OF USER PERSPECTIVES TOWARDS TECHNOLOGIES AND SOLUTION DEVELOP 161	PMENT
16	ANN	NEX 3 - OTHER PROJECT PROPOSALS	
1	6.1	Wellbeing at work: Sharp@Work and IdealAgeMode	163
	16.1	.1 Methodological approach in Sharp@Work	165
1	6.2	EMPOWERMENT FOR DISABLED PEOPLE: PROJECT COMETA	
	16.2	.1 The methodological framework	175

Abstract

The PhD research explores how user-centred and participatory service and product design can be instrumental for the definition of novel healthcare approaches towards patient empowerment and personalised medicine. Indeed, healthcare is undergoing a true revolution towards new paradigms, where the traditional reactive approach based on symptoms and disease management is progressively giving way to a systemic approach oriented to proactive, preventive and personalised medicine. In such new trends the technological innovation and, in particular, ICT and mobile technologies, at the heart of digital transformation in all sectors of the society, play the role of key enablers.

The research adopts Frayling's "research through design" model [Frayling 1993] and explores the practices and processes of design through an action research approach considering the preparation, development and participation in two EU funded research projects, that have provided the opportunity to make use of co-design and participatory approaches for boosting user involvement and innovation in the field of healthcare.

The purpose of the work is therefore, on the one hand (i) to explore which role design can play to redefine healthcare in a context in which economics, demographics and digital technologies put pressure towards innovative ways in medicine, and on the other hand (ii) to investigate the use of codesign and participatory design tools for the development of new products and services for a healthier lifestyle and for a sustainable engagement of people in their long-term healthcare management.

The research described in this work has been conducted through involvement in the design and implementation of two specific projects related to empowerment of citizens with regard to health and to the use of ICT as a means to provide empowerment instruments.

From an editorial point of view, the work is structured in three parts as follows:

- Part 1 provides an overview of the current trends in healthcare and the background to which the work is linked. This part covers also the methodological approach followed and the state-of-the-art analysis. The methodological approach followed in the development of the PhD project with focus on how design can be used to develop solutions for healthcare, but also to drive and support the paradigm shift towards Predictive, Preventive, Personalized, and Participatory healthcare, the so called P4 medicine. The analysis of the state of the art, in particular in the field of digital technologies and services, is focused on the evolution of digital technology and how such technology is currently perceived and used in the healthcare sector, by patients, but, in general, by all users, as the path towards P4 medicine involves more actors. A large part of the state-of-the-art analysis has been conducted in preparation of and within the course of the EU projects, which constitute the core of the work.
- **Part 2** is the core part of the work. It consists of the description of the projects and the work done according to an action research approach. It focuses, in particular with regards to the design approach adopted in the two projects and how design methods have been used to achieve the objectives of the project. The two projects, namely PEGASO and NESTORE focus on the prevention aspects of healthcare targeting specifically adolescents for the prevention of obesity and related comorbidities and elderly people within the concept of healthy ageing.
- Part 3 concludes the work with some reflections and concluding remarks. It focuses on the potential scenarios for the evolution of healthcare, trying to depict a role for design, also with regard to future research within the European arena where design researcher have the opportunity to take a leading towards the co-creation of a novel healthcare approach engaging patients and professionals in a participatory approach.

Part 1 – Setting the scene

1 The binomial design-healthcare

The relevance of the binomial design-healthcare is increasing and application of design to develop new services in the area of public health and in the empowerment of citizen in managing their own health is growing in scope and can impact several areas of application: from the design of mobile apps to the design of care pathways to the design of new care models as a whole. Several design disciplines become relevant, such as interaction design, user-centred and participatory design, design of communication, etc.

The scope of this work is therefore to investigate further such binomial, in consideration of the new trends in medicine and leveraging the experience conducted through the development and participation in European funded research as an experimental field to investigate the growing role of design as integrated discipline for the development of new pathways in healthcare towards patient empowerment and personalised medicine.

1.1 New services in Healthcare: current status and trends

Healthcare is undergoing a true revolution, towards new paradigms for all actors involved, first of all on the scientific and clinical side, where the traditional reactive approach based on symptoms and disease management is progressively giving way to a systemic approach oriented to predictive, proactive, preventive and personalised medicine, the P4 medicine The concept of P4 medicine was introduced and illustrated by Leroy Hood in "A personal view on Systems medicine and the emergence of proactive P4 medicine: predictive, preventive, personalised and participatory" [Hood 2012]. In such new trends the technological innovation and, in particular, ICT and mobile health play the role of key enablers. Indeed, the digital transformation, which is encompassing all economic sectors, is characterised, among others, by the so-called "big data" where enormous amounts of digitalised information and data have

to be managed, stored, analysed and used when needed. This in turn is made possible thanks to advanced sematic annotation and algorithms, often referred to as artificial intelligence, that allow to understand and interpret the information in relation to the specific application field, making sense to seemingly incoherent amount of data, allowing the development of new models and new approaches to consolidated fields of applications.

The healthcare sector is one of such examples where consolidated models of care are undergoing a profound transformation also thanks the digital revolution; indeed, as evidenced also in [Flores 2013], three converging megatrends are behind such transformation:

- 1. The progress of the bio-molecular disciplines, the so called "omics", and the increased ability to understand the biological complexity of disease;
- 2. The digital revolution, with the explosion of the Internet of Things (IoT) and the "big data" phenomenon, the digitalization of medical/clinical data together with the enhanced capacity to store and analyse and make sense of such amount of information; and
- 3. A population always connected, with the large use of social networks where people (with the role of citizens, consumers or patients) communicate with others, provide information and most importantly have access to information.

The role of the individuals, that more and more take interest in managing their own health, also in unconventional ways – one should also think of the booming of the wellbeing sector – is central to such revolution, also thanks to the growing number of empowerment tools (see also the growing number and impact of consumer health and wellbeing apps as well as instruments for home diagnostics). Consumers – citizens and patients – and their new attitudes and awareness with regard to health are actually driving the transformation in healthcare. The advent of eHealth with the digital management of patient information and the wide adoption of Electronic Health Records (EHR) has changed the way healthcare is managed in particular from an administrative point of view, concepts such as patient empowerment, personalized medicine will have an impact on the

development of new healthcare models that will become patient-centric as opposite to the current disease-centric models.

As mentioned above P4 medicine focuses on prevention and on individual and population wellbeing. Thanks to the results coming from the Human Genome project¹, P4 postulates that, ideally, the risk of disease can be predicted at cellular level well before symptoms develop and therefore the actual occurrence of disease can be prevented through the participation of the "patient" in preventive actions. P4 leverages large-scale social participation; patients must be activated and engaged to become protagonists of their wellbeing. They must be willing to collect and share personal health data. As Flores and colleagues indicate in [Flores 2013], "...the driver of an emerging P4 healthcare system will be information consumers can use to better manage their health". In the same papers the that authors claim the P4 approach, combining the integrated/multidisciplinary approach of systems medicine with the active participation of networked users, will reduce the incidence of disease while providing a more cost-effective healthcare.

¹ <u>https://www.genome.gov/12011238/an-overview-of-the-human-genome-project/</u>

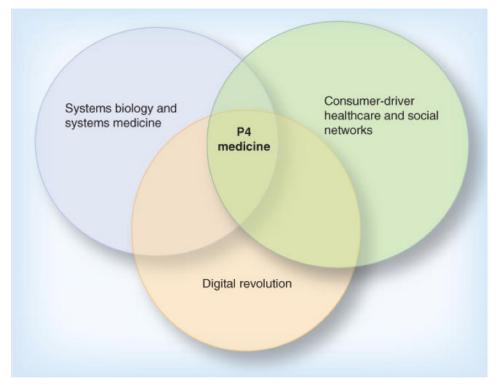


Figure 1 - Three converging megatrends driving the transformation of healthcare. P4 healthcare is emerging at the intersection of these megatrends. (Source Flores et al. [Flores 2013])

Within this trend, novel healthcare models based on e-health and m-health are being adopted with an approach that has initially focused on services related to organisational aspects and gradually moving towards the support of clinical aspects. Several initiatives are taking place to promote full adoption of e-health, which must include the entire healthcare ecosystem, the patients first of all, with a participative approach that starts from prevention. Indeed, as indicated earlier, the P4 medicine approach calls for an increased role of the patients, which need to be more empowered and become managers of their own health starting from the status of being health, taking action before the onset of disease. With regard to the P4 approach Prevention and Participation are the core elements that call for patient active engagement and where the role of designers can be best exploited. Current EU research has stressed the role of the patient for the development of new healthcare models and asks for projects showing evidence of User Centred Design in the proposed research approach.

1.2 Design methods and research

"The nature of design as an integrative discipline places it at the intersection of several large fields," [Friedman 2000] fields of thinking and pure research and fields of practice and applied research. The fields of theoretical study are the natural sciences, the humanities and liberal arts, and the social and behavioural sciences. The fields of practice and application are human professions and services, creative and applied arts, and technology and engineering. In his view there are four areas of design research: Philosophy and theory of design, research methods and research practices, design education and design practice.

Accordingly, this work, analysing the application of design research tools and methods to a specific discipline, in the area of human professions, services and technology, focuses on an *application of design practices in the field of healthcare*.

The application of design approaches to social challenges has significantly expanded over the last several decades, and design research has developed to cover multi-dimensional and multi-disciplinary research. Health and healthcare services are among the social challenges that are at the focus of significant interest for both design practitioners and design researchers. For example, *service design* [Meroni 2011] has led to new opportunities to address improved products and services in the field of healthcare; focussing on prevention (one of the key challenges and trends in healthcare) behaviour design - based on psychology and behaviour change theories – allows to design products and solutions able to influence human behaviour [Michie, 2011]. Furthermore, the advent of digital transformation and the impact on all economic sectors, public and private, calls for innovative approaches in the field of public health, in the broader definition as "a state of complete physical, mental, and social well-being and not merely the absence of disease or infirmity" (WHO 1948), therefore encompassing prevention and social determinants, and focussing on the

person, rather than on the illness.

Design Thinking (DT), as well as user-centred design (UCD), are increasingly being applied to issues in the area of healthcare, in particular for issues related to behaviour as a determinant for wellbeing. Indeed, health behaviour change is an obvious area in which these approaches may be successfully applied [Michie 2011].

The use UCD techniques, such as ethnography and prototyping, are very promising to involve user in adopting technologies for managing own health, leading towards patient empowerment. Numerous examples of the use of UCD and design thinking in this area are described in literature [Brown 2010], [Donetto 2015], and [Matheson 2015].

Another important contribution is the use of co-design for health-related research, such as a recently described research approach called and experience-based co-design (EBCD). This participatory research approach draws upon design tools and ways of thinking in order to bring healthcare staff and patients together to improve the quality of care [Donetto 2015].

1.3 The European political agenda

A more cost-effective healthcare is a key priority of the European political agenda; "Better Health and care, economic growth and sustainable health systems" together with "Digital transformation in Healthcare" are two of the key objectives of the EU research in the H2020 programme, and many projects have been proposed and funded to further the research in these areas. Active involvement of users and patients, as well as the development of sustainable care models that respond to the new needs and exploit the advancements enabled by bio-molecular research and by the **digital revolution** are key elements (and often pain points) of such projects. In particular the use of digital technology is a novelty for both healthcare professionals, and citizens and patients; sustainability of approaches such as 4P is driven by the adoption and continued use of digital technology. Design methods, such as UCD or participatory and co-design, can be beneficial to understand the motivation factors to empower all actors in the

new healthcare models.

1.3.1 European Research: the call for user participation in healthcare

To further underline the role of the European Research, as a relevant playing field for experimenting novel approaches in healthcare and the central role of the user towards personalised approaches in healthcare, it is worth to recall some of the key areas of investigation funded and how the research conducted in this work, finds its roots in the EU priorities.

The increasingly relevant role of ICT in healthcare had been recognised already during the previous Framework Programme, FP7. However, a full integration of the two areas of research had not been achieved. Indeed, ICT and Health were two separate programmes under different directorates. ICT for health was, however, an important part of the ICT research with many dedicated calls for proposals, and in the health research programme, mostly focused on traditional approaches and on furthering progress in medicine, elements of social innovation calling for novel approaches were present. Key areas of research in FP7 can be identified under the following labels:

"Personal Health Systems"

"Personalised health, active ageing, and independent living"²

"Social innovation for health promotion"

The approach taken in H2020, now at its end, is that of an integrated approach in recognition of the digital transformation permeating all sector of society and economy, but still lagging behind, for different reasons, in the area of healthcare. Key areas of research in H2020 can be identified under the following labels:

 $^{^2}$ Under this area of the work-programme, within the context of the call ICT-2013.5.1, the project PEGASO has been funded.

"Personalised Medicine"³

"Better Health and care, economic growth and sustainable health systems"

"Digital transformation in Healthcare"

In all of these areas, explicit reference is made to user-centricity in the research work.

Leveraging these opportunities, and responding to European calls, we have achieved two successful submission, which are central and integral part to this work.

1.4 The promising role of design

The complexity of problems in healthcare requires different competences and expertise to approach the problem. Generally, looking into problems with a multidisciplinary approach, enhancing technology and information transfer among different disciplines, has provided new insights and original viewpoints leading to innovation in many industrial sectors. However, as Dunchan and Breslin [Duncan 2009] wrote, "While the discipline of design is the core of innovation in many industries, it is not widely known or practiced in health service organizations despite a natural affinity between design and medicine. Understanding and employing the power of design in health services will allow medical institutions to develop more effective health services, enhance patient satisfaction, and meet important human needs."

More recent research, also within the context of EU research and as evidenced by a growing number of projects addressing healthcare through the Design lens, there is evidence of the growing intertwining between healthcare and design and the relevance of the role of design in the development of healthcare products. For instance, thinking of the industry of medical products, we can intuitively understand how interaction design,

³ Under this area of the work-programme, within the context of the call SC1-PM-15-2017, the project NESTORE has been funded.

for instance is very important for complex machines, such as diagnostic equipment that need to be operated by humans. More in general we have seen how design is linked to ergonomics and the application of User Centred Design (UCD) in the field of different medical products and devices.

The digital revolution mentioned above, and the trend of medicine to evolve towards a P4 model, strengthen the importance of design to anticipate how to best develop products, services and process that fit such new healthcare model.

The focus is, in particular, on two Ps: Preventive and Participatory, which we see as linked to each other, and which both are related to the concepts of empowerment and engagement.

The medicine of the future will have the person (patient) at its focus. The new paradigm calls for a shift:

- from symptoms the person is sick and in need of care, the focus is to cure the symptoms and from symptoms understand the causes;
- to causes (prior to the occurrence of disease) the person is at the centre of the care process with his/her genetic characteristics, lifestyle, environment, etc.; by analysing such information a risk assessment can be performed, leading to the design of tailored interventions or recommendations with regards lifestyle modifications (or other specific preventive interventions) that may anticipate the occurrence of disease and related symptoms.

In this respect medicine becomes preventive. In order for the approach to be successful, it needs to engage citizens with a participatory process where tools, services and care models are co-designed with the citizens and with the participation of all the sector actors.

At the same time, we see that the role of designers is changing, and has changed, significantly from design for people to design with people. Towards this change designers have developed different competences to involve users, into the design process and design in a collaborative way. The role of the design becomes therefore to better understand the broader physical and social environments in which services and technologies will operate and how they relate to the contexts of the citizen/patient life.

Although the concepts of wellbeing and lifestyle have permeated peoples' daily life, also thanks to wearable technologies, fitness apps, and the opportunity to easily access information from the Internet, still the healthcare sector remains focused on the medical technology and economics aspects in order to cure the disease and administer its cost values and people are not regarded a relevant factor within this system. The need for broader thinking, in a system approach, where relative factors in the environment and characteristics of individuals can support early prediction is what the P4 medicine calls for. Indeed, in order to understand and include such factors, individuals need to be involved actively in their everyday health. Participatory approach is a way to integrate participant involvement in different phases of the process.

Participatory methods are centred on the principle that participant engagement can provide value throughout planning and implementation of interventions, leading to results that directly reflect on a community's needs and perceptions.

In the design of innovative interventions, services, products, and models, which is the scope of research, participants are given an active role so that they can contribute to the direction and methods of the research itself. Multiple benefits are associated with the use of participatory methods in health and care settings, including developing collaborative and productive partnerships with participants, providing participants with a voice and leveraging participant engagement to stimulate positive change [Jagosh 2011, Jagosh 2012] and the design of better tailored products and services.

2 Aim of the Work and Methodological Approach

Based on the trends described above, the promising results coming from

initial projects and experiments applying design methods to healthcare and the future of healthcare driving towards a 4P medicine, this work comes from the observation that design is a discipline more and more relevant for the development of solutions for healthcare and that design techniques can be used to empower citizens in managing their own health through their direct involvement in co-design and participatory design processes. Objective of this work is therefore to understand better how the binomial design-healthcare can be further developed and exploited to provide solutions and approaches that address the needs of the new healthcare models implied by the 4P trend. The work has considered the different dimension of the 4P, with a major focus on the application of design-based approaches in research and development projects of novel solutions for prevention and empowerment of the patient/citizen.

Through the work performed and the analysis of the results achieved in the research projects, the work would like to understand how the application of design-based approaches (UCD and participatory design, in particular) has been effective in the different phases of the research in terms of requirements capture, actual involvement of the users, capability to transfer the findings and the requirements to the development phase, capability to develop and "design" an overall user experience that can motivate users towards real empowerment. The objective is that of determine a new approach to healthcare research that adopts participatory approaches in the spirit of the P4 medicine. Although it is obvious that it is the specific healthcare professionals that define the clinical objectives of the research and the end points of the (clinical) trials, the role of the designer can be relevant in several ways:

- as a mediator across the different disciplines involved;
- as a facilitator for the user involvement and participation in the research;
- as a key actor in the communication of the research aims and results ensuring that information is properly built and addressed to the intended targets.

In this respect this work aims at providing contributions as follows:

Methodological – P4 is a novel approach to medicine. The core of such new approach lies in scientific disciplines linked to biology and genomics with key enablers in the digital technologies that allow collection, analysis and interpretation of data, artificial intelligence, etc. It is therefore a complex multidisciplinary field. In terms of ecosystem, in particular when we look at prevention, the involved actors are numerous and with different interests. The user/patient is at the centre, but there is a complex ecosystem of relations and information around him. Research projects that exploit Design Thinking as an approach to address complex problems and that have embedded UCD and participatory design from the beginning yield the promise to achieve sustainable results.

Proactive – Based on the experience from the projects, understand how design can best be applied to develop a model – in perspective also in business terms - of healthcare fostering P4.

As said, the aim of this work is to investigate the role of Design in healthcare in light of the P4 trend. P4 brings a number of challenges as it is at the intersection of several disciplines that need to develop common languages to interoperate effectively. In particular it stresses the concept of empowerment, for patients, first of all, but also for other actors, such as healthcare professionals, that need to engage with novel technologies – digital technologies mainly – developing trusted relationship in support of their professional activities.

The methodology of the research has therefore included three main strategies: Field Research, State of the Art Review and Action Research (i.e. Project Work).

Field Research strategy includes tools such as conferences, research networks, journal survey on topics regarding "mobile health", the "future of healthcare" "digital tools for healthcare services", "design for healthcare", "digital transformation", and discussion with experts from the research networks – including the partners networks in different EU research projects and proposals – which have been used to gather

information about the problem. The results of field research form the background on which the work has been developed, and, more important, they have been the foundation of the project proposals, in order to determine the key areas of research and innovation that have to be addressed and how they can be addressed – taking a design drive approach - with a potentially winning strategy.

State of the Art Review including Literature Review has been done in three main areas has been done in three main areas: (a) Mobile Technologies in Healthcare, (b) Design thinking towards Service Design, (c) Methods, approaches and tools for social interaction and user empowerment in healthcare. State of the art analysis is described in Section 3. The state-of-the-art analysis has also been relevant to define the technological approach to be used in the projects.

Action Research has been performed through direct participation in two research projects, PEGASO and NESTORE, in which UCD and co-design tools, mainly in the form of participatory workshops, have been used to gather data and guidelines for the development of solutions. PEGASO can be seen as the focus project in which I have taken part with a leading role in the definition phase and then as project manager. In the project NESTORE, I developed the overall concept defining the methodological approach. As the project was funded, I took part in the first phase of requirements definition and in the first workshops and focus groups conducted with users. The main elements of the project work are reported in Sections 6 and 7, with more details given in Annex 1 (the project PEGASO) and Annex 2 (the project NESTORE).

In both projects, the approach is based on Frayling's "research through design" model and explores practices and processes of design through the direct participation in projects, exploring the theme of prevention.

The research analyses the use of design to develop approaches products and services supporting empowerment at different levels, which have the potential of contributing to a new model of healthcare based on prevention and proactive care. As said, the work has been performed focussing on two main projects addressing two different grand challenges:

- Prevention of obesity and related illnesses, conducted within the EU funded project PEGASO;
- Support to healthy ageing and management of chronic diseases, which is another key priority in the EU agenda for healthcare, within the project NESTORE.

In addition, within the course of the work there has been the opportunity to apply design methods to other healthcare related themes such us ageing in the workplace and development of strategies for engagement of disabled children in sports' activities.

2.1 Research questions

There is a synergic binomial between design-based approaches and interventions towards new models for healthcare and wellbeing. The P4 medicine: predictive, **preventive**, personalised and **participatory**, in particular with regard to the preventative and participatory dimensions, focussing on people empowerment and active participation, clearly calls for expertise and multidisciplinary capabilities that can be exploited in design methodologies and tools, such as workshops, focus groups etc. Literature shows that in projects that address different aspects of healthcare and wellbeing, design-based approaches have shown potential winning strategies; such strategies can be instrumental for the take-up of P4.

The main research question is therefore that of contributing a design perspective to the debate on the future of healthcare with focus on the 4P medicine. How can **design be integrated in the overall transformation** that healthcare is undergoing? How can design, as a discipline, **contribute to respond to the grand challenges** of healthcare that are driving transformation?

If we postulate that the pathway towards 4P is the way for the future of medicine and healthcare, what is the role that design can have in each of

the dimensions? The main question is therefore articulated as follow according to the 4P:

Predictive medicine can intervene upstream and is founded on the progress of genetics and genomics disciplines in concurrence with technological developments; with the increased collection of personal health and lifestyle data, the advent of big data, and improved analytics, it is possible to generate better insights earlier. This will allow to "anticipate issues with unprecedented precision," pinpointing behaviours to avoid and actions to take before risk factors even arise. However predictive medicine also presents significant ethical issues that put the individual at the core of the process. They must be willing to collect and share personal health data, they need to understand who has access to such data and how they will be processed. *Can design processes be used to mediate and to involve and educate users and institutions in and ethical use of "prediction", and how can they be applied*?

Personalised medicine is a move away from a 'one size fits all' approach to the treatment and care of patients with a particular condition, to one which uses new approaches to better manage patients' health and targets therapies to achieve the best outcomes in the management of a patient's disease or predisposition to disease (NHS). Although the concept is not new, recent progress is key to its take-up in the common medical practice. However, in addition to understanding how our body reacts to therapies, the empowerment of citizens and willingness to follow a therapy is central and it falls within the well-known topic of "adherence". Taking a personalised approach to empower adherence can reinforce the efficacy of personalised medicine. What is the role of design in this domain?

Preventive medicine has the goal of promoting health and well-being and prevent disease. The role of the citizen is central, pro-active approaches and interventions need to be targeted to address specific risks and classes of populations. Prevention is a focal area of research in the EU, also to address key challenges such as juvenile obesity, healthy ageing, and other

issues that bear a significant economic burden. In this area has focused the project-based research, with the following research questions: Which design methods and approaches are best applicable to the different target population? How can effective solutions be co-designed with users? Can new healthcare models based on prevention be effectively designed?

Participatory medicine may be seen to be including all of the above and using participatory approaches typical of co-design, as well as co-creation tools to actively involve all key stakeholders in the development of personalized products, services and solutions is the way forward. The key research question is therefore, how can design methods foster the development of a participation culture and a healthcare model based on the active participation of citizens and patients?

3 State of the art analysis

The State-of-the-art analysis presented here has been guiding the development of the project proposals (PEGASO, NESTORE and Sharp@Work) allowing to develop an understanding of key design issues in current solutions and identifying the most relevant fields of investigation for the design of the research as well as for addressing potential solutions to be investigated with the user participation and feedback.

3.1 ICT and the market of healthcare and wellbeing

ICT and mobile technologies are key innovation instruments in the process of empowering patients and citizens in taking healthcare in their own hands.

Indeed, based on the understanding that many diseases can be prevented thanks to a healthy lifestyle, there has been a trend towards the development of technologies that help people in self-monitoring their lifestyle so that they can become aware of their behaviour and take actions in order to improve such behaviour towards healthier lifestyles. Healthy lifestyle is an effective prevention strategy and can be applied at different level of prevention, being most effective as primary prevention strategy.

The analysis of the state of the art has therefore focused on digital technologies and instruments that can support prevention through a strategy linked to behaviour change.

The success and the uptake of such technologies by citizens requires that they are developed following good design practices consider users at the centre of the wellbeing process. Indeed empowering citizens with instruments that fulfil their needs and that can move positive emotion, jointly with the progress in the medical fields and in particular in the areas of "omics" (see Chapter 1.1) are key factors for the development of successful "business models" underpinning P4 medicine⁴.

With the increasing role of ICT in different fields of applications, also healthcare is undergoing a very significant revolution. The past years have marked a key turning point in the history of the Internet. Convergence of major trends is occurring which is driving changes in people behaviour and expectations. These trends include the exponential rise in use of smartphones and tablets, increased Internet access speeds, the development of IoT and Big Data, new business models driven by online commerce and app stores, the impact of social online communication, and software delivery transitioning from prior PC/internet models to cloud-based services accessed with touch-based devices (smartphones and media tablets).

With more than five billion mobile users worldwide and a massive global network, mobility is attracting significant attention among the healthcare and life sciences community.

Indeed a 2014 report from PriceWaterhouseCoopers' Health Research Initiative (HRI) entitled "Healthcare delivery of the future: How digital technology can bridge the gap of time and distance between clinicians and consumers" [HRI 2014] provides compelling arguments for a change in how patients with chronic medical issues are monitored in the home setting, together with how patients communicate with their healthcare providers and the healthcare system as a whole. At the occasion of the release of the report, Simon Samaha, MD, Principal, PwC stated that "the adoption and integration of digital technology with existing healthcare processes has not yet fulfilled its potential to transform care and value for patients"; the next

⁴ This analysis does not consider the medical and clinical aspects, which are outside the scope of the work. The work focuses on the use of design methods to engage and involve citizens in becoming co-producers of their health and wellbeing. It may be noted however how the scientific progress bears requirements in terms of how to communicate development to the public. In this respect understanding key levers to best inform the public to avoid misuse and misinformation are very relevant and the tools of communication design can best serve a correct scientific communication, avoiding the traps of the well-known phenomenon of the "fake news" and their diffusion in the social media. Accuracy and reliability of information and their source is indeed one of the key problems of giving patients an active role in healthcare management.

decade will therefore be critical. The report, based on a survey made with over 1,000 industry leaders, physicians, nurse practitioners, and physician's assistants in the United States, indicated the following main priorities for the future of e-Health as see from the clinician point of view:

- Put diagnostic testing of basic conditions into the hands of patients: Close to 42% of physicians are comfortable relying on at-home test results to prescribe medication. → Although not yet very strong, this finding may also be seen as a positive with regard to the acceptance of sensing technologies by clinicians as reliable means to obtain data for medical purposes.
- 2. Increase patient-clinician interaction: Half of physicians said that e-visits could replace more than 10% of in-office patient visits, and nearly as many consumers indicated they would communicate with caregivers online. → Although percentage is not very high, this result confirms some of the findings of the PEGASO project, where the teenagers interviewed indicated that online contact and consultancy with experts is very important. The provision of reliable services and means to communicate with physicians and caregivers is a key target for innovative models of digital healthcare. The uptake of reliable and trustable online communication with healthcare providers would lead to new and more cost-effective ways to provide care and counselling, with satisfaction of both doctors' and patients' needs.
- 3. Promote self-management of (chronic) disease using health apps: 28% of consumers said they have a healthcare, wellness, or medical app on their mobile device, up from 16% last year. Nearly 66% of physicians would prescribe an app to help patients manage chronic diseases such as, e.g., diabetes. → This target is amongst the most promising for the evolution of the market. A key requirement is, of course, reliability and trust on the service. The use of apps also requires a careful design of the user interaction and attention to elements such as engagement, usability, etc.
- 4. Help caregivers work more as a team: 79% of physicians and close to 50% of consumers believe using mobile devices can help physicians to better coordinate care. → While in most cases the end user of e-/m-health services is the patient, the capability to provide an ecosystem of services able to support the whole value network of stakeholders is a winning element towards market success. In view of this when designing the system the whole stakeholders value network has to be considered.

3.2 Patient/citizen centred approaches

Any care process is built around a relationship between patient and doctor [Guarneri 2016]⁵. Any doctor has a better chance of achieving maximum result by engaging in a productive relationship with a collaborative patient. Patient's empowerment aims at creating the best possible conditions for that to happen. Patient empowerment and participation, more in general, is central to the uptake of new models for healthcare and the concept of patient participation is central to P4 medicine.

The concept of patient empowerment is not new; it dates back to the 1960's when "social action and self-help ideologies have placed an emphasis on the rights and abilities of individuals and communities rather than deficits or needs".

Over the decades the issue has attracted growing interest and, today, patient empowerment is considered a potential tool to reduce healthcare costs and improve efficiency of the health systems, reinforcing healthcare quality. Patient empowerment has become an element of high priority in the EU health strategy, supported by national and regional health authorities.

Even though the concept of patient's empowerment is widely known, it is difficult to find a commonly agreed definition of empowerment both in literature and among practitioners. A common element to many existing definitions of Patient Empowerment is that it is considered a means of improving health care effectiveness, increasing the efficacy of treatment as well as transforming the relationship between healthcare providers and patients. Effective policies for prevention may also leverage services and tools related to empowerment.

During the early phase of the research, after a literature review, the

⁵ The analysis performed here has been published in previous work and has been conducted within the scope of the EU project PALANTE (PALANTE project has been co-funded by the European Commission under the ICT PSP Programme, GA 297260. PALANTE has started in February 2012 and has been completed in July 2015).

following definition has been adopted [CEU 2013, EPF 2015]⁶.

"[Empowerment] is the situation where an individual is an active member of his/her own disease management team. Patient empowerment integrates multiple concepts that allow a patient to effectively self-manage his/her disease. In a context of ageing population and increasing number of chronic patients, it is considered a key tool to reduce healthcare costs and to improve quality and efficiency of the health delivery process. ICT applications already help to empower patients (...)".

It is therefore clear that empowerment involves several subjects and requires actions at different levels in the Healthcare Systems. There are a few distinctive elements that can be considered as pre-conditions for effective empowerment policies and approaches [Guarneri 2016]:

Engagement: the patient actively participates in accessing appropriate care, attending and preparing for appointments and using additional resources to maintain a high level of continued involvement in their care

Knowledge: the patient understands his or her condition, is aware of treatment options but also has a basic understanding of their health care system including benefits, available resources and health care consumer rights.

Collaboration: there is a perceived partnership in care and the patient seeks to participate in shared decision-making about their care. He or she can practice assertive communication and active listening and has a reasonable level of trust in their health care provider and the system.

Commitment: the patient is committed to goals/expectations of his/her own treatment approach.

Tolerance of Uncertainty: the patient's ability to balance the probabilities and risks of treatment paths for instance through shared decision-making

⁶ <u>http://www.eu-patient.eu/globalassets/campaign-patient-empowerment/epf_briefing_patientempowerment_2015.pdf</u>

processes.

These five points may be considered as foundation stones. Any empowerment approach, to be effective, has to deal with them and, of course, there are many different ways for doing so. Analysing the different approaches to support effective empowerment, the research has focused on understanding, by means of experimenting with different target audience and for different needs, how to best apply design for the development of product/service systems and in general, ICT-enabled solutions, that can support different approaches to empowerment.

3.3 mHealth

As the Saturday Essay of the Wall Street Journal of the 9th of January 2015 titles, The Future of Medicine Is in Your Smartphone; mHealth therefore emerges as a field with potential to play a significant role in the transformation of healthcare in the direction of user empowerment and participation.

As expressed in the mHealth Green Paper [CEC 2014], "mHealth solutions support the changing role of patients from a rather passive, to a more participative role while enhancing their responsibility over their own health through **sensors** that detect and report vital signs, and **mobile apps** that encourage them to adhere to diet and medication".

According to the above, healthcare, wellbeing and fitness apps are the key elements together with sensing technologies, the key instruments of mobile health in the hands of the users.

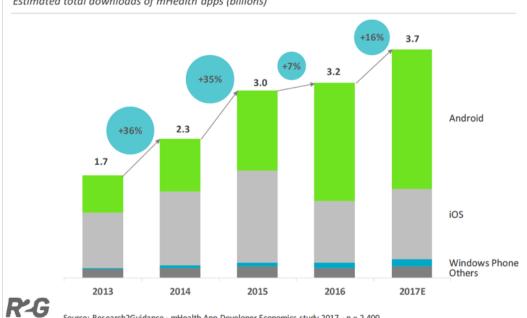
3.3.1 The healthcare apps' market

The market for mobile apps has developed very rapidly becoming a key driver of mHealth deployment and uptake, leveraging increasing penetration of smartphone.

The consulting company research2guidance issues every year a report on the mHealth apps market providing comprehensive and up to date information on this sector and its trends. According to their estimates [R2G 2017] a total of about 325,000 health apps are currently available across multiple platforms on the global market, with 78,000 new health apps added in 2017 alone.

With the market becoming more mature, it has been noted that although the digital health market has started its development that's to outsiders (mostly player coming from the ICT/telecom industry) the interest in developing solutions is growing also within stakeholders from the healthcare industry, health insurances first of all.

Despite the growth and the number of players and apps available, only a fraction of mHealth publishers have found a way to monetize on it. The 7th mHealth Developer Economics Report released by research2guidance indicates that despite the high number of market news with regard to, e.g., new sensors, new financing rounds or partnerships, the core business of mHealth app publishing is still developing at a moderate speed, although the growth on the demand side has slightly taken up again after a significant drop in 2016.



Estimated total downloads of mHealth apps (billions)

Research2Guidance - mHealth App Developer Economics study 2017 - n = 2,400

Figure 2 – Estimate growth of mHealth apps downloads (source research2guidance - mHealth App Developer Economics study 2017) Multi-platform publishing is becoming the norm, with 75% of mHealth publishers developing for both iOS and Android; other platforms currently don't play any major role. Health insurance companies are expected to become key players in the market and trends point to this direction, however they have any yet taken up this expected role; the majority (85%) of companies in the market assume that patients would be willing to share their health data with health insurance companies in return for a cheaper plan, health recommendations or research purposes. There is indeed the need to convey the value given by sharing health information; in order to this to occur due attention needs to be given to privacy policy and regulations, so that they can sustain effectively the new healthcare directions. In general, however there is a need to evolve from this business model, also considering that currently apps from health insurance providers are not above the average quality of the other mHealth apps.

Integration of mHealth apps into the healthcare system is expected to slowly evolve over the next five years. Business potential for apps supporting such integration will continue to grow. In the project PEGASO a pilot approach to allow user-generated data into the patient personal health folder was made. A small survey conducted with general practitioners and paediatrician confirmed that there might be value in the approach. The complexity of the security procedures, however, may be a showstopper on the citizen side (it has also to be noted that in PEGASO the pilot was conducted with teenagers, making the issue even more significant).

Within the patient journey, follow-up monitoring is the phase most influenced by mHealth apps. In general, the impact that apps will have on the patient journey from seeking information, receiving diagnosis and treatment as well as prevention is rated high. The highest impact is seen on providing follow-up advice and coaching after the initial doctor's visit.

Such booming market raises however concerns as to whether adequate research and testing take place prior to the apps being launched on the

digital stores. Concerns also relate to the efficacy of using mobile apps and digital health solutions, in general, and to the attrition rate [Baysari 2015].

Online interventions to promote health behaviour, healthy eating, physical activity, alcohol consumption and smoking have shown relatively small but statistically significant effect sizes [Webb 2010]. Determinants of effectiveness are still unclear [Kohl 2013]. In a review of 15 studies examining the effect of computer and web-based interventions to promote healthy eating in the younger population, Hamel and Robbins [Hamel 2012] reported that children and adolescents would participate in these interventions and that positive changes in both behavioural and physical outcomes can occur. However, these changes resulting from participation are short lived. They suggested that any benefit from interventions must be sustained with post intervention strategies with interventions integrated in school settings and including individual or personalised feedback.

As for mobile applications, the focus has mostly been on chronic conditions, and few intervention studies have been conducted utilizing smartphones [Fiordelli 2013]. Nevertheless, mobile phones hold great promise as an intervention delivery channel because they can enable deeper integration into users' everyday lives [Klasnja 2012].

3.3.2 Wearable sensors

Individual monitoring is an important element of the P4 strategy where empowering people with information and data about themselves is fundamental for the development of awareness about own health and habits. Wearable sensors are the main instrument for the collection of data related physical and behavioural habits.

A wearable device allows a continuous monitoring of the physiological parameters in an unobtrusive way. Sensors, embedded in smart bracelets or smart garments, are able to measure movements as well as physiological parameters. In the field of sport and fitness, in particular, the market today offers a wide choice for such devices, at different prices and with different features. All these devices connect to and exchange data with smartphones. The modern smartphones are monitoring systems by themselves, as they embed sensors that, for instance, can monitor movement or heart rate. Smartphones, in general, are able to connect to different types of devices, including DIY (Do It Yourself) medical devices, collecting data and information, making them real information hubs for their users.

The use of smartphones is constantly growing among teenagers, but also in the older generations, thus increasing the diffusion of wearable monitoring devices that rely on new generation phones as main user interface.

The smartphone also allows surfing the Internet: all data collected about physical activity can be shared with friends in social network. Social networks effects on physical and mental health and the powerful role they can play in health promotion are well documented [Berkman 2000, Cohen 2004] in their ability to channel long lasting positive competition.

In spite of their potential, market studies (such as that conducted by Endeavour Partners, 2014⁷,⁸) indicate that although the rate of adoption increases in time, the abandonment rates are still quite high, and attention needs to be paid to engagement strategies.

⁷ https://medium.com/@endeavourprtnrs/inside-wearable-how-the-science-of-human-behavior-change-offers-the-secret-to-long-term-engagement-a15b3c7d4cf3;

⁸ https://medium.com/@endeavourprtnrs/inside-wearables-part-2-july-2014-ef301d425cdd.

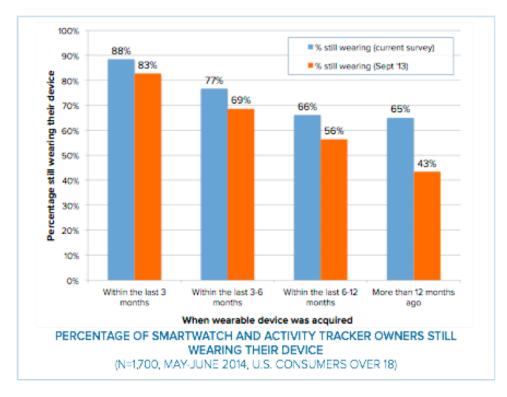


Figure 3 – Rate of usage of wearable devices (Source: Endeavour Partners)

"The lack of long-term utilization raises the stakes for any company incorporating wearables and related data into its products or services. It's not enough to sync with, link to, or work alongside one of the current devices on the market, or to partner with one of the many start-ups to design an even better device. **Designing a strategy to ensure sustained engagement is the key to long-term success in this highly competitive space**."

Due to their potential and ever-increasing features, wearable sensors remain a fascinating technology for research projects in the field of healthcare and wellbeing and they have been studied in all the projects conducted within the course of the PhD development. Starting with the project PEGASO, where smart garments and smart bracelets have been developed in co-design with teenagers, and then in NESTORE, where the focus has been more in the co-design of the overall approach to understand the best wearable devices to support the solution⁹.

3.4 Mobile and Social media

Across the western world, there has been a dramatic rise in the number of people who engage with social media. Although different social networks often have different elective field of application, the phenomenon cuts across all generation with popularity of a particular social network varying with age.

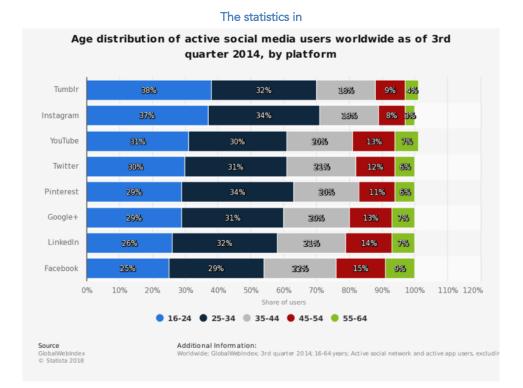
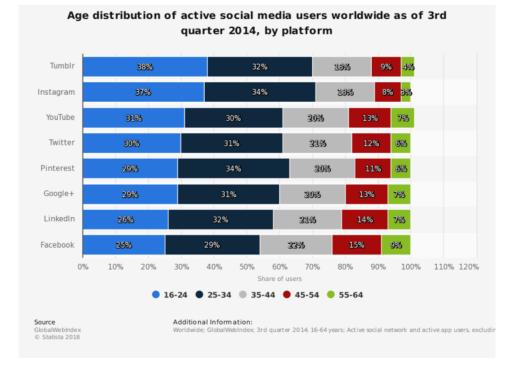


Figure 4¹⁰ show the distribution by age of active social media users worldwide sorted by platform.

⁹ It should be noted that when the project PEGASO started, in 2013, the market of wearable sensors was still very fragmented (with opportunity potential for a start-up that would also be responsible for the design of the sensing system) and we wanted to design a PEGASO brand that would be appealing for our teenagers' target audience. In NESTORE, started in 2017, learning from PEGASO, and also in consideration of a much more developed market and the different target (healthy elderly people, over 65), in the design process we have focused on the overall experience, through the design of personalised wellbeing pathways.

¹⁰ https://www.statista.com/statistics/274829/age-distribution-of-active-social-media-users-worldwide-byplatform/





Although social media is changing also the way interaction between individual and healthcare organisations and professionals will take place, currently information on the use of social media for healthcare communication is quite fragmented. A systematic review has been performed in [Moorhead 2018], which has analysed 98 research studies that included also benefits and limitations of using social media for communication among the general public, patients, and healthcare professionals.

The analysis identifies a number of studies that outline benefit of social media for healthcare communication, for instance with regard to the possibility to address the general public with means that are of immediate impact for communication, such as videos. In addition, social media can be useful for the provision of peer and emotional support for people that can share personal experiences. The limitations are mostly related to the problem of privacy and to the fact that information is often inaccurate and while this may be true, in general, for information on the Internet, the paper indicates that the phenomenon is amplified in social media where

individuals can upload any type of information and opinion regardless of quality and accuracy.

In all cases research on the use of social media for healthcare is still of exploratory nature [Ventola 2014]. The review evidenced a number of gaps that need to be addressed, such as the effectiveness and continued effectiveness of social media communication in healthcare, the measures to ensure quality of the information provided, the risks related to privacy and to the permanence of the digital footprint, the impact of social media for behaviour change and promotion of healthy lifestyle.

3.5 Behaviour Change

Health status is influenced by multiple factors including genetics, social factors, environment, and behavioural attitudes. Indeed, behaviour has a great influence on health and is responsible for many illnesses and pathologies.

The 3-4-50 framework, originally developed by Oxford Health Alliance¹¹, indicates that three behaviours are responsible for four main categories of pathologies causing more than 50% of deaths.

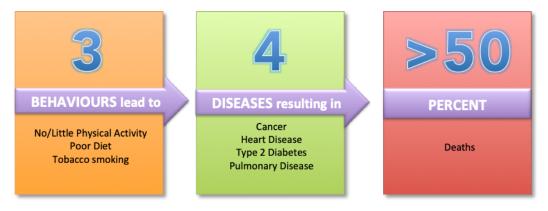


Figure 5 – 3-4-50 Framework (Oxford Health Alliance)

This framework can also be used to design and target strategies for interventions towards preventative actions in terms of behaviour change.

¹¹ http://chsresults.com/3-4-50/

For this reason, prevention is among the key policies in public health, and a number of interventions have focussed on changing behaviour intervening early to counteract or decrease the negative impacts that come from risky behaviours. Designing behaviour change interventions¹² means to understand the motivational and volitional processes leading to abandoning behaviours, which may compromise health in the short, but primarily in the long term, in order to adopt and maintain healthy behaviours.

In this direction successful approaches are those targeting small, manageable changes [OHill 2009]. For example, behaviour change towards more physical activity can improve life expectancy, control weight, and may also prevent the occurrence of a number of diseases. Healthy behaviours during youth, particularly in school settings, are more cost-effective than intervening in later stages in life when habits and attitudes are more difficult to modify.

Changing health behaviour (i.e. encouraging a healthy lifestyle) is a difficult task but one which can be facilitated through the integration of appropriate and evidence-based planning frameworks. An interesting framework that has been used with the project PEGASO is the Behaviour Change Wheel [Michie 2011].

¹² <u>"Designing for Behavior Change Curriculum"</u>. Designing for Behavior Change Curriculum.

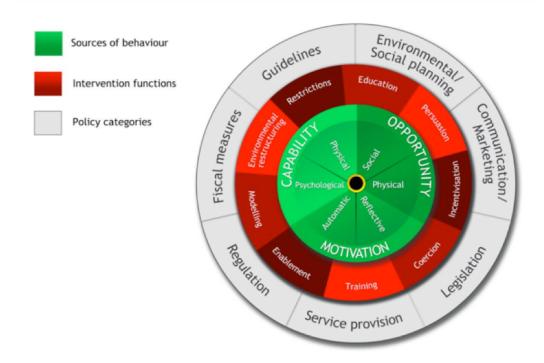


Figure 6 - Behaviour Change Wheel (Michie et al. 2011)

At the heart of this behavioural system is a framework for understanding behaviour. According to the model, three inter-related factors underpin behaviour, namely: capability, motivation and opportunity (Figure 7). Capability is defined as the individual's psychological and physical capacity to engage in the activity and may include the necessary skills and knowledge. Motivation is defined as all brain processes that may energize and direct behaviour, not just goals and conscious decision-making and may include emotional responding and habitual processes. Finally, opportunity is defined by all the factors that lie outside of the individual that make the behaviour possible.

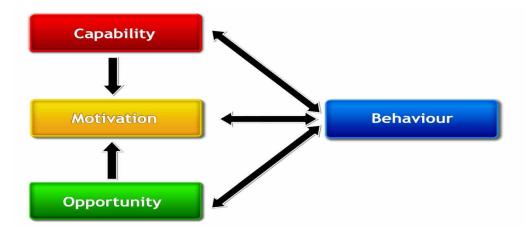


Figure 7 - The COM-B system: a framework for understanding behaviour (Michie et al. 2011)

In any behaviour change intervention, one or more of these components in the behavioural system may be the target for change. Indeed, the causal relationships between the components of the system can serve to minimise or heighten the effects of particular interventions by leading to changes elsewhere.

Of importance is the fact that this model is not only a model of behaviour but it is also provides a framework and basis upon which health-behaviour intervention can be designed. In the context of PEGASO, for instance, this model has been used to identify the behavioural targets and which components of the behavioural system would need to be changed in order to achieve the target behaviour. The adoption of innovative technologies can be a fundamental support for the implementation of the strategies.

Part 2 – Design perspectives for the 4P Medicine and the EU research playfield

This section focuses on the research work performed to understand how the practises of design have contributed and can contribute to the pathway towards the 4P Medicine, also in relation to the concept of patient empowerment and active role of the citizen in self-managing health. Accordingly, the following approaches have been used:

	Role of design	Approach
Predictive & Personalised	Centred on patient specific clinical information; Relevance of personal characteristics and attitudes.	Desk-based research; web and literature search.
Preventive and Participatory	Person-centric; Proactivity of user and co- design of services and solution; Central role of participatory approaches	Application of participatory design approach to motivate and empower target population, through practice-based research in EU projects

4 Predictive and Personalised Healthcare

Current healthcare systems can be generally described as reactive. They are characterised by the following:

- Patients contact healthcare following the presence of symptoms.
- Patients are the passive recipients of treatments and interventions suggested by professionals.

The reactive approach to healthcare is expensive and, to some degree, ineffective in meeting the needs of today's population, from healthy individuals to multimorbidity and chronically ill.

Stopping disease even before symptoms appear is the view promoted by the P4 medicine and a promising way forward for healthcare transformation and sustainability: solutions in this direction are identified within the two following main categories, predictive care and preventive care.

- **Proactive care** solutions stratify at-risk individuals based on known algorithms and ensure that preventive action is taken to intervene well before the onset of symptoms, let alone illness.
- **Predictive care** solutions leverage cutting-edge technologies and sophisticated machine learning data algorithms to not only stratify risk, but even predict risk and intervene even further upstream. Knowledge of genetic predisposition, together with other personal information such as lifestyle, environmental conditions, etc. have the prospect of shifting medical practice from its current emphasis on diagnosis and treatment to prediction and prevention. Indeed in 2001, the European Commission stated that: "A [genetic] revolution in health-care is anticipated through a move towards more prevention rather than cure. . ."

Proactive care allows to stratify individuals based on key risk factors and leads to the development of systems based on prevention with a pro-active and participatory role of the citizens

Predictive care solutions go a step further, intervening upstream, looking at genetic determinants as well as lifestyle, environment, and other determinants (e.g. social conditions) Technological developments are furthering this concept; with the increased collection of personal health and lifestyle data, the advent of big data, and improved analytics, we can generate better insights earlier, anticipating potential issues and determining behaviours and pathways to take before risk factors become concrete.

Web search and literature on predictive medicine focus mostly on the medical and ethical aspects, in particular about performing genetic tests. The concept of the "healthy ill" is presented and it is argued that that most of the people taking preventative medication on the basis of genetic predisposition may never have developed the disease. Furthermore,

medications often carry undesirable side effects. On the contrary, population-based prevention measures (such as quit smoking or encouraging healthy diets and lifestyles) have little adverse effects and are also less expensive.

While it is recognised the relevance of genetics (and the need for genetic testing) for specific risks, stress in put rather on social determinant and modifiable rick factors such as lifestyle, leading again towards the everincreasing relevance of prevention and empowerment, where instruments that foster participation and co-creation of solutions, involving healthcare professionals and target population within identified environmental contexts and ecosystems can be effective.

The coarse analysis performed, confirmed the initial take that in the field of predictive medicine, focusing mostly on the genetic components, the role of design-based approach is limited. Targeting the citizens, focus can be put on designing effective information campaigns (outside the scope of this research), while co-design approaches can be used to design solutions to improve therapeutic adherence for personalised medicine (although this is a general issue, in particular for the case of multi-morbidities and complex care pathways).

5 Preventive and Participatory Healthcare

Understanding the user role and motivation towards preventive healthcare has been the focus of the project work performed. Taking advantage of the strategic challenges identified at EU level, and the opportunities for funding of research activities, specific projects and the work therein have been used as case studies for the application of design-based research and to understand the effectiveness of different tools to establish a dialogue between researchers and study subjects, to motivate target population to take part in the research, and to motivate the target population to develop a culture and a practice of prevention.

All projects have at their core the concept of empowerment. As said,

prevention, either primary or secondary, is a target priority for novel strategies in healthcare and the old models of care, based solely on the physician-patient relationship, are no longer adequate and citizens must become active and informed participants in the healthcare processes [Guarneri 2016].

There are several ways to empower the patient and put him at the heart of the healthcare process with an active role. The most common are:

Education: It is difficult for patients to do what they don't understand, so the first step to improve patients to take on a more active role in their health care is to educate them. Education is perhaps as important to health as filling prescriptions. Citizens need to know all they can about their disease, so that they can take active part in the care process¹³.

Information: An educated patient needs to rely on proper information. Information gathering is not an easy task and being an active information seeker is helpful in shaping the right mind-set. The issue for the patient is, on one side, not to be misled by wrong or inaccurate information and, on the other side, not to be overwhelmed by information overload. Internet is very relevant to find information, which however needs filtering. In addition, the use of sensing technologies to monitor own status is also important.

Communication: Proper communication is essential but often, looking at care processes and at the communication flow among the involved players, deficiencies can be spotted in several cases. Good communication requires all players to have the right information easily accessible otherwise the care process may be harmed or even compromised. Improving communication is not only a matter of providing players with the right tools, it also requires keen attention to the process, which sometimes calls for process reengineering, including the development of tools that better fit and are tailored to the process. When proper communication protocol and

¹³ Helping patients take charge of their chronic illnesses – Family Practice Management, AAFP (www.aafp.org)

processes are not in place, even the best tools may turn out to be ineffective, at best.

Motivation: Keeping motivation high is a key success factor. Motivation depends on many things. Inevitably, motivation has ups and downs but there are approaches and techniques that can help to keep it high. To keep going, clear and reachable goals are a must. On the contrary, when motivation is low, people are likely to stop gathering information, keeping themselves properly documented about their health and they are likely to be less compliant with their set care path.

In the projects focus has been put on the latter, **motivation**, combining UCD and participatory design with relevant behavioural theories and approaches in relation to the target populations.

Focus of the project has been on the grand challenges of sustainable healthcare, taking into consideration the recent trends in medicine and adopting "design" as a methodological approach to address the key challenges.

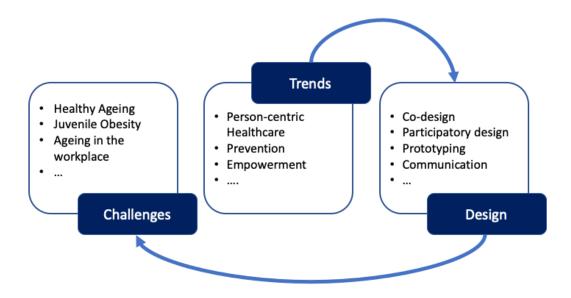


Figure 8 – Addressing Grand Challenges through design.

More specifically, also following the key priority of the EU research and political agenda, challenges addressed are juvenile obesity, healthy ageing

and ageing in the workplace.

All projects have adopted a similar methodological scheme based on the Design Thinking process, as defined by Stanford, although the specific tools used are different in the various projects due to the specificities of the frameworks of the different projects.

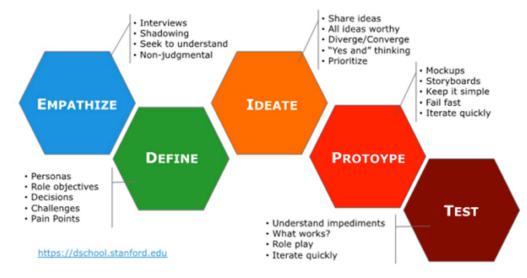


Figure 9 – Design Thinking Process (source Stanford)

As shown by the picture below, the Design Thinking process is fully aligned with the standard scheme for UCD as specified by ISO, and represented below.

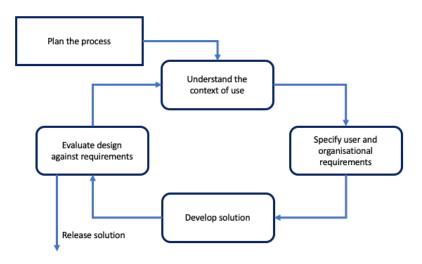


Figure 10 – ISO-13407 User Centred Design General Scheme

Indeed, in all projects the User Centred Design approach (UCD) has been implemented considering the target population at the centre of the system in a palingenetic process. This approach has been considered useful to motivate and engage users, which is an essential requirement for systems' acceptance and efficacy rather than forcing to accommodate technologies, products, or services.

In the UCD approach, three main elements have been integrated: user involvement in all stages of the problem-solving process, multidisciplinary research and development team, and iterative design process to refine the solution set.

The classical Double Diamond has been adopted in the development path from the challenge to the solution. According to this approach four steps are defined, in a series of two "diverge/converge" cycles.

In the first cycle "Discover/Define", users are confronted with exploring possibilities that are matched to "requirements" for a first definition of potential outcomes. In the second cycle "Develop/Deliver" users are involved in the co-design of different possible solutions that are jointly tested to deliver the outcome of the process.

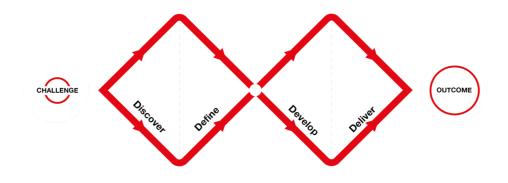


Figure 11 – Double Diamond (British Design Council)

6 PEGASO and Juvenile Obesity

6.1 The Grand Challenge

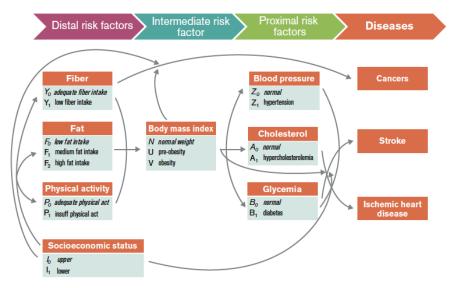
The continued growth in the prevalence of overweight and obesity is a cause for serious concern in all regions of the world, and the phenomenon is increasingly becoming a global pandemic.

According to WHO estimates, overweight and obesity were responsible for 4.72 million deaths and 148 million years lived with disabilities in 2017. Among the causes of death, the excess weight passed from 16th place in 1990 to 7th place in 2007, until it reached 4th place in 2017.

It is estimated that there are today 2.1 billion overweight or obese people in the world, about 30% of the world population. If the growing trend of the phenomenon remains unchanged, in 2030 about half of the people in the world will have a weight excess, with dramatic clinical, social and economic implications.

Overweight and obesity go far beyond the aesthetic problem: much more serious diseases and complications on a medical level may occur. The following picture represents the model adopted by OECD/WHO as tool to identify strategies to prevent Non-Communicable Diseases (NCD). The model shows how, indeed, the Body Mass Index (BMI, as an indicator for obesity) is a key risk factor.

More specifically, the CDP model explicitly accounts for three groups of chronic diseases: stroke, ischemic heart diseases, and cancer. In the model, proximal risk factors, such as high blood pressure, high cholesterol, and high blood glucose, have a direct influence on the probability of developing such chronic diseases. Distal risk factors, such as low intake of fruit and vegetables, high fat intake, and insufficient physical activity have an indirect influence on chronic diseases. The indirect effect is mediated by the BMI, which acts on proximal risk factors as well as directly on disease events.



Note: states written in *italic* are considered the reference state (i.e., relative risk equal to 1) in the evaluation of the relative risks

Figure 12: The Chronic Disease Prevention (CDP) model

On the economics side, Obesity is now responsible for a total cost of approximately 2000 billion dollars, which corresponds to 2.8% of the global gross domestic product and the entire GDP of Italy. Roughly speaking, the impact of obesity on the global economy is comparable to that of cigarette smoking and that of all wars, acts of armed violence and terrorism.

The excess weight generates both significant direct costs, largely attributable to the treatments and hospitalizations for the associated conditions, and indirect costs, linked to loss of productivity due to illness and early mortality.

The following figure refers to a study conducted in the United States and provides a broad classification and overall composition of the different costs.

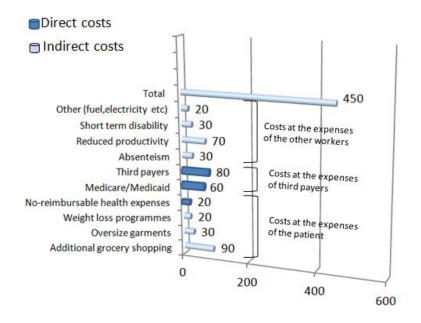


Figure 13. Obesity Expense Composition (Euromonitor, 2014)

In Italy the total direct costs of obesity amount to \notin 4.5 billion and the indirect costs to \notin 4.5 billion¹⁴.

Obesity among children and young people is a phenomenon that is spreading at global level. The World Health Organization estimates that more than 30 million excess weight children currently live in developing countries and 10 million in developed countries.

The condition of obesity among children deserves particular attention because it is recognized by the literature as a predictive of obesity in adulthood. It is estimated that at least a third of children and about half of overweight adolescents¹⁵ remain in this condition, thus compromising healthy ageing.

Overweight or obese children run a greater risk of poor health in adolescence and adulthood.

Obesity among children is also often related to psychosocial problems such

¹⁴ Italian Barometer Diabetes Observatory (IBDO).

¹⁵ As of 2007, the WHO European Region has launched the Childhood Obesity Surveillance Initiative (COSI) to monitor the trend of excess weight and associated factors, including sedentary lifestyle, in children from 6 to 9 years old in the European countries.

as low self-esteem, bullying at school, poor school performance, eating disorders and depression, which lead to health and economic problems in adulthood¹⁶.

Finally, social factors concur to the spreading of the phenomenon. Currently the most widespread living conditions among children during the age of growth are often characterized by a so-called "obesogenic" environment. The offer of "junk food" has expanded considerably, it is easier and less expensive to buy high-calorie and fatty foods; this is associated frequently with a reduced energy expenditure due to low levels of physical activity, creating a dangerous vicious circle.

6.2 Specific Objectives

With the ambition to tackle this global challenge, the project PEGASO¹⁷ addresses the "prevention of obesity" in the target population of the adolescents. PEGASO responds to the EU FP7 call issued in 2013, under the ICT Work Programme, Challenge 5: ICT for Health, Ageing Well, Inclusion and Governance.

As indicated by the call, ... The focus will be on development of solutions that empower the individual, in a social context, to improve and manage personal life as a citizen, elderly, patient, consumer, civil servant or worker...

More specifically the proposal was conceived as a research endeavour to respond to the following:

Personalised Guidance Services for lifestyle management and disease prevention. The aim is the development of **personalised services**, which enable individuals, from the younger to the elder population, to become **co-producers** of their health and maintain good health status. This will include: (i) a "virtual individual" model, which comprises the personal

¹⁶ OCSE Health at a Glance: Europe 2018

¹⁷ The project and the approach are described in detail in Annex 1.

characteristics of an individual (e.g. personal profile, preconditions, risk factors, unhealthy behaviours, preferences, physical activity, sleep, mental status etc.); (ii) advanced sensors to acquire data on lifestyle aspects, behaviour and surrounding environment; (iii) intelligent systems for recognition of behavioural trends and prediction or early detection of health risks on the basis of heterogeneous data, including data acquired by sensors and individual self-assessment; (iv) a supportive environment to engineer awareness about healthy behaviours, offer **personalised guidance and provide support to behavioural change**; (v) development of a new ecosystem of stakeholders, engaging also actors such as fitness, food and lighting industry, schools, health insurance companies, policy makers and media; (vi) innovation in organisational models and business models for ICT-enabled disease prevention.

In the call the technology aspects were dominant, and the key technology areas were identified. However, in its wording "personalised" and "coproducers", the call also clearly identified elements leading towards the concept of "empowerment" and stressing the central role of the user for the development of the solution.

Given the grand challenge of obesity as a predictor for pathologies in adulthood, the project focused on the aspect of prevention for the adolescent population.

Working with teenagers is also relevant from the theoretical aspects of design, as it focuses the process of user centred design to a "fragile" population in terms of "maturity of decision process". Specific objective of the project was the development of a system, based on a set of digital technologies, that involved adolescents in the development of a "culture of prevention" and adoption of behavioural changes towards healthy choices in lifestyles. Through provision of information and development of awareness about the challenge ahead and the related risks, teenagers may start on a path leading to behavioural changes towards healthy lifestyles, and maintain such novel lifestyles in time.

The first strategic choice in the design of the research was to work with schools. The educational setting gives a framework of trust both for the students as well as for the families and the project takes also an educational valence.

Working within the framework of the EU research and being the specific call quite prescriptive with regard to the technologies to be addressed, the solution was pre-identified and focussed on the development of a "product" that could be used by the target audience to foster a positive behavioural change. Pre-selected components of the solution are:

- A wearable system, to develop awareness about the "self"
- A mobile gaming system, as educational element about key aspects of healthy behaviour, namely nutrition and physical activity
- Social interaction, coaching, and gamification, as motivational elements to keep the good work.

Given the above, the focus of "design" in the project was mostly on product design; service design was also investigated with the intent of developing services that could support the approach, also with an active role of external actors in the overall ecosystem. However, the service design aspect, was not well defined in the proposal definition phase and was therefore less developed in the overall solution.

6.3 Design approach and tools

According to the UCD scheme, the first step was to understand the ecosystem and to define the process to work with the target population.

The following ecosystem of stakeholders was designed:

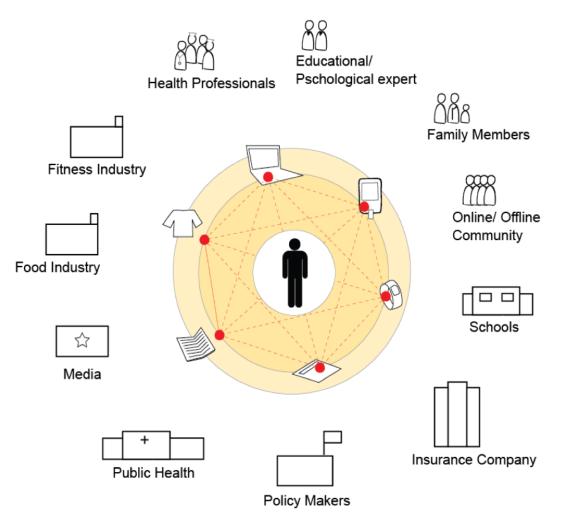


Figure 14 - Ecosystem of Stakeholders in PEGASO

The scheme, putting at the centre the adolescent, was used to determine the focus of the intervention and the main actors to be considered in the sphere of influence.

As mentioned above, the key strategic choice was to work with schools, which were considered the main stakeholders with a key role to play in terms of education and information. Furthermore, it was considered that schools are trusted institutions and that a positive alliance could be formed with the researchers. In Italy we involved two schools in different city areas with different socio-economic backgrounds.

The principles of the Double Diamond were applied according to the following scheme.

Phase	UCD Intervention	Participants
1. Discover	Informative material, commercial devices, questionnaires and Focus Groups, diaries	Researchers Small groups of students
2. Define	Mock-ups; data collection to form a coherent set of user requirements	Researchers Small groups of students
3 Develop	Prototypes – 3 iterations	Researchers Small groups of students
4. Deliver	Pilot project - evaluation	400 students recruited to engage in the pilot study across the country partners in IT, ES, UK.

Together with the schools, the interaction protocol between experts and teen-agers was defined and the first series of workshops and focus groups took place.

During this Discovery phase we used mainly the following tools (see table below) to understand how our target audience would perceive and relate with technology, on one hand, and with the concept of health and wellbeing on the other hand.

Focus Group	 A first set of focus groups was organised to raise awareness about the scope and goals of PEGASO at conceptual level. Then dedicated focus groups were organised to: a. Present the state of the art and explore the teens awareness and experience with commercial sensing devices and opinions about design of future devices; b. Explore the concept of serious games technologies for health management by adolescents.
Co-design	This method was used to collect information about the students understanding of health and wellbeing by designing

	the first mock-ups of some of the PEGASO apps, as well as for the design of smart garments and bracelets.
Questionnaires	To gather quantitative data about teenagers and their current lifestyles in order to characterize the sample of users.
Brainstorming	To explore adolescents understanding of health and technology, to explore their understanding of 'state of the art' with regard to social media, gaming and technology in general

During the "Define" phase we used mostly co-design. Following up on the results of the "Discover" phase, students worked with different types of mock-ups, in particular for the design of the PEGASO guidance system and the look and feel of the interfaces.

This type of interaction has been continued also in the "Develop" phase where the functions developed were tested by the teens at the different steps in the development. Small modifications were made.

Finally, the system was delivered and evaluated with about 400 teen-agers.



Figure 15 – The PEGASO Wearable System

The evaluation focused mainly on the following points:

System and Technology acceptance, usability and long-term use.	Analysis of use of the PEGASO system, rate of abandonment. Questionnaires to understand issues with technology. These measurements also give a secondary assessment of motivation and engagement.
Reliability in assessing the teen-agers lifestyles and their changes	Analysis pre-post by means of questionnaires, and comparison with data collected through the PEGASO apps and the sensors.
Efficacy of the system in encouraging lifestyle change;	Analysis pre-post by means of questionnaires, with focus on the eating habits and on physical activities.

6.4 Analysis of results

PEGASO, was an interesting learning experience, the first project in which we applied UCD at large scale, involving a growing number of users. It is also the only project that has been completed and fully evaluated.

The main limitations of the approach used can be found at methodological level: in PEGASO users (students in high school) were considered as "subjects" cooperating with experts guiding the process [Sanders 2008]; co-design was limited to the aesthetics of e.g. smart garments and apps and to the interaction design. Furthermore, a number of limitations in the approach were inherent due to the involvement of schools. While involving schools was a winning approach to ensure the involvement of the target population, in the design of the experiment we did not take into account the fact that we did not have total freedom in the selection of our users. In particular a key point of the original method, that we had to skip in the actual practice of the project, was the identification of "champions" of the approach that would then provide support in the development of a community of users that would gradually increase till the final pilot. Aware

of the fact that "one size cannot fit all", especially in the case where we need to take into account the delicate psychology of teens and in consideration of such heavy technology centred approach, we had designed an approach in which the community of users would increase based on an initial set of strongly involved group that would engage in an "evangelisation" process. This approach could not be followed as we had a limited access to the students and we could not develop a community beyond the boundaries of a class, where all the students were involved.

Furthermore, the schools deemed the project appropriate for the secondyear students. This choice had a significant impact on the approach. Over the almost four year of the project we dealt with three different groups of students for the different phases of the system development, meaning that the students that led to the requirements' definition were not the once that followed the system development and finally the system was delivered to a different group of students for the final evaluation.

The project was completed with some success as we could prove that the approach generally works. We had good results in terms of awareness generation – students at the end of the process demonstrated increases know-how with regard to the concept of healthy lifestyle; in particular the work on nutrition, with a dedicated app targeting the quality of nutrition, rather than the quantity, was very successful and the final pilots could record moderate changes in habits as well as increased awareness. The approach to nutrition was also appreciated at expert level, as it aims at overcoming negative consequences by looking at nutrients rather than calories, which may develop into excessive attention to this aspect of nutrition, which (in adolescent in particular) might lead to eating disorders. Given the approach, the project was asked to start a process of certification of the app, so that practitioners may advise patients on its use, where appropriate.

The following picture provides an overview of the incremental approach adopted in PEGASO to support behaviour change, in order to sustain

motivation.

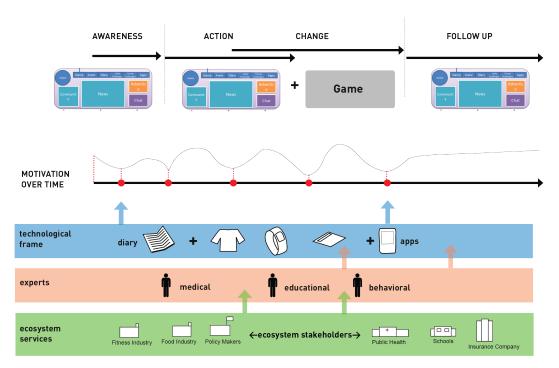


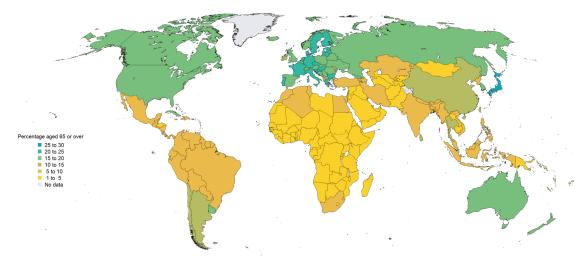
Figure 16 – Incremental approach in PEGASO to sustain behaviour change

7 NESTORE and Healthy Ageing

7.1 The Grand Challenge

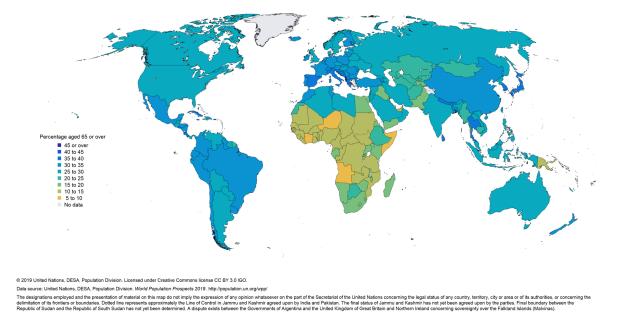
The world's population is ageing more rapidly than at any time in history. The two maps below, showing the percentage of population over 65 in 2020 and the projection towards the end of the century give an indication of the magnitude of the phenomenon.

Percentage of population aged 65 or over, 2020



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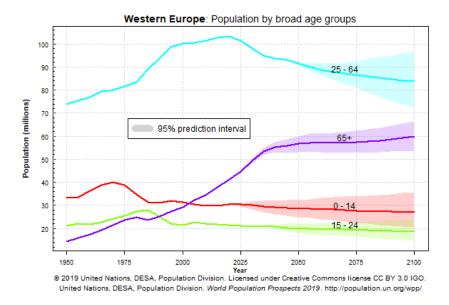
Data source: United Nations, DESA, Population Division. World Population Prospects 2019, http://population.un.org/wp/ The designations enceptional and the second of the second one of any point on National Second on the second of the Second



Percentage of population aged 65 or over, 2100 (medium-variant projection)

Figure 17 - Population over 65 years of age 2020 and 2100

Life expectancy has been going up in almost straight line of three months per year since 1840. In the Western Europe it is expected that the percentage of population over 65 will grow from the current 21% to more than 30%. The graph shows a significant decrease of population in working age, with an increase of the population over 65 and a small decrease of population below 25.



Due to the longer life expectancy and the declining fertility rates, the proportion of people aged over 65 years is growing faster in most of the developed countries. By 2030, the population ageing will lead to an increase in the proportion of people aged 65 and over from 17.4 % to 25.6 %. In general, we live longer and even though the ageing process entails more health complications, we all want to remain in the company of our friends and family, continue to live in places that are familiar and comfortable to us, and maintain our mental and physical autonomy. The emerging social aspect related to ageing population introduces some challenges to society and health care systems. Without adequate adjustments, i.e. social, economic and demographic policies as well as changes in people's behaviours, the process can trigger negative consequences in the long term. In order to maximize the wellbeing of older people and to reduce the economic burden of their care, the health systems should promote and actively support, as much as possible, policies for "healthy ageing"¹⁸.

¹⁸ Healthy ageing is the process of optimising opportunities for physical, social and mental wellbeing to enable

7.2 Specific Objectives

With the ambition to tackle this global challenge, the project NESTORE¹⁹ addresses "healthy ageing" in the target population of "healthy people" over 65 (i.e., people that have already retired). NESTORE responds to the EU H2020 call **SC1-PM-15-2017: Personalised coaching for well-being and care of people as they age** issued in 2017, under Challenge 1 "Health, demographic change and well-being".

As indicated by the call, ... aims at developing and validating radically new ICT based concepts and approaches for **empowering and motivating people** in need of guidance and care due to age related conditions, in cooperation with their carers where relevant, and to help them improve and maintain their independence, functional capacity, health status as well as preserving their physical, cognitive, mental and social well-being...

More specifically the proposal was conceived as a research endeavour to respond to the following:

Proposals should develop a proof of concept of radically new solutions for a **personalised "virtual coach"**, building upon intelligent ICT environments, access to relevant physiological and behavioural data, new forms of accessible interaction based on tangible user interaction concepts, open platforms and emotional computing. **Usability and ease of user interaction should be essential design elements of the "coach"**.

The "coach" should provide **personalised advice**, guidance and follow-up for key age-related issues in daily life which impact the person's ability to remain active and independent, for example diet, physical activity, risk avoidance, preventive measures, lifestyle and activity management, leisure, social participation and overall wellness. The goal should be to preserve physical, cognitive, mental and social well-being for as long as possible and

older people to take an active part in society without discrimination and to enjoy an independent and good quality of life.

¹⁹ The project and the approach are described in detail in Annex 2.

to facilitate interaction with carers (where relevant).

Solutions should build on and apply **multi-disciplinary research** and include intelligent algorithms beyond state-of-the-art capable of reasoning, autonomous learning and adaptation to **personal needs**, **emotional and behavioural patterns, conditions and preferences as well as the users' living environment and their social connections**. Solutions should be integrated seamlessly in existing every-day activities and provide desired information in fast and efficient manner. Attention theft by ICT (consuming too much of the user's time) should be avoided.

Proposals should address relevant ethics and gender aspects and should also assess related legal and regulatory questions such as ownership of data, data protection/privacy, liability and consumer protection. It is crucial that users are involved and drive the innovation at all stages of design and development, including user acceptability, satisfaction and impact in realistic settings.

Given the above, in addition to product design, i.e., "the coach" and its embodiment, the focus of "design" in the project is mostly on service design, i.e., the content of the coaching services, "the personal pathway of wellbeing" that has to be tailored to the specific environment and needs of the individual elderly person, taking into account the overall ecosystem.

7.3 Design approach and tools

According to the principles of participatory design, the methodological approach followed in NESTORE provides for users to be involved in the design of the solution throughout the project duration.

The following ecosystem of stakeholders was designed:

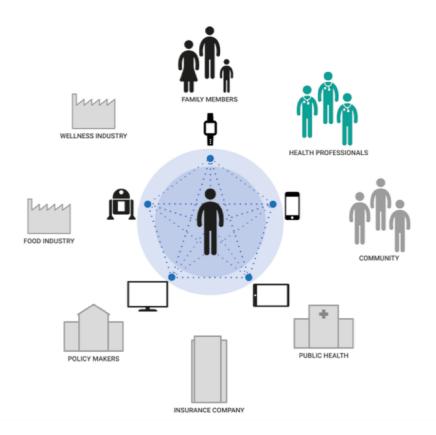


Figure 18 – Ecosystem of Stakeholders in NESTORE

The scheme, putting at the centre the elder, was used to determine the focus of the intervention and the main stakeholders to be considered in the sphere of influence.

As in PEGASO, the central element of design is the definition of a solution able to foster motivation and to support people to stay healthy and live longer in their home. In consideration of the target audience the focus is no longer on behavioural changes, rather on a "gentle nudge" to leverage on interests and social environment to design and keep pathways of wellbeing, which also the family members can get involved in or support.

The Double-Diamond approach was used according to the following scheme.

Phase	Co-Design Intervention	Participants
1. Discover	Exhibition in a box /	Researchers

	Thinking with Things	Small groups of selected users
2. Define	Probes and Mock-ups; Data collection for user requirements	Researchers Selected users at pilot sites
3 Develop	Prototypes – iterative approach	Researchers Selected users at pilot sites
4. Deliver	Pilot project - evaluation	Users (about 60) engaged in the pilot study across the country partners in IT, ES, NL.

The overall method draws on the value of 'thinking with things' as a means to build understanding of the factors end-users identify as being important in the design of digital health services and devices.

The pathways of wellbeing themselves can be seen as a set of services that can be created to help people to achieve different goals in order to stay healthy according to identified wellbeing dimensions.



According to the scheme above, and based on co-designed technological solutions, the system - "NESTORE Coach" – can suggest activities and tasks to stay on the pathway and achieve goals, according to people's interests. The result of co-design was an object that responds to the user

using a tangible interface and that is able to interact vocally, together with a set of wearable and environmental sensors to detect situations, mood and to monitor user's activities.



Figure 19 – The NESTORE System

7.4 Preliminary results

Taking stock of PEGASO results, NESTORE was designed taking as a basis the SOC and HAPA psychological theories to understand and take into account the motivational aspects and the Double Diamond approach for the design. The approach is more participatory and in the initial phases aims at discovering ideas with a diverging approach where values and beliefs of the target population are considered, while the specific solution is then designed in the second phase. With regard to PEGASO we see two fundamental improvements in the approach: at technology level the project did not identify specific solutions, leaving to the workshop with users the selection of specific technologies; at system level we tried to embed a flexibility with regard to "content" opening the solution to providers that can be external to the ecosystem of the partners in the project and that can be discovered making use of the internet, so that the best fit among user interest and "healthy" activities and task can be found to ensure engagement. In addition, with regard to the user involvement, peer learning and communication will be used to promote the solution and

enlarge the community of users. In NESTORE we have taken the first steps in moving from the paradigm of "user as subject" to the paradigm of "user as partner". NESTORE is ongoing and results will be available in late 2020. The system developed is now being installed at the users' homes and will undergo a six months evaluation in realistic conditions.

8 SHARP@Work and Ageing in the Workplace

8.1 The Grand Challenge

"The accelerating pace of demographic change will prove to be one of the key factors shaping the development of society in the coming decades ... demographic change will also induce profound macroeconomic structural changes which will exercise an influence on all the key markets – the labour market, the markets for goods and services, and capital markets." [Boersch-Supan 2001]

The workforce in Europe and in the industrialised countries, in general, is becoming older and this pattern is expected to continue over the coming decades. In addition, as people are ageing more slowly, this also means that they will need to continue to work later in life [Toossi 2012] and even that they may need to sustain retirement systems with additional income to support themselves during a longer retirement.

To give a measure of the demographic phenomenon, the following graph, published in "The Economist" (Buttonwood, Vanishing workers²⁰) is very indicative.

²⁰ https://www.economist.com/news/finance-and-economics/21702477-can-debt-fuelled-model-growth-cope-ageing-populations-vanishing

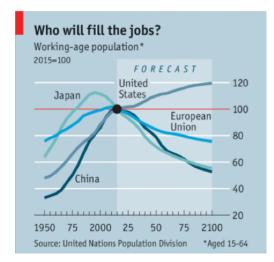


Figure 20 - Vanishing Workers: general demographic trends (Economist.com)

The impact of such demographic trends on social policy and on how to finance retirement is a key topic on the political and social agendas in all the EU countries. In addition, as highlighted in the working paper "Labour Market Effects of Population Aging", financing retirement is only one side of the issue; the workforce is shrinking, as the birth rate is decreasing and retiring people are not replaced at a rate that guarantees keeping the level of productivity required by the western economies. Keeping people at work longer is needed both to alleviate the burden on the welfare system, but also to ensure productivity levels. As the workforce ages, organizations and societies must sustain workers' motivation, wellbeing and health through their later years of employment. Countries need to maintain the wellbeing and quality of life for their populations and both employers and societies need to preserve the health of their older workers to contain health-care costs [Bruxillo 2015].

Ageing well at work and staying longer active and productive is a key priority of the European Union, as highlighted in Lisbon Strategy for Growth and Jobs, already in the year 2000. Among the different actions discussed if the Lisbon Strategy, two are recalled as specifically relevant:

 Implementing active ageing strategies with more training for those over 45, financial incentives for prolonging working lives, gradual retirement, use of part-time work and improvements to the working environment; and 2. Reforming public pension systems while securing the sustainability of public finances through fiscal consolidation.

Reforms of the public pension systems are already taking place. In the EU15 states, the general retirement age is 65 years. In most new Member States, the retirement age will be raised to the same level over the next decade. Denmark, France, Germany and Spain have decided to increase the retirement age from 65 to 67 years, while the goal is 68 years in Britain and Ireland. For the main part, the changes in retirement ages will occur in the 2020s. Many countries, among which Denmark, Finland, Greece, Italy, and The Netherlands, have decided to link the retirement age to life expectancy, which according to current projections would imply that, in some countries, retirement age could reach 72 by 2050. It is therefore more relevant than ever that policies, approaches and solutions are designed and implemented to ensure that workers can be motivated to stay longer at work and that reconciliation policies and support actions are put in place to ensure that potentially conflicting needs coming from the requirements on productivity and (potentially) decreasing health and motivation can be recomposed.

8.2 Specific Objectives

With the ambition to tackle this global challenge, the project SHARP@Work²¹ focused on the issue of "age management" in the workplace targeting works over 50 (i.e., people that are ageing and whose capabilities may be declining). SHARP@Work responds to the EU H2020 call SC1-DTH-03-2018: Adaptive smart working and living environments supporting active and healthy ageing issued in 2018, under Challenge 1 "Health, demographic change and well-being".

As indicated by the call, ... Digital solutions can support older individuals in being and staying actively involved in professional life for longer **by designing fit for purpose working environments** and by enabling flexible

²¹ The project and the approach are described in more detail in Annex 3.

management of job-, leisure- and health-related activities **considering their needs at the workplace, at home and on the move**, with a particular focus on social inclusion, health needs and job retention.

More specifically the proposal was conceived as a research endeavour to respond to the following:

Proposals should develop and validate digitally enabled **adaptive services and solutions** leading to smart work environments for older adults, supporting them to remain actively involved in professional life, helping them to sustain and renew their work and personal life related skills and support independent active and healthy lifestyles while taking into account reduced capabilities due to age-related health risks and conditions.

Proposals should be based on trans-disciplinary research, involving behavioural, sociological, psychological, medical and other relevant disciplines, including gender and cultural aspects.

• • •

Proposals should build on active user engagement (e.g. employee participation at the workplace) in order to ensure the understanding of user needs, safeguarding ethics, privacy, security and regulatory aspects (e.g. labor law). Attention theft and impeding physical activity by ICT should be avoided. Concepts should aim at realistic and verifiable benefits for flexible and sustainable job longevity measures and the consortium should include the necessary stakeholders to validate all relevant issues. The validation should take place in real settings (at workplaces and at home as required). The approach should demonstrate improvements in quality of life and/or improved health and safety for older adults, better management of aging workforce leading to a win-win for employers and employees, health and social system efficiency gains, business and financing models and organisational changes required for service delivery.

Given the above, the focus of "design" in the project is mostly on adaptive "design of services" and on design of "tools for organisational changes" to support age management in the workplace.

8.3 Design approach and tools

The use of design thinking and leveraging the recent work on the theme of "design for engagement", adopting psychological models related to the concept of person-environment and person-job fit are the focal elements of the methodological approach.

A key element of the approach is the analysis of the individual to provide tailored services. The project applies the concept of **I-deals (Idiosyncratic Deals)** supported by a one-to-one negotiation between the worker and the employer organisation. Literature on the subject shows that older workers, more that younger workers, show unique characteristics, linked to the richer background of experiences. The aim is therefore to design an environment that allows flexible service creation and offering able to match the needs of the individual worker within the respect of the company rules and values.

Active user involvement and engagement are at the basis of the project. The methodological approach leverages co-creation and co-design techniques. This is done in a dual manner: by involving the full ecosystem of stakeholders in the requirements, development and testing of the solution, but also by developing a solution in which all actors – workers in particular – can be active subjects in the definition of their own wellbeing (empowerment through negotiation).

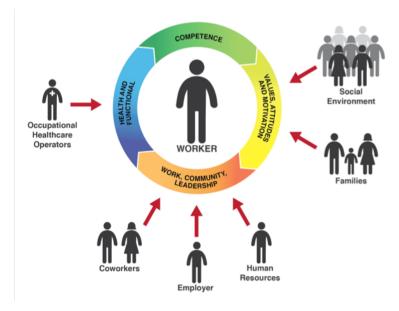


Figure 21 – Ecosystem in SHARP@Work

Design techniques can be used to develop a meta-language able to describe and reconcile the different cultures and perspectives within a business organization, such as: the company owners (and/or their representatives), the human resource function, and the workers – as individuals as well as a category.

Phase	UCD Intervention	Participants
1. Discover	Analysis of working environment, questionnaires, cultural probes	Researchers Stakeholders in the company (HR, workers, unions, company healthcare services)
2. Define	Development of personas and scenarios	Researchers Stakeholders in the company (HR, workers, unions, company healthcare services
3 Develop	Prototypes – iterative approach; Pre- testing at living lab	Researchers; Users at pilot sites; All stakeholders

4. Deliver		Users engaged in the pilot
	Pilot project - evaluation	study across the country
		partners in IT, ES, UK.

8.4 Consideration on the approach

In Sharp@Work, we have recognised the relevance of the Double Diamond approach to stimulate the creativity process of the users, but the key innovation in the approach is having considered a user/usage ecosystem, the enterprise, which is composed of multiple subjects with multiple and sometimes diverging interests. The theoretical foundation in SHARP@Work lies in the concepts of workability and P-E fit, which underlie the need to design novel organisational structures where individual needs (in the specific case the ageing population) have to meet the needs of the organisation and the solution has to be beneficial for both. In Sharp@Work the aim is not to design a specific solution, but to understand which enablers will allow the key actors to define their own solutions and services, how such solutions can be proposed to the other actors in the ecosystem and how they can be negotiated, instantiated and adopted. Additionally, by combining the user²² involvement and creativity in the definition of the key building blocks of the solution, with the use of a living lab for prototypical testing of specific solutions, in Sharp@Work we had the objective of involving actors surrounding the core enterprise eco-system and that are very relevant for overall market dynamics, such as policy makers and regulators, healthcare authorities, unions, etc. Such opportunity to co-design with such stakeholders within the context of the living lab gives the opportunity to understand potential adverse effect and design against such events. In Sharp@Work users were seen as partners in the research to be empowered with tools and instruments to propose, test and negotiate personalised services (see also the concept of i-Deals [Rousseau 2006] that was proposed in the project) that could be beneficial

²² User in this context includes the different actors that have an interest in the operation of an enterprise. The target is to co-design solutions to support ageing workers, but without disregarding

for their health and improve the overall working experience.

Part 3 – Discussion and Conclusions

Through the work performed within the projects PEGASO and NESTORE, as well as in the overall research activities performed to develop and setup the projects (and this includes also the research work done for the preparation of the proposal Sharp@Work), the research has tried to address and respond to the main research question, and related sub-questions related to the four dimensions of P4 medicine.

How can **design be integrated in the overall transformation** that healthcare is undergoing? How can design, as a discipline, **contribute to respond to the grand challenges** of healthcare that are driving transformation?

This last part of the work therefore tries to directly address the initial question drawing some conclusions that can also guide design researchers to lead key areas in healthcare research, specifically where the role of the patient/citizen becomes prominent and increase the visibility of "design" as a methodology to design research projects within H2020 and Horizon Europe.

More specifically the section focuses on:

- Conclusions form the work performed in the EU research projects:
 - Efficacy of design approach for the development of the solution
 - How design can be embedded in future healthcare research projects
- The future of healthcare: conclusions from the research performed in the projects
- General considerations on the need for co-creation in healthcare and increased cooperation between patients and professionals

9 The role of "design" in healthcare research

Starting from the analysis of the work and results of the projects described earlier there are three steps that can be considered:

- At project design level: Research on new services and technologies in general - and for healthcare specifically, where the human dimension is

central - can be enhanced by the adoption and application of design. Indeed, there are many synergies that can be exploited: **an approach based on Design Thinking**, defined as a conceptual model able to achieve solutions to complex problems through a creative vision and strategy, **is applicable starting from the development of the research idea** and be central to the development of the research itself.

- At project execution level: Analysis of methods and tools adopted in relation to the different users' ecosystems and services, to understand interrelations and mechanisms for the application of the different tools.
- **Post-project level**: Lessons learned towards the definition of guidelines for the development of future research projects centred on Design Thinking.

Project design

The Design Thinking approach has been adopted from scratch, at project definition level, with an approach centred on the "person" both as a participant of the research as well as the recipient of the results. Of course, in relation with the complexity of the problem, there is the need address multiple categories of users and they all need to be represented in an ecosystem to be involved directly as project partner or, indirectly, in the form of project consultant or advisory board.

In this way, the full ecosystem can participate to become co-creator of the solution under different perspectives:

- as pure "user" \rightarrow the patient;
- with a dual role of "user" but also "service provider" → the healthcare professionals;
- as provider of services and technologies.

Indeed, a good design of the project in terms of involvement and development of the stakeholders' ecosystem allows for the elaboration of unforeseen solutions, coming from the ideas and creativity of the *users* during the project execution phase.

Another key aspect in the project design is multi-disciplinarity. Bold ideas need, nonetheless, to have a solid theoretical background. At research level it is therefore needed to identify the key disciplines that can be leveraged to achieve valid and sustainable results. In the experience of the projects, in addition to technology research, a significant contribution has come from the joint work with psychological disciplines and theories. Indeed, in all three projects, which are all strongly pushing and supporting the concept of user empowerment, also through notions such as those of healthy behaviour, it has been fundamental the identification of behavioural theories and their embodiment in the different element of the solutions.

Even though the cases addressed in the projects have different targets in terms of user involvement, they have many similarities in the overall research areas that have been addressed and in the design of the solution they have benefited from a common approach. In a framework of (multi)user centricity, a multidisciplinary approach has been applied, covering:

- Research on current approaches to prevention and care (including studies on patients' empowerment);
- Research on behaviour (change) theories and approaches;
- Research on how technologies can be used to support healthy and active lifestyles both in young people as well and in the older generations, developing a culture of prevention as well as a proactive self-care approach.

Indeed, the identification of companion behavioural theories and psychological background has been a key component for a sound design of the projects. Paraphrasing Sander [Sanders 2002] "Designers and human scientists – psychologist specifically – will need to work together. Psychologists will bring frameworks for the understanding of the user behaviour and motivational factors to the table, while designers know how to synthesize and embody ideas and opportunities".

In the three projects, a project methodological approach based on Design Thinking and applying UCD for the development of specific artefacts and solutions has been used, while selected behavioural theories for the specific user categories and application field and environment have been called up to sustain the approach. The following table shows the mapping

Project	Target User	Behavioural Theory applicable ²³
PEGASO	Teen-agers / Students	COM-B and BCW
NESTORE	Healthy older people	SOC and HAPA
SHARP@Work	Workers (ageing)	PE-Fit and iDeals

Project Execution

The role of design is central to all projects and the research has adopted a User Centred Design approach (UCD) considering the target population at the centre of the system. The UCD approach integrates three main elements: user involvement in all stages of the problem-solving process; multidisciplinary research and development; and iterative design process to refine the solution set.

The path followed in the project work has been a benchmark to understand which tools can be used in the different settings, and how design can be used and a methodological framework to develop solutions and models for healthcare.

Indeed, having different target in terms of expected type of solution and audience, has allowed to evaluate how the application of a similar approach and tools has worked in the different settings.

The first projects, PEGASO, focused on prevention of obesity and more generally of lifestyle related conditions, has led to the development of a system composed of devices and apps aiming at supporting teenagers to lead a healthy lifestyle, leveraging behaviour change theories. The second project, NESTORE, is focused on healthy ageing and therefore addresses people at retirement age supporting them in leading a healthy lifestyle to

²³ The theories are described in Section 3.5, and in Annexes 1, 2 and 3, where details on the projects are given.

delay the physical and mental decline linked with age. Sharp@Work²⁴ focuses on ageing of workers; it targets therefore people in their 50's. In SHARP@Work the design approach has involved the entire ecosystem of stakeholders in the workplace with the objective of developing new working models and the related support infrastructure for an age-wise enterprise.

Even though, the third project has not been funded and therefore the work has not been performed, the three projects can be seen as part of a single learning process in applying Design Thinking and UCD in EU research in healthcare and indeed it possible to identify and describe a path in which we have improved, enlarged and enriched the scope, as schematised in Figure 22 below:

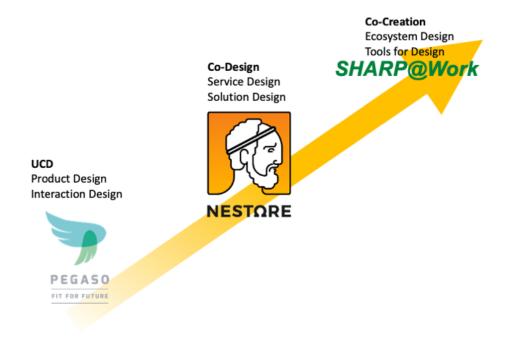


Figure 22 – Evolution of Design Approach in the projects

The following table, in addition, summarises provides an overview of the design approach adopted across the projects.

²⁴ As indicated earlier, Sharp@Work was not funded.

	Design Methodology	Involved stakeholders and roles	Focus of Design Activities
PEGASO	UCD Focus Groups and Questionnaires throughout the requirements definition and development phase. Final pilots testing integrated solution, with focus on usability and adherence.	Final users (teen-agers); Users as subjects guided by experts	Products and interfaces Focussing on aesthetics and interaction design. Services defined by experts.
NESTORE	Co-Design Double Diamond approach with user workshops throughout the progressive phases of the project. Incremental development and testing of solution. Final pilots testing integrated solution. Sub-study on a reduced number of subjects to evaluate	Final users (elderly people); Users as partners in the co-creation process	Services/solutions, Focussing on meaningfulness to people. Understanding how technology is perceived by users, adoption and use of technologies in personalised manner to provide relevant services aligned with user preferences.

Table 1 – Overview of key characteristics of the design approach adopted in the projects

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understand enterprise values and

Incremental development of system

testing of solution with involvement

Pilot test of integrated solution in

selected enterprise environments.

and Living Labs for prototypical

culture and user needs

of external stakeholders

Co-Design

Sharp@Work

Co-Design	Ecosystem of users – the enterprise	Enterprise
Double Diamond approach	All key stakeholders involved in the	Infrastructu
involving multi-actors' workshops to	co-creation process. Partnership	workers an

co-creation process. Partnership between the designer and the users.

e Ecosystem

tural solutions to empower workers and enterprises to design and develop (personalised) services and solutions to "healthy ageing in the workplace" taking into account the cultural company environment.

Focus on empowering the key actors with tools so that they can become the creator of their solutions, with an i-deal approach.

Post project considerations

All the projects have been motivated by the need to address and find solutions to a number of grand challenges in healthcare, with an impact at social and economic level. Design Thinking is an approach specifically suited to tackle "wicked problems", i.e., the addressed healthcare grand challenges, leveraging different tools and methods that are able to actively involve the key stakeholders and users in the co-creation of the solution.

European research projects are a good playfield to experiment, though they have limitations due to several factors which range from budget issues, to – more important – that designing the project in the right way and with embedded flexibility is fundamental as there is a limited space to make changes.

Analysing the project history, it is possible to state that "design" as a methodological research field can be a key factor of success, both for the funding of the proposals, as well as for the development, testing and validation of the results.

Describing the project methodological approach according to the Design Thinking process can yield success in the project evaluation. Indeed, we can envisage, also looking at the coming framework programme, significant opportunity for design researchers to effectively prepare proposals and lead projects in the field of healthcare.

The Framework Programme Horizon 2020 has paved the way for research on user empowerment and prevention in healthcare. More recently prevention has also been linked to early prediction, thanks to the applications of technologies such as big data and artificial intelligence. As and example, a call²⁵ expiring in the near future (mid-June 2020) specifically

²⁵ SC1-DTH-02-2020 "Personalised early risk prediction, prevention and intervention based on Artificial Intelligence and Big Data technologies"

addresses this area of research.

The next Framework Programme, Horizon Europe, will continue to offer opportunities for design researchers. The following extracts²⁶ provide a reference on the main keywords and make evident the relevance of addressing this area of research with a design driven approach.

.... These challenges call for more health promotion, better disease prevention and more effective solutions to manage diseases and reduce disease burden as well as health care systems throughout the EU that are reformed to become more accessible, sustainable, resilient and efficient in promoting and protecting everyone's health and delivering health care of high quality to all citizens. To that end, **new approaches for integrated and person-centred health care are required**, which take into account **specific needs of citizens and population groups** throughout the life course, the influence of environmental, behavioural and socioeconomic risk factors on human health and well-being, the **opportunities offered by new tools, technologies, and digital solutions**, and are built on a competent, reliable, secure and competitive European system of health care service developers, suppliers and providers.

... It will also require that new, better and more cost-effective health care services supported by innovative tools, technologies, and digital solutions become available that respond to the health needs of citizens and populations for promoting and protecting their health, preventing and managing their diseases, and assisting them in pursuing a longer, independent and active life in a rapidly changing society. Unleashing the full potential of digital technologies and health data will be a strong driver to achieve this outcome. Cooperation with other sectors will maximise societal benefits, drive innovation and ensure optimal impact. Accordingly, R&I interventions under Cluster 1 Health will be oriented towards the following six health-related challenges:

- Staying healthy in a rapidly changing society;
- Living and working in a health-promoting environment;
- Tackling diseases and reducing disease burden;
- Ensuring access to sustainable and high-quality health care in the EU;

²⁶ https://ec.europa.eu/research/pdf/horizon-europe/annex-1.pdf

- Unlocking the full potential of new tools, technologies and digital solutions for a healthy society;
- Maintaining a sustainable and globally competitive health-related industry.

Indeed, although the work-programmes are not yet available, under the coordination of the National Contact Points in the different countries, preparatory work for definition of the calls is under way.

It is important that design as a discipline, takes an active role also during this phase to underline its potential key role for the overall research field. It is possible to select among the topics listed above those where design driven research can be most effective and take action in the preparation of the future research arena (for instance the ones highlighted in bold).

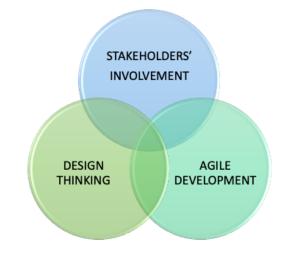
As expressed above "Design" can govern the research in some areas of the future healthcare, in particular where there is a strong user involvement or where technologies (in particular complex technologies such as Artificial Intelligence and Big Data) need to be "humanised". Indeed, successful adoption of novel technologies depends on effective involvement of stakeholders in the decision and design process and users, in particular the healthcare professionals that are determinant in the adoption of the technologies for novel models, need to be in the loop and need to trust the technology. Approaching the issue within a Design Thinking framework can lead to successful project. Designer can and should become promoters of research addressing healthcare in Horizon Europe.

The experience with PEGASO and NESTORE (and partly also with SHARP@Work) has shown that design has been perceived as a credible coordinating discipline, able to drive research with a convincing approach. The opportunities offered within the Horizon Europe framework can then be seized taking stock from the learning experience conducted in FP7 and H2020.

The following main guidelines should drive the development of future projects:

More specifically, during the development of the proposal, specific

attention needs to be given to three main components, intertwined and interdependent, as indicated below:



Stakeholders Involvements → Partnership	As mentioned all through the document, a key element of success, is the involvement of the key stakeholders in the project. This means that, in addition to the partners required for the development of the technical solutions, there is the need to carefully consider how to involve the overall stakeholders' ecosystem, and the users in particular, in your project work. Should/Can they be partners? And if not, what is the best way to approach them and secure their active involvement? For example, expert opinions for stakeholders such as the healthcare professional may be covered by instruments such as Advisory Boards. Involvement of patients and citizens needs to be done by means of associations or through the participation of specific entities that can guarantee access to them ²⁷ . Budgetary issues are also relevant to this analysis, as the

²⁷ In PEGASO, for instance, the involvement of schools to get access to teen-agers, was a smart choice. However, involving them with separate cooperation agreements and not as project partners, was not the best decision, as they did not fully buy in the methodological approach proposed in the original project set-up.

Design Thinking → Methodology	The adoption of Design Thinking as a methodological approach should be considered. The DT phases need to be mapped to the project development process. It should be stressed that DT should not remain at the level of a theoretical process. It is important to ensure that also the actual development of the solution follows a similar approach, for instance through the adoption of Agile methodologies. For each of the elements of the solution the successful testing phase needs to be followed by implementation and adoption (or development of guidelines for adoption)
Agile methods → Implementation	Agile methods for the development of solution map well to DT, starting from the prioritization of requirements and ideas to prototyping, developing, and testing. Short development cycles (if needed "fail fast" and adjust) should be adopted. A working solution must be ensured at all key verification points of the project.

The above are just a few pivotal elements and difficulties of various nature may be encountered during the project execution. However, a welldesigned project is a fundamental stepping-stone to effective and successful project management during the active phase. Although the considerations above can be seen as of general applicability for a designled project in a non-design application field, they are particularly relevant in healthcare, as there is the need to establish a reliable partnership with healthcare professionals through a rigorous methodological approach that can be managed by the key stakeholders and integrated in their professional practice.

At a more general level, an interesting analysis of challenges for researchers in healthcare can be found in [Groeneveld 2018] where the need to communicate the value of design has been reported as a key issue. Referring to prior work of Boks and Baggerud [Boks 2015] the paper also reports about the growing interest by designers, although current curricula may prove insufficient for the complex nature of the healthcare contexts [Norman 2016]. In this respect, the framework afforded by the EU research offers a level playfield for all actors, and design researchers in particular, to experiment novel approaches and solutions in a design perspective.

10 The future of healthcare: the vision empowered by P4

"In 10 years, everyone will have his or her genome sequenced. ... Within 10 year, we also envision a hand-held device that can prick your finger, take a fraction of a droplet of blood and quantify several thousand organspecific proteins in five minutes. ... Thus, transition from health to disease may immediately be identified and acted upon."

This is the vision for the future of healthcare as presented in "A personal view on systems medicine and the emergence of proactive P4 medicine: predictive, preventive, personalized and participatory" [Hood 2012]. A vision according to which it will be very easy to understand individual health risks based on simple clinical exams with the support of computational power and Artificial Intelligence able to decode the information.

Of course there are significant ethical issues to be solved for such a vision to become a reality and they involve, for instance, issues related to access to information (who can access and more important who can act), as well as "right to know", patient auto-determination, etc. However, even with the awareness for such big issues to be solved, it is evident that the vision calls for a strong user-centred approach, where the user is not only a patient at the centre of the care process, with a "passive" role as in traditional reactive medicine. Here we envisage an empowered citizen, an activated patient, able to manage his/her own health and able to contribute to the care process providing first of all data (see for instance the concept of "quantified self") that can add to the global knowledge, but more important a citizen that is health-wise, informed about his personal health risks, and educated to perform what is appropriate to maintain good health. Indeed, and paradoxically, being in good health is a chronic condition that requires appropriate action to avoid progressing to a different status, which is less healthy than the current one. A (overly-) simplified scheme of the "being healthy" process can be represented as follows, where the "adverse event", in red, is any event that will cause moving from the "healthy status" to the "unhealthy/pathology" status, while the text in green describes in general terms the type of actions that allow the "healthy status" to be maintained in time.

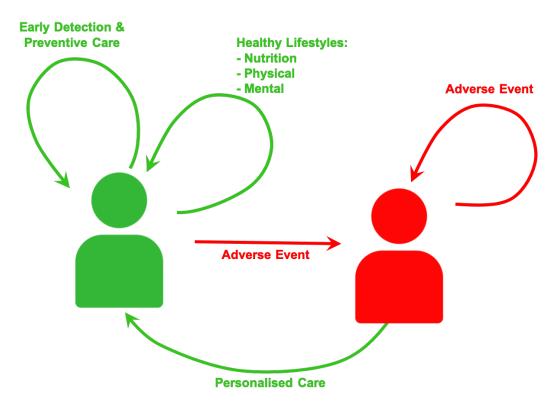


Figure 23 – Staying healthy: a simplified scheme

The objective of the future proactive healthcare is to move the stress from "pathology" to "good health" putting in place actions and measure to ensure that this step can be taken successfully.

The scheme, evidently, calls for a cooperation between the healthcare professionals and the population, as individuals, as families, as groups. The following table provides examples of the respective roles:

	Healthcare professionals	Patient / citizen
Early detection and preventive care	*** Continuous Risk Assessment based on genetic data and other data (including patient generated); Support to patients in interpretation of data, so that they can understand risk and take appropriate steps.	** Provision of data: having data from the patient, but also from family and relevant groups (e.g. ethnicity); Performing regular and early checks (also based on personal risk factors).
Healthy Lifestyles	** With the abundance of information available in the Internet, it is important that healthcare professionals take an active role to ensure that patients are not mislead by inaccurate or false information and guidelines	*** Informed people will know their personal risks and may be encouraged to conduct a risk adverse lifestyle. Knowing risks is not automatically linked to risk avoidance; therefore, tools and instruments to support continued motivation are very important. Science-based and verified information and guidelines are a strong

Table 2 – Examples of role/actions of the two key actors' categories in maintaining wellbeing and health

		requirement.
Personalised Care	***	*
	It will be possible to provide drugs in a tailored and personalised manner, with a better understanding of effects	Provision of data and understanding of the direct involvement in the care pathway.
	on the individual.	

The examples provided above show how the role of the healthcare professional will evolve to take advantage of the progress in the "omics" and the availability of data and elaboration/interpretation algorithms; however the true revolution is in the role of the empowered citizen that needs to embrace prevention as a philosophy for life starting from the early years of life (and even before birth).

In this vision it is fundamental, and here "design" as a discipline may have a relevant role, to understand the motivating factors for the individuals so that they can become empowered and contribute effectively to the new approach. Designing for behavioural change, as experimented in the projects described, in a close cooperation with psychologists and behavioural experts, is the natural path to follow.

10.1 More than user centred: a multiuser-driven ecosystem

Within the course of the research, in the framework of the EU projects where we have tested, and are still testing, design approaches, the main focus has been on the so-called end-user, represented by the patient. Indeed, in their paper, Leroy and Flores [Hood 2012] recognise this central role as also shown in Figure 24.

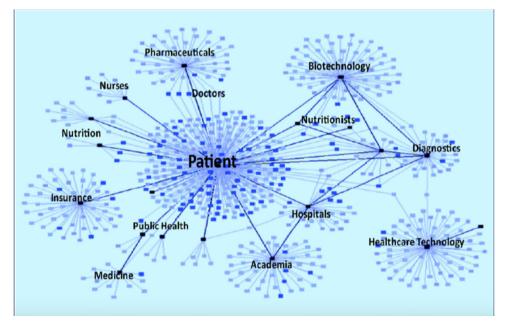


Figure 24 – Interacting components of Healthcare Systems (Source Leroy et al. [Hood 2012])

The picture clearly shows the central and dominant position of the patient. However, it also gives evidence of the fact that the system is multi-actor and multi-user and that design of new healthcare models and system need to deal with such complexities.

This has been recognised also in all the projects such where the patientcentred model, did take into consideration – although at different levels of detail - also the complex relationships with the full ecosystem of stakeholders.

Nonetheless, for instance in PEGASO, the application of UCD was focused on the teenagers, which were the subject of the intervention, considering the other stakeholders as "surrounding ecosystem" and mostly in terms of:

- Influence that they may have on the teenagers' behaviours (e.g., community, family and health professionals); and
- Provision of services to support the behaviour change process and healthcare services in general (other actors in the schematisation drawn above).

This has been a limitation of the work, as all actors have vested interests and may become showstoppers to the actual take up of the solution. Indeed, we have overcome this over-centrality of the final target user in the approach taken in Sharp@Work, where the key role of other actors is more evident, as in the work environment there is a need to balance the (sometimes) conflicting interests of the parties involved. For this reason, in Sharp@Work the methodological approach included two complementary pathways:

- The use of the Double-Diamond for co-design with the key parties in the industry environment (Workers, HR Departments, Employers, Unions, etc.) to take advantage of the creativity of the system users, while understanding each other boundaries of freedom and operation;
- The use of the Living Lab for fast prototyping and testing of pilot solutions in realistic operational environments to take into consideration the role and needs of other "environmental" stakeholders (e.g. policy makers) identifying also adverse factors that specific solutions may (unwillingly) generate.

Indeed, in complex systems such as healthcare, the need to ensure that the design approach does not overlook roles and interests of the many different actors is a key factor for success. Not only to ensure that the system provides relevant services in terms of their content, but also to ensure the development of a sustainable model from the economic point of view. Indeed, as we recognise the central role of the citizen/patient, we need, at the same time, to move from a patient centred design to a systemic approach, which we could call Environmentally Ergonomic approach.

It is noted in addition that, both in PEGASO and in NESTORE, a strong focus was put on the devices through which the "final users" interacts with the services and the system, putting a strong emphasis also on the aspect of interaction design and on the object that enables such interaction, leading to the concept of Life Companion in PEGASO and of the Personal Coach in NESTORE, which can be embodied in different objects depending on users' preferences and conditions. The concept of Life Companion (which can evolve to the NESTORE Coach) is very relevant as it provides a view on an evolvable support for users to lead a healthy lifestyle (see Annex 1 for a short description of the Life Companion concept). The role of the designer is to ensure that requirements are correctly collected and mapped into the final product and solution.

This device-centricity is not relevant for the Sharp@Work solution were the object of co-design would be an infrastructure able to support a set of capabilities, where users can negotiate services taking into account the interests of the different parties. The focus is therefore in understanding the needed capability set and in the development of a meta-language that supports negotiations among the different parties. The role of the designer as facilitator is the key element in this approach, where the focus is not on a specific solution, but in creating the environment that can support a plethora of solutions personalised on the individual and on his environment.

11 The need for new policies for Co-Creating Health

Projections in Europe show that by 2050 there will be fewer than two working-age people per non-working age person in many EU member states²⁸. The cost of care is also due to continue rising as more specialised interventions become available and the prevalence of chronic conditions increases²⁹.

Co-creation and digital transformations in healthcare are increasingly seen by policymakers as potential ways to address the challenge of providing increasingly expensive care to a growing population of patients with a shrinking workforce of healthcare professionals. In addition to this wider recognised need, social changes are pushing towards a change of paradigm. However, to actually and effectively bring co-creation into healthcare remains a challenge.

Basic tools and technologies for some form of co-creation - i.e., the

²⁸ http://ec.europa.eu/eurostat/statistics-explained/index.php/Population_structure_and_ageing

²⁹ http://ec.europa.eu/eurostat/statistics-explained/index.php/Healthcare_statistics

internet, location tracking, wearable devices – are already well used in healthcare. Already in 2014, Pew Research reported that 72% of Internet users searched for health-related information³⁰. In addition, a growing number of healthcare apps is becoming available and the continuous rise in popularity of wearable fitness devices has led market analysts to suggest that this is still a growing market.

Nonetheless, even though such technologies have gained trust with the "end-users", their actual use for co-creation in healthcare is still limited. There is, in particular, a lack of integration between health app data and electronic health records; furthermore only a few of such apps have considered adding such capability.

Technical interoperability is indeed one of the key barriers to co-creation between patients and healthcare professionals. Within PEGASO, addressing this issue, and allowing the possibility for data collected through wearables in the EHR (Electronic Health Record) for consultation by the family physician (GP, General Practitioner), was identified as an important feature and potentially a booster for the overall system's adoption³¹ also by healthcare practitioners that can easily access information their patients' lifestyle. It is underlined that access by GP needs to specifically authorised by the app users. In this respect the privacy ensuring complex procedures (specifically for uploading data to the EHR) were judged too cumbersome by the teen-agers that did not use this feature in practice.

Towards this goal, in November 2015, the European Commission adopted

³⁰ https://www.pewresearch.org/fact-tank/2014/01/15/the-social-life-of-health-information/

³¹ The feature was provided within the Italian Pilot setting, thanks to the cooperation with Lombardia Informatica. A showstopper, however, where the complex authentication procedures that where considered cumbersome by the participating teenagers. A positive evaluation of the feature was given by the healthcare professional, although there is always the issue of trust on the data. This raises the need for certifying apps and devices. With regard to this, it is underlined that the approach taken in PEGASO for healthy eating, was positively received during the course of the pilot in Spain and this element of the app did undergo a formal certification and approval by TICSalud, the healthcare agency in Catalunia entrusted with the mission to enable the transformation of the health and social care model through ICT.

the Refined eHealth Interoperability Framework (ReEIF)³², which is to ensure that disparate and diverse organisations can share information and knowledge between their respective ICT systems. However, the focus of the ReEIF is on exchanges between healthcare providers (hospitals, physicians and pharmacies) and makes few recommendations that would allow patients to participate in that data exchange

To take a real step forward towards co-creation between healthcare professionals and patients, we need to move beyond concepts of interoperability at institutional level to addressing integration with consumer electronics and ambient information from patients' everyday interactions.

Technical standards will be a very important tool; however, new governance models will have to be established that allow data from outside the healthcare establishment to be integrated into clinical records and used for clinical decision-making. These models are slowly emerging in the field of chronic care, in particular Chronic Obstructive Pulmonary Disease (COPD) and diabetes.

A further significant challenge to co-creation in health lies in changing the relationship between healthcare professionals and patients so that the patient is seen as active partner. As mentioned at the start of this work, current systems are focused of cure of disease and doctors are paid to respond to needs patients' needs rather than prevention. On the other side citizens are not rewarded for maintaining lifestyle that keep them healthy.

For the potential of co-creation in health to be realised, modern healthcare systems would have to be adapted, also in economic terms, to create shortterm returns for providers and patients for maintaining health, rather than treating illness. At the same time, the system should be flexible to ensure to respond to needs in the case of pathology and when the patient cannot be actively engaged.

³² http://ec.europa.eu/health/ehealth/docs/ev_20151123_co03_en.pdf

A potential new concept of healthcare would be one in which patients can share the data and information they generate into the decision-making process, but in which the system can support them when needed. This paradigm would be fully coherent with the characteristics of the P4 medicine.

12 Concluding remarks

This work has leveraged the opportunity given by the recent EU calls for research projects in the field of healthcare where a specific mention of adopting UCD and actively involving users in the process was made, to reflect on the evolving role of design for healthcare, based on the experience performed in designing and actually running a number of such research projects.

The work has been conducted within the projects, but also as part of the preparatory activities for the preparation of the project proposals and submission, where the different complementary fields of research have been analysed. The project work has been considered within the wider frame of the evolution of the healthcare sector, led by the three converging megatrends as indicated in the introduction, (i.e.: The progress of the bio-molecular disciplines; The digital revolution; and the "always on" population), and underlying the development of the P4 medicine, giving some interesting insights on the role of the patient, on how empowerment can be fostered and a culture of prevention and participation can be developed.

The stated objective of the work is to dig in the binomial healthcare-design to see how this has been applied in the developed research projects in order to draw some conclusions of more general nature and to give answers to the research questions, as well as to better understand how design, as a methodological approach, can be a reference framework for the development of future projects in the field of healthcare.

It has become evident how the healthcare ecosystem has become more

complex and how, through the definition of the research projects there has been an evolution with an ever-increasing role and significance of the design process. From the traditional design of products for healthcare where users are involved mostly as subjects with regard to aesthetics and ergonomic consideration, to the design of a novel approach to enterprise to empower workers to design, propose and negotiate services that can help them in working in productive manner as they age, and where the enterprise as a whole participates in the co-creation process.

Indeed, we see that, in the future P4 medicine, design has a significant role at different levels starting from the design of communication towards the lay users, to understanding how the empowered users and professionals can be engaged in P4. Also, the strong role played by digital technologies in his overall revolution has an impact not only on patient and citizens, but also on the healthcare professionals at all levels that have to embrace a new approach to care.

The work performed in the projects has shown that indeed use of participatory design is important for users to appropriate the novel approaches and become active part in the health system. Methods that allow users to be creative, such as the Double Diamond, are proving effective as they leverage people's beliefs and values. Understanding such values is fundamental to develop prevention models. Health, of course, is a value to people, but it is perceived differently at different ages and there is a need for different educational approaches. With teen-agers the role of statutory education is fundamental and indeed schools embrace several educational projects. The plus for students that have been involved in PEGASO has been to take part in a process that has seen them as main characters in the development of a system that can help them put into practice what they learn in theoretical didactical modules.

For an actual take up of models based on prevention it is important to integrate the role of the empowered citizen that are more and more sensitive to the theme of health and wellbeing with the world of the professional healthcare. It should be possible to integrate user generated data with the data provided by the healthcare system and health practitioners need to be engaged and empowered to make use of such rich information in their daily practice. This is what is postulated by 4P medicine and European research is going in this direction, with new calls on personalised medicine. The results from this future research will inform the development of new "business" models for healthcare based on prevention and user participation.

Going to back to the proposed research questions, the following summarises the responses that can be provided on the basis of the work performed:

How can **design be integrated in the overall transformation** that healthcare is undergoing? How can design, as a discipline, **contribute to respond to the grand challenges** of healthcare that are driving transformation?

As the experience developed in the project has demonstrated, design can effectively address challenges in healthcare. In particular the Design Thinking process together with UCD and co-design can provide effective tools to involve citizens in the care process and can help in promoting "prevention" as a novel philosophy in healthcare. Furthermore, the success of design-led research shows an important potential for future research in healthcare, to shape the overall (digital) transformation seizing the opportunities offered by the coming R&I programme of the EU Commission "Horizon Europe".

More specifically with respect to:

Predictive medicine - Can design processes be used to mediate and to involve and educate users and institutions in and ethical use of "prediction", and how can they be applied?

Indeed, there are strong ethical issue related to which extent we can adopt "predictive medicine". However, there is potential where prediction can allow to act on modifiable factors, such as risky behaviours, and again provide support to design for behaviour change. More in general design

thinking can be used as an instrument to model the decision process from prediction to intervention, taking into consideration the different roles of the actors involved taking into account privacy, patient self-determination, etc.

Personalised medicine. What is the role of design in this domain? The term refers to treatment and care of patients in a personalised manner, in particular with reference to pharmacological approaches and care protocols tailored on the individual. Indeed, the concept of "presa in carico adopted by Regione Lombardia for patients with complex chronic conditions, goes in this direction considering the patient in his/her entirety as a person. However, in this approach the patient is still a passive subject. With a complex therapy, the notion of adherence to therapy becomes relevant. Taking a personalised approach to empower adherence can reinforce the efficacy of personalised medicine. I have been recently involved in the preparation of a proposal for an H2020 project where we want to design personalised communication strategies to reinforce adherence. Understanding users' motivation with design driven approaches can support the achievement of better outcomes.

Preventive medicine. Which design methods and approaches are best applicable to the different target population? How can effective solutions be co-designed with users? Can new healthcare models based on prevention be effectively designed? Prevention is the core of the projects developed. Experience has shown that approaches need to be tailored to the specific target population. For instance we have seen that brainstorming and creative sessions, using also graphic tools and leaving freedom of expression have worked better with the younger population (PEGASO, teen-agers) although often it has been difficult to converge; on the contrary guided workshops with techniques such as "exhibition in a box" have worked well with the elderly population in eliciting requirements and understanding the relation with technology. In all the projects, solutions meeting the user needs have been developed and tested, even though the level of maturity of the development reached, in some cases was not sufficient for ensuring a smooth user experience.

Participatory medicine. How can design methods foster the development of a participation culture and a healthcare model based on the active participation of citizens and patients? The experience has shown that participatory methods are effective to involve users in the managing their own health, and this can be the basis to develop new healthcare model based on the active participation of citizens and patients. Large scale testing is required for a full cost-benefit analysis, ensuring the participation of healthcare authorities in the piloting of services and comparing costs.

13 Bibliography

- [Armenta 2018] Armenta, Bibiana & Scheibe, Susanne & Stroebe, Katherine & Postmes, Tom & Van Yperen, Nico. (2018). Dynamic, not stable: Daily variations in subjective age bias and age group identification Predict Daily well-being in older workers. Psychology and Aging. 33. 559-571. 10.1037/pag0000263
- [Baysari 2015] Baysari, M. T.; Westbrook, J. I. "Mobile Applications for Patient-centered Care Coordination: A Review of Human Factors Methods Applied to their Design, Development, and Evaluation". Yearbook of Medical Informatics. 10 (1): 47–54. (2015-08-13) doi:10.15265/IY-2015-011
- [Berkman 2000] Lisa F. Berkman, Thomas Glass, Ian Brissette, Teresa E. Seeman "From social integration to health: Durkheim in the new millennium" - Social Science & Medicine 51 (2000) 843-857
- [Boersch-Supan 2001] Axel Boersch-Supan "Labor Market Effects of Population Aging" - NATIONAL BUREAU OF ECONOMIC RESEARCH, 1050 Massachusetts Avenue, Cambridge, MA 02138 - December 2001.
 Working Paper 8640 – http://www.nber.org/papers/w8640 [Cohen 2004] Sheldon Cohen "Social Relationships and Health" - American Psychologist (2004), 59(8), 676-684.
- [Boks 2015] Boks C. and Baggerud B. 2015. "What design students think are hot topics: an analysis of 20+ years of industrial design master projects". In Proceedings of the 17th International Conference on Engineering and Product Design Education (E&PDE15), Great expectations: Design Teaching, Research & Enterprise. 318-323. Glasgow: The Design Society
- [Bruxillo 2015] Bruxillo, D. M., Cadiz, D. M., & Hammer, L. B. (2015). Supporting the aging workforce: A review and recommendations for workplace intervention research. Annual Review of Organizational Psychology and Organizational Behavior, 2, 12.11-12.31. doi:10.1146/annurev-orgpsych-032414-111435

- [CEC 2014] Commission of European Community. Green Paper on mobile Health ("mHealth"). COM (2014) 219 final. Brussels, 10.4.2014.
- [CEU 2013] Council of the European Union Reflection process: Innovative approaches for chronic diseases in public health and healthcare systems Brussels, 23 September 2013;

https://ec.europa.eu/health/sites/health/files/major_chronic_diseases/d ocs/reflection_process_cd_final_report_en.pdf

- [Chamberlain 2012] Paul Chamberlain & Alaster Yoxall (2012) 'Of Mice and Men': The Role of Interactive Exhibitions as Research Tools for Inclusive Design, The Design Journal, 15:1, 57-78, DOI: 10.2752/175630612X13192035508543
- [Clark 2005] Clark, A. & Moss, P. "Listening to Young Children. The Mosaic Approach." - London: National Children's Bureau. (2005).
- [Cohen 2004] Cohen, S. "Social Relationships and Health". American Psychologist, 59(8), 676-684. (2004) http://dx.doi.org/10.1037/0003-066X.59.8.676
- [Duncan 2009] Alan K. Duncan, Margaret A. Breslin (2009). Innovating health care delivery: The design of health services. Journal of Business Strategy 30(2/3):13-20. DOI: 10.1108/02756660910942427
- [Elliott 1990] Elliott, G. R. & Feldman, S. S. "Capturing the adolescent Experience" in At the Threshold: The Developing Adolescent (pp.1-13). Cambridge MA: Harvard University Press. (1990).
- [EPF 2015] European Patients Forum EPF Background Brief: Patient Empowerment; 15 May 2015 - <u>http://www.eu-</u> <u>patient.eu/globalassets/campaign-patient-</u> <u>empowerment/epf briefing patientempowerment 2015.pdf</u>
- [Fiordelli 2013] Fiordelli, M., Diviani, N., and Schulz, P. J. "Mapping mHealth research: A decade of evolution". Journal of Medical Internet Research, 15(5), 95. (2013)
- [Flores 2013] Mauricio Flores, Gustavo Glusman, Kristin Brogaard, Nathan

D Price, and Leroy Hood "P4 medicine: how systems medicine will transform the healthcare sector and society" - Per Med. 2013; 10(6): 565–576.

- [Frayling 1993] Frayling, C., 1993. Research in Art and Design. Royal College of Art Research Papers 1, 1,1-5
- [Fried 2007] Fried, Y., Grant, A. M., Levi, A. S., Hadani, M., & Slowik, L. H. (2007). Job design in temporal context: A career dynamics perspective. Journal of Organizational Behavior, 28, 911-927. doi: 10.1002/job.486
- [Friedman 2000] Friedman, K. Design knowledge: context, content and continuity. In: D. Durling and K. Friedman, eds. Doctoral Education in Design: Foundations for the Future, La Clusaz, France, 8-12 July 2000. Stoke-on-Trent: Staffordshire University Press, pp 5-16
- [Freund 2000] Freund, A. M., & Baltes, P. B. (2000). The orchestration of selection, optimization and compensation: An action-theoretical conceptualization of a theory of developmental regulation. In W. J. Perrig & A. Grob (Eds.), Control of human behavior, mental processes, and consciousness: Essays in honor of the 60th birthday of August Flammer (pp. 35–58). Mahwah, NJ: Lawrence Erlbaum.
- [Glaser 1967] Glaser BG Strauss AL (1967) The discovery of grounded theory: Strategies for qualitative research New York: Aldine de Gruyter.
- [Groeneveld 2018] Bob Groeneveld, Tessa Dekkers, Boudewijn Bon and Patrizia D'Olivo (2018). "Challenges for design researchers in healthcare". Design for Health, 2:2, 305-326, DOI: 10.1080/24735132.2018.1541699
- [Guarneri 2014] Renata Guarneri, Mauro Brivio, Giuseppe Andreoni and Mazzola Marco "Engaging teen-agers in the adoption of healthy lifestyles for the prevention of obesity and related co-morbidities: the approach of PEGASO"- Proceedings of HealthInf2104 - Special Session on Signals and Signs Understanding for Personalized Guidance to Promote Healthy Lifestyles, SCITEPRESS Digital Library

- [Guarneri 2014a] Renata Guarneri; Giuseppe Andreoni; Active Prevention by Motivating and Engaging Teenagers in Adopting Healthier Lifestyles, "Digital Human Modeling. Applications in Health, Safety, Ergonomics and Risk Management", Lecture Notes in Computer Science Volume 8529, pp. 351-360, 2014, Springer International Publishing. DOI 10.1007/978-3-319-07725-3_35, Print ISBN 978-3-319-07724-6, Online ISBN 978-3-319-07725-3
- [Guarneri 2016] Maria Renata Guarneri, Marco Decandia Brocca, Luca Piras; "Patient's empowerment and behaviour change: complementary approaches in EU projects PALANTE and PEGASO", Proceedings of PPmH, EAI International Conference on Personal, Pervasive and mobile Health, Budapest 14-15 June 2016
- [Guarneri 2016a] Maria Renata Guarneri, Paolo Perego; "Games and Gamification for Healthy Behaviours: The experience of PEGASO Fit 4 Future", Proceedings of GOWELL, EAI International Conference on Games fOr WELL-being, Budapest 14-15 June 2016
- [Hamel 2012] Hamel, L. M. and Robbins, L. B., "Computer and Web-based interventions to promote healthy eating among children and adolescents: a systematic review. Journal of Advanced Nursing, 69(1), 16-30. (2012)
- [Hood 2012] Leroy Hood and Mauricio Flores "A personal view on systems medicine and the emergence of proactive P4 medicine: predictive, preventive, personalized and participatory" – New Biotechnology, Volume 29, Number 6 - September 2012
- [HRI 2014] Health Research Institute "Healthcare delivery of the future: How digital technology can bridge the gap of time and distance between clinicians and consumers" – Nov. 2014; https://www.pwc.se/sv/pdf-reports/healthcare-delivery-of-thefuture.pdf
- [Ilmarinen 2009] Ilmarinen, J. (2009). Work ability-a comprehensive concept for occupational health research and prevention. Scand J Work Environ

Health. 2009 Jan; 35(1):1-5.

- [Jagosh 2011] Jagosh, J., Pluye, P., Macaulay, A. C., Salsberg, J., Henderson, J., Sirett, E., & Green, L. W. (2011). "Assessing the outcomes of participatory research: Protocol for identifying, selecting, appraising and synthesizing the literature for realist review" - Implementation Science, 6, 18.
- [Jagosh 2012] Jagosh, J., Macaulay, A. C., Pluye, P., Salsberg, J., Bush, P. L., Henderson, J., & Greenhalgh, T. (2012). "Uncovering the benefits of participatory research: Implications of a realist review for health research and practice." – The Milbank Quarterly, 90, 311346.
- [Kanfer 2013] Kanfer, R., Beier, M. E., & Ackerman, P. L. (2013). Goals and motivation related to work in later adulthood: An organizing framework. European Journal of Work and Organizational Psychology, 22(3), 253-264. doi:10.1080/1359432X.2012.734298
- [Keller 2017] Keller, A. C., Igic, I., Meier, L. L., Semmer, N. K., Schaubroeck, J., Brunner, B., et al. (2017). Testing job typologies and identifying atrisk subpopulations using factor mixture models. Journal of Occupational Health Psychology, 22, 503-517. doi: 10.1037/ocp0000038
- [Klasnja 2012] Klasnja, P., and Pratt, W. "Healthcare in the pocket: Mapping the space of Mobile-phone health interventions". Journal of Biomedical Informatics, 45, 184–198. (2012)
- [Kohl 2013] Kohl, L. F. M., Crutzen, R., and de Vries, N.K. "Online prevention aimed at lifestyle behaviours: A systematic review of reviews". Journal of Medical Internet Research, 15(7), 146. (2013)
- [Kroemer 2006] Kroemer, K. H. E. "Extra-ordinary" Ergonomics. How to accommodate small and big persons, the disabled and the elderly, expectant mothers and children. Chapter 8. Boca Raton FL: Taylor and Francis Group. (2006).

[Lang 2016] Lang AR, Craven M, Atkinson S, Simons L, Cobb S, Mazzola

M., "Human factors multi-technique approach to teenage engagement in digital technologies health research" - Human–Computer Interaction Series, Linda Little et al. (Eds): Perspectives on HCI Research with Teenagers (2016). DOI 10.1007/978-3-319-33450-9_4

- [Lorenz 2009] Lorenz, L. S., & Kolb, B. (2009). Involving the public through participatory visual research methods. Health Expectations, 12, 262274.
- [Maccoby 2002] Maccoby E.E. "Gender and Group Process: A Developmental Perspective" - Current Directions in Psychological Science 11: 54-58 (2002)
- [Meroni 2011] Meroni A. and Sangiorgi D. (2011). Design for Services. Aldershot, UK: Gower Publishing.
- [Michie 2011] Michie, S., van Stralen, M. M., & West, R. "The behaviour change wheel: A new method for characterising and designing behaviour change interventions". *Implementation Science : IS*, 6, 42. (2011) <u>http://doi.org/10.1186/1748-5908-6-42</u>
- [Moorhead 2018] Moorhead, S Anne et al. "A New Dimension of Health Care: Systematic Review of the Uses, Benefits, and Limitations of Social Media for Health Communication." Ed. Gunther Eysenbach. *Journal of Medical Internet Research* 15.4 (2013): e85. *PMC*. Web. 31 Aug. 2018.
- [Norman 2016]. Norman D.A. 2016. "When you come to a fork in the road, take it: the future of design". She Ji: The Journal of Design, Economics, and Innovation 2 (4):343-348. DOI: 10.1016/j.sheji.2017.07.003.
- [OHill 2009] James O Hill "Can a small-changes approach help address the obesity epidemic? A report of the Joint Task Force of the American Society for Nutrition, Institute of Food Technologists, and International Food Information Council" - The American Journal of Clinical Nutrition, Volume 89, Issue 2, 1 February 2009, Pages 477–484
- [R2G 2017] Research2Guidance (2017), "mHealth App Economics 2017 Current Status and Future Trends in Mobile Health"

[Rousseau 2006] Rousseau, D. M., Ho, V. T., & Greenberg, J. (2006). I-deals:

Idiosyncratic terms in employment relationships. Academy of Management Review, 31, 977-994. doi: http://www.jstor.org/stable/20159261

- [Sanders 2002] Sanders, Elizabeth. (2002). From user-centered to participatory design approaches. 10.1201/9780203301302.ch1.
- [Sanders 2008] Elisabeth B.N. Sanders and Pieter Jan Stappers "Cocreation and the new landscape of design" – CoDesign, Taylor and Francis, March 2008
- [Sanders 2014] Sanders, E. B.-N. and Stappers, P. J. (2014) Probes, Toolkits and Prototypes: Three Approaches to Making in Co-designing. In CoDesign: International Journal of CoCreation in Design and the Arts. Special Issue on Making. Vol. 10, Issue 1
- [Schmittdiel 2010] Schmittdiel, J. A., Grumbach, K., & Selby, J. V. (2010). System-based participatory research in healthcare: An approach for sustainable translational research and quality improvement. Annals of Family Medicine, 8, 256259.
- [Schwarzer 1992] Schwarzer, R. (1992). Self-efficacy in the adoption and maintenance of health behaviors: Theoretical approaches and a new model. In R. Schwarzer (Ed.), Self-efficacy: Thought control of action (pp. 217-242). Washington, DC: Hemisphere.
- [Sniehotta 2005] Sniehotta, F. F., Schwarzer, R., Scholz, U., & Schüz, B. (2005). Action planning and coping planning for long-term lifestyle change: Theory and assessment. European Journal of Social Psychology, 35, 565–576
- [Standoli 2016] Carlo Emilio Standoli, Maria Renata Guarneri, Paolo Perego, Marco Mazzola, Alessandra Mazzola, and Giuseppe Andreoni; "A smart wearable sensors system for counter-fighting overweight in teenagers"; Sensors (ISSN 1424-8220; CODEN: SENSC9) international, peer-reviewed, open access journal on the science and technology of sensors and biosensors, MDPI Open Access Journal; Sensors 2016,

16(8), 1220; doi:10.3390/s16081220.

- [Thabane 2010] Thabane, L., Ma, J., Chu, R., Cheng, J., Ismaila, A., Rios, L. P., ... & Goldsmith, C. H. A tutorial on pilot studies: the what, why and how. BMC medical research methodology, 10(1), 1. (2010).
- [Toossi 2012] Toossi, M. (2012). Labor force projections to 2020: A more slowly growing workforce. Monthly Labor Review, 135, 43-64. doi: https://www.bls.gov/opub/mlr/2012/01/art3full.pdf
- [Ventola 2014] Ventola CL. "Social Media and Health Care Professionals: Benefits, Risks, and Best Practices". Pharmacy and Therapeutics. 2014; 39(7):491-520
- [Webb 2010] Webb, T. L., Joseph, J., Yardley, L., & Michie, S. "Using the Internet to promote health behaviour change: A systematic review and meta-analysis of the impact of theoretical basis, use of behaviour change techniques, and mode of delivery on efficacy". Journal of Medical Internet Research, 12(1), 4 (2010)
- [Zacher 2014] Zacher, H., Feldman, D. C., & Schulz, H. (2014). Age, occupational strain, and well-being: A person-environment fit perspective. In "The Role of Demographics in Occupational Stress and Well Being" (Vol. 12, pp. 83-111). Bingley, UK: Emerald. doi:10.1108/S1479-355520140000012002

13.1 Other relevant Web sites

The listed web sites are not specifically referenced in the document, but are very relevant to the work as they have inspired some of it, or they represent some of the results, such as the web sites of the projects on which this work is based:

- MacColl Center for health care innovation (http://maccollcenter.org/)
- Patient Empowerment Living with Chronic Disease, The European Network on Patient Empowerment (www.enope.eu)
- Insignia Health Products and solutions to improve self-management of care (http://www.insigniahealth.com/)

- Helping patients take charge of their chronic illnesses Family Practice Management, AAFP (<u>www.aafp.org</u>)
- The PEGASO Project Personalised Guidance Services for Optimising lifestyle in teen-agers through awareness, motivation and engagement (www.pegasof4f.eu)
- The PALANTE Project Patients leading an managing their healthcare through e-Health (<u>http://www.palante-project.eu/</u>)
- The NESTORE Project Novel Empowering Solutions and Technologies for Older people to Retain Everyday life activities (https://nestore-coach.eu/)

Annexes

The material annexed hereafter describes in some detail the EU research projects, providing for each of them the thematic area of healthcare and wellbeing addressed, together with the design methods adopted for the involvement of the key stakeholders and the definition of the best solution.

Of the research projects described, one of them, PEGASO has been completed in July 2017 and can be fully analysed to understand the results and to reflect on methodological as well as practical errors. NESTORE is currently ongoing, in its third year of activity, the solution is currently being installed for the final user validation. The other projects have been developed, but no funding was received and have been put on hold.

14 Annex 1 - The project PEGASO

PEGASO was the first project in the area of healthcare, with an active participation of users in the design of the solution. The project addressed prevention of obesity and related co-morbidities and focused on teenagers, as it was felt that this was the age in which an intervention is needed and there is a need to create awareness about maintaining good health as they become more independent from the influence of parents and start choosing their ways. Still teenagers are easy to influence and though the authority of parents in put under discussion, there is a need to set up good behavioural models that can they appropriate and make their own. For this reason, involving them in the design phase and throughout the development of the system was the approach to follow. Although the system was not developed to a state of maturity and stability that users would be happy with, we got positive results and evidence that a system such as PEGASO can work to promote healthy behaviours.

14.1 The rationale behind PEGASO

Lifestyle-related illnesses are among the top healthcare challenges in Europe. As an example, the rapidly increasing prevalence of overweight

and obesity among children and adolescents reflects a global 'epidemic' worldwide. Due to the associated serious medical conditions, it is estimated that obesity accounts for up to 7% of healthcare costs in the EU. Obesity in younger age groups has been recognized as an alarming key predictor for obesity in adulthood, but also entails a number of short and long-term health complications along with greater risk of social and psychological problems [Guarneri 2014, Guarneri 2014a].

Addressing the obesity issues requires a **comprehensive approach** taking into account the individual's **physical-physiological** characteristics, **personality** as well as the **social** and **psychological** environments influencing decisions and habits in their everyday life.

As indicated in the report from the World Health Organization "Populationbased prevention strategies for childhood obesity" (December 2009)³³ among the key strategies tackling the risk of obesity in young individuals, a great relevance should be given to actions developing awareness and enhancing motivation for changing behaviour towards healthy diet (nutrition) and physical activity (active lifestyle).

14.2 The UCD approach

Taking a UCD approach, in the project PEGASO we have addressed primary prevention, by involving teenagers (students from high schools around 15 years' age) in the development of a solution to support them in conducting a healthy lifestyle. During the course of almost four years a solution based on product/service system, with services oriented at prevention and lifestyle management was designed, developed and tested to support personal wellbeing and health.

The approach, based on three levels of intervention, enables users to become co-producers of their wellbeing by:

• Generating self-awareness (understanding own lifestyle by means of self-

³³ http://www.who.int/dietphysicalactivity/childhood/child-obesity-eng.pdf

monitoring tools and acknowledgement of risks associated to unhealthy habits) [Standoli 2016];

- Enhancing and supporting motivation to take care of health with a short/medium/long term perspective (through serious games and various gamified approaches) [Guarneri 2016a];
- Change of behaviour towards a healthy lifestyle and active selfmanagement of health (by means of personalised feedback and taking advantage of gamification).

Four levels of engagement towards persuasion for user empowerment in healthcare have been considered for the development of the solution and have led the co-design activities: awareness of risks, motivation, affective learning and behaviour change [Guarneri 2016]³⁴.

From a conceptual point of view, in order to provide all the different features required to achieve the overall goal, the PEGASO system architecture has been conceived to include the following elements:

- Individual Monitoring devices and tools (e.g. wearable sensors, multimedia diaries, serious games for the acquisition of physical parameters and to sustain motivational aspects of the adolescent's healthy behaviour.)
- Feedback System (e.g. a dashboard showing progress towards goals and

³⁴ As already published in [8], here the definitions of the different phases in the approach leading to behaviour change are reported:

Develop Awareness: teenagers need to be aware of what they are doing; what is right and what is wrong for their healthy living. Some of them are unconsciously and automatically acting, and often under estimate or have no clear notion about information they receive. Monitoring lifestyle of teen's activity, collecting parameters and integrating their own data will enable self-awareness on their current situation. Through developing self-awareness and self-reflection, the user can frame the problem or the opportunity area to act upon or intervene. **Create Motivation**: it is important to motivate teenagers to change their behaviour and sustain motivation in the long-term. The actors in the ecosystem are requested to offer "healthy" (or healthier) benefits and services satisfying their needs or desires. This is quite challenging, since motivation depends on many factors as well as emotions, psychological environment and personality. The system needs to provide constant different layouts of motivational activities where experts, technological frame monitoring and stakeholders services come into play.

Affective learning is the "highest" learning goal. The learner should trust in something that will happen in several years from now. The use of a constructivist learning model and special media like "social games" are appropriate to reach this goal.

Enable Behaviour Change: once teenagers have awareness and motivation, it is important to involve experts and use PEGASO to support the behaviour change process and reinforce existing virtuous behaviours. The turn from old unhealthy behaviours into new healthier ones has to be monitored through technology on a longer period.

providing personalized suggestions towards healthy modification of the lifestyle; implementing behaviour change interventions according to the COM-B (capability, opportunity, motivation, and behaviour) model.)

 Social connectivity and engagement (sustained support to motivational aspects through social networks and community of peers concerning physical activity, food consumptions and everyday habits through different gaming strategies).

The main challenge has been to design a system that guarantees the correct integration of all the planned features and diverse devices, to provide personalised services able to support end-users to create their personalised paths towards healthy lifestyles.

In order to ensure that user views and expectations would be reflected in the solution a user-centred approach was adopted involving users, students, in the different phases of design and development.

Agreements with schools were signed, and informative sessions were organised to ensure that the purpose of the research was clear to all the involved parties: students, first of all, as key target of the intervention, but also teachers and parents as secondary users and sponsors of the initiative.

Informative and feedback sessions with parents as well as meetings with the reference teachers were conducted along the entire duration of the project. The students were involved at different stages:

- At the start of the project through a series of user workshops and focus groups for the requirements definition phase; this phase involved a large number of students in different schools and of different ages and was key for defining the main directions of the project. Preliminary design of the system was achieved, in order to start the development phase. This phase lasted for six months.
- Throughout the duration of the project, along the system development phase, in a number of pre-pilot tests at different moments in time in the development of the PEGASO solution; this phase lasted slightly over two years, involving more students from single classes. In Italy the project was

integrated in the POF (Piano di Offerta Formativa)³⁵ of the involved schools due to the fact that it could be integrated with the healthcare and wellbeing modules of the second classes that focus on prevention of dependencies and sexual education. The fact that the project was open for participation only by second classes meant that at each school year we had a different group of students, which was different from the initial project design and did bear some impact on the overall project results. During this phase the student tested and evaluated the system at different stages of its development.

 During the final phase of the project, in the final pilot for testing the overall integrated solution. This phase lasted over six months; some difficulties were encountered due to problems with software and hardware development, nonetheless the system could undergo an overall evaluation that was very valuable for future projects. The experience conducted in PEGASO was very relevant for the development of the project NESTORE that was submitted in the final phase on PEGASO.

14.3 Project start: Requirements Definition Phase

As mentioned, this phase was fundamental for the design of the PEGASO system and a multi method approach was adopted to gather requirements and first sketches of potential solutions.

As literature shows, the needs of teenagers are varied [Kroemer 2006] and evolving as they develop during the teenage years [Elliot 1990]. A multi method approach was adopted to meet such changing needs and capabilities and "to find methodologies which play to young people's strengths rather than their weaknesses" [Clark 2005]. The concurrent use of different methods allows participants with different competencies and skills to impart their views and needs on the themes discussed, and on the technologies and tools presented. This way not only does the approach consider UCD in the development of the technical products; mobile apps, serious game, wearable sensors, but the UCD ethos pervades the design and development of methods for eliciting teenage user requirements.

³⁵ Piano di Offerta Formativa = Plan of Educational Offer

The following four methods were combined for the requirements collection phase: Focus groups, Co-design, Questionnaires, and Brainstorming.

The table below shows goals and justification for choosing this combination of methods [Lang 2016].

The same approach was used in the three countries where PEGASO was tested. Where figures are referred to in the tables, they relate to the Italian set-up.

Focus group	Co-design	Questionnaires	Brainstorming
A first set of focus groups was organised to raise awareness about the scope and goals of PEGASO at conceptual level. Then dedicated focus groups were organised to: c. Present the state of the art and explore the teens awareness and experience with commercial sensing devices and opinions about design of future devices; d. Explore the concept of serious games technologies for health management by adolescents.		about teenagers and their current lifestyles in order to characterize the sample of	-

Table 3 Methodological approach used for data collection

	Focus group	Co-design	Questionnaires	Brainstorming
Justification for method	Need to identify key issues and elements for a more structured investigation of the PEGASO system as a whole and its constituent parts.	Direct involvement of teenagers through a design activity. Overcoming some limitation of groups' interviews, involving teenagers more actively.	To quantify and characterize data from teenagers in a structured way, in order to better understand the target population.	The brainstorming activity enabled researchers to introduce the PEGASO concepts gradually in an informal manner so that teenagers might acclimatise themselves to the topic prior to the focus group and other activities. To provide opportunity for non-verbal expression of ideas for those who are less confident in a focus group/ discussion activity.

Focus group	Co-design	Questionnaires	Brainstorming
Three groups per each focus group round, as follows: Mixed group: 6 to 10 teenagers (50% male, 50% female) Male group: 6 to 10 teenagers per group. Female group: 6 to 10 teenagers per group.	During Focus groups, regarding the following aspects: - Functionalities and look and feel of PEGASO system of mobile apps; - Aesthetics of smart garments; - Aesthetics and functionalities of smart bracelets.	Short questionnaire about the adolescents' habits related to the main PEGASO aspects: - Smartphone - Social media / network - Physical activity	Same as FG but group numbers split into smaller groups 2-4 for brainstorming exercise.

14.3.1 Focus groups

Focus groups have been selected as an appropriate form of qualitative data collection for user requirements capture. The goal of this method was the exploration of the role of technologies for health management by adolescents. Figure 25 below shows the organisation of the activities and themes in the focus groups.

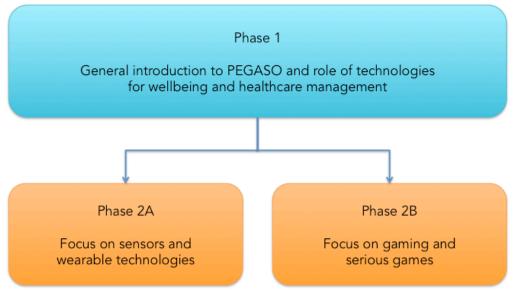


Figure 25 – Organisation of Focus Groups' activities

In order not to limit the scope of the discussion a semi-structured focus group enquiry was used. In addition, a sample size of 10/12 students with equal representation from both male and female was considered to be an important element to study design. Although not rigidly separated, the focus groups were organised in single sex groups (mainly for phase 1, with focus on the overall system and on the individual perception of health and wellbeing) and mixed groups (mainly for phase 2 dedicated to use of technologies). This was done for various reasons such as:

- It was considered that perception about health and wellbeing might differ between sexes, as puberty impacts males and females in different ways. In consideration of the fact that the involved students might be familiar to each other, as they belonged to the same school, we wanted to create an open discussion without feeling of embarrassment or self-censorship (Tonkiss 2012). Single sex groups allowed for more open talk openly about views on health and healthy behaviour³⁶ [Maccoby 2002].

- On the other hand, mixed groups were included in the study design so that discussion about technology would be inclusive of a mixed gender perception.

14.3.1.1 Methodology

Focus groups were conducted by one moderator and at least one observer. The moderator guided the discussion, while the observer kept track of opinions expressed during the session and made notes, which provided additional context to the audio files recorded during the sessions.

Each participant and where appropriate (under 16 years of age) their parents received an informed consent form at least one week before each focus group, in order to decide upon participation. The aims of the Informed Consent were:

- 1. To present the PEGASO project to the participant, in order to get familiar with the project scope and objectives.
- 2. To describe the Focus Group methodology and contents.
- 3. To get permission for Video Recording during the Focus Group.
- 4. To guarantee the respect of the Country regulations about privacy.

Each focus group was conducted in a private room arranged for the group discussion. Recording equipment was organized in order to capture all the participants' responses, and chairs were arranged in a circle to facilitate participation by all individuals. When participants arrived, informed consent was obtained, and moderators answered any questions participants had. All the focus groups were structure in similar manner, although differences existed due to the different subjects being discussed

³⁶ There is evidence to suggest that males and females interact differently in mixed-sex as opposed to same-sex groups [34]. The adolescent years not only are influenced by the development of peer relationships, identity formation but also impacted by the physiological changes associated with puberty, and subsequent relationships with members of the opposite sex. Following consultation with teachers the decision to conduct both mixed and single gender Focus Groups was to ensure that findings would not be linked to the dynamics associated with adolescent developmental behaviours.

14.3.1.2 Structure of Phase 1 Focus Group

The structure of the focus group consisted of 6 stages:

Table 4 – Organisational structure of Focus Group Phase 1

Introduction	Short introduction to explain to the participants what a focus group is, its purpose, the topics to be discussed, the duration, the roles and expectations of participants
Icebreaking	Familiarisation of participants with each other to promote interaction and discussion
Warm up Activity	Familiarisation of participants with the topics of health and technology use in preparation for the main discussion. This stage was used to investigate the participants' level of awareness about the following topics: • Teenagers & Health • Use of Technology for Health Purposes • Use of Gaming for Health Purposes Use of Social Network for Health purposes
Main Activity	The main activity consisted of a 30/40 minutes group discussion with semi-structured questions exploring the teenagers' general opinions on the PEGASO system. The goal of this stage was to investigate the most important features that the teenagers consider relevant for system acceptance, and to understand drivers and functions to increase their level of motivation. In particular, the main themes of discussion were:

	 Theme 1: Technology for healthy living. Impressions on the use of technology for healthy living Theme 2: Features of Technology. Features that technology should have to be interesting for teenagers. Short/Long term usability, physical features, incentive/disincentive Theme 3: Use of Technology in different contexts. Schools, home, gym, clubs etc Theme 4: Information sharing: people that teenagers would like to connect with and share information. Friends, parents, teacher and experts. Notification and feedback system. Theme 5: Current awareness or use of technologies.
Post discussion prioritization	The objective of this stage (20 – 30 minutes) was to co- design the PEGASO system with the teenagers. Teenagers were asked to think about what were the important elements of the product for them. Participants selected three themes/concepts among those that have been discussed and they used them to develop a campaign slogan to be aimed at adolescents.
Close	Final considerations/questions and close of session.

14.3.1.3 Structure of Phase 2a Focus Group

The structure of this wearable technology trial and follow up focus group consisted of two separates days, as depicted in Figure 26 Figure 25 below.

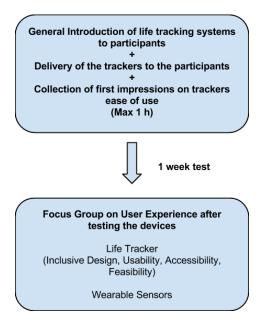


Figure 26 - Study structure in two steps

During the first day students were given a set of commercial wearables to familiarise with the technology and understand their use. Misfits and Withings were provided due to their difference in aesthetics and materials. The related apps to control the wearables were downloaded by the student of their smartphones. The students could use the devices for one week.

The second day was dedicated to collection of feedback and co-design of features that wearables should have, based on their experience with the devices tested.

DAY 1	
Introduction	Explanation to participants about the purpose and structure of the session.
Icebreaking	To familiarise participants with each other and to obtain more info about participants
Warm up Activity	To familiarise participants with each other and to collect information about life tracking attitudes.

Table 5 - Organisational structure of Focus Group Phase 2a - Day 1

Main Activity	To introduce the participants the life trackers and deliver them to the participants.	
	The moderator explains to the participants what a life tracker is. He illustrates with different types of tracking devices.	
	Provide each participant one type of life tracker to get the first information about the inclusivity of the design, in terms of activation.	
	Analysis of life trackers ease of use during un- packaging and set-up.	
Close	Collection of first impression on trackers ease of use.	

Table 6 - Organisational structure of Focus Group Phase 2a – Day 2

DAY 2		
Introduction	Explanation to participants about the purpose and structure of the session.	
Main Activity		

	usability of the apps.
	• Theme 4: General opinion about the devices' feedback
	system.
	• Theme 5: User Experience. Users opinion about their
	experience of use.
	• Theme 6: Using technology in different context of use.
	• Theme 7: Information Sharing. People that teenagers
	would like to connect with, share information. Friends,
	parents, teacher and experts. Notification and feedback
	system.
Close	Bring focus group to a close and tie up any final
	queries.

Structure of Phase 2b Focus Group

The structure of the focus group consisted of 6 stages:

Introduction	Short introduction to explain to the participants what a focus group is, its purpose, the topics to be discussed, the duration, the roles and expectations of participants
Icebreaking	Familiarisation of participants with each other to promote interaction and discussion
Warm up Activity	Used as a rapid ideas generation exercise to allow participants to familiarise with the topic in preparation for the main group discussion.
Main Activity	To allow participants to think about how a game designed to promote healthy lifestyle should look like.
Post discussion prioritization	Make participants think about the most important features that a serious game, designed to promote healthy lifestyles among teens, should have.

14.3.2 Questionnaires

Questionnaires on technology use were used to obtain additional quantitative information to use jointly with the results from the focus groups.

14.3.3 Co-design activities

In line with the UCD approach, co-design activities represent an important step in this approach because as they can actively involve the final users in a design process where the teenagers are the main actors in the definition of a service that will be designed for them.

Co-design activities, therefore, took place during the focus groups with regard to the look and feel of the apps and with regard to the aesthetics of the sensorised garments and the aesthetics and functionalities of the smart bracelet. The research team proposed initial designs to guide the students in the process. Students expressed preferences with regard to the technologies and the type of interaction they preferred. Based on the initial results from co-design the developers' team started the implementation phase.

14.3.4 Results

Results from this first phase, which was fundamental for the development of the system³⁷, defined the key requirements for the PEGASO system and helped to understand which elements would play a role in developing in the teenagers awareness about health and how they could be motivated to maintain healthy and balanced behaviours.

Based on this first phase the results have been organised according to the

³⁷ UCD was applied throughout the duration of the project. This first phase however was key for setting the main directions along which the solution was developed. During pre-pilots and pilots, modifications and further improvements were made, but conceptually the system was defined during this phase.

following categories: awareness of health; health and technology; PEGASO system.

A table with the set of requirements derived from this phase are included in Annex 1. The set of requirements is very rich and not all of them could be implemented, as during the project a number of limitations were experienced. Nonetheless the UCD approach adopted received positive feedback by all the people involved, including teachers and parents that could see and experience the value of the project content. This initial phase was also the most creative and fun for all participants, as we worked from scratch with the target users, creating expectations and an appropriation of the system that they helped design and implement.

Teenage Awareness of Health

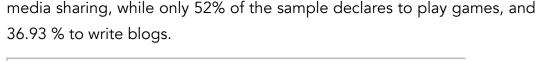
Teenagers understanding of health seemed to focus more on psychological wellbeing health, rather than on the physical impacts of healthy/unhealthy behaviours. It is also evident that awareness about health priorities would be influenced by the modes of feedback from the system. This is an important element of the design, in consideration of the target audience that may be easily influenced.

Teenagers mostly associate the idea of health with two main specific domains:

Emotional domain (Social, well-being, fun and happiness, friendship)

The most important domain emerging when asking teenager about health and being healthy, is the emotional domain. Fun, happiness, and positive feelings, in general, have been indicated as relevant factors to be healthy. Teenagers consider friends as a source of happiness, which eventually fosters good health. As a consequence, the social dimension is the main relevant aspect for them.

Results of the technology use questionnaire demonstrate how relevant these social aspects are for teenagers (see Figure 27), considering that 98.9 % of teenagers report using social media for chatting, and 79.89 % for



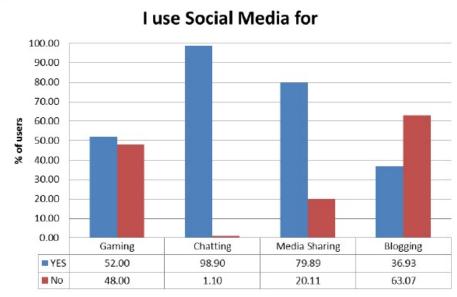


Figure 27 - Use of social media by participants (Questionnaire)

Good & Bad Habits (Nutrition, sport, weight, but also addictions)

The second concept frequently introduced by teenagers in relation with the idea of "health" is the importance of having good habits. Self-care and nutrition, but also hygiene and diet are of great importance to stay healthy. Healthy habits are often associated to physical activity and sport.

Bad habits discussed by teens are related to prohibitions. Drug use, alcohol and smoking were indicated as the most dangerous habits for health in 100% of the brainstorming discussion about health.

Concept of body image has an influence on young users. Gender split needs consideration, in particular referring to the aspirational models for male and females. Male are more inspired by and oriented to the sport domain, favourite athletes and social group activities. Females are more influenced by models from fashion and magazines.

The temporality of health behaviours was discussed and considered to be a potentially challenging aspect of the project with regard to teenagers growing up and their use of technology over time changing in respect to their behaviour.

Health & Technology

When prompted about technology and health the teenagers' reactions indicated that they see it as strongly related although not always in a positive sense. In particular, the excessive use of technology – referring e.g. to being always on - is considered as negative for health. Other links between technology and "health" related to Fun and sport (e.g., the machines for physical activity: exercise bike, treadmill, etc. and the gym is main place associated to them); and hospital-based technologies. They did not yet see the use of technology for personal health.

In general, teenagers strongly relate technology with the concept of health, even if it is quite evident that their feeling is not always positive. The main issues related to technology, is about changing this negative image and turn into a positive, a health companion and not a dangerous tool.

Gaming and Social Networks

Within technologies the areas of games and social network received a specific attention.

The concept of gaming is generally perceived as a positive factor for the health, both for the physical and emotional domain. Gaming is in fact an idea associated with fun (*PC, Internet*) and passions (*sport, soccer*). Sport is perceived as a game that fosters physical activity and is good in general for the health.

Trying to link the idea of game to health, teens associate video gaming with fun, if they do not become alienating for the user. Immediate mentions of two particular videogames consoles that deliver modes of interaction that foster physical activity, e.g., the Nintendo Wii that proposes games that simulate sports and that require the user to move while playing.

Social Networks have a direct influence on the emotional level. This sometimes may be negative, depending on the reactions. Health and social relationships were associated with the teenager's awareness of psychological health and wellbeing as opposed to physical.

Given the specific topic of PEGASO, related to health and prevention, some attention needs to be given to topics such as control and privacy. All the teenagers agreed on the need of some control mechanism to prevent and report bullying attack inside the social network.

14.3.4.1 PEGASO system

The PEGASO system, at HW level, is composed of a smartphone and by wearable sensors: smart bracelet and smart garment. On the smartphone a PEGASO app would be used as an instrument to gather data from the individuals, as well as to give feedback on their behaviour.

14.3.4.2 Smartphone

Smartphone was demonstrated to be the main technological device used by teenagers and could be the primary interface to collect and analyse data from users.

Results of the technology user questionnaires demonstrate that, of 184 teenagers, 93% report having a Smartphone (100% in Spain, 93 % in UK and 91% in Italy).

The presence and the use of the Smartphone are so intense, that teenagers consider the Smartphone as "part of their life". Teenager demonstrated awareness of this overwhelming use of Smartphone, that they sometimes associate it to a bad habit.

For teenagers the most important and appreciated aspect of having a smartphone is being connected with other peers, to share confidences, experiences, in sum sharing their lives with friends. And their life is shared with instant messages, but most of times through sharing of multimedia contents: images, videos, music files.

A second relevant aspect is that Smartphone satisfies both their need to entertain, escape from the daily stress, and to keep control of their life, sharing and accessing contents that they only decide. Usability and ease of use are relevant user requirements. This can be translated in:

- The need of one single app able to manage the basic functionality of the system (*"Handy, Intuitive, one single app for everything, accessible for all the OS"*). The excessive number of applications has been identified as a limit for motivation.
- Multi-OS compatibility. Data collected from the sample population demonstrates that, in Italy, 44% of teenagers has an Android phone, 41% an iPhone and 15% other phones, while in Spain the percentage are, respectively, 65%, 12% and 23%.
- Personalization (User Interface, additional levels of functionality, etc.)

14.3.4.3 Wearable Sensors

Basic services, such as those related to location (positioning based on GPS and additional algorithms to infer position in the absence of the GPS signal) and basic motion sensors to detect physical activity, are provided through sensors embedded within the smartphone. In addition, the system would make use of a smart bracelet and a smart garment for additional monitoring, based on context of use and specific activities.

14.3.4.3.1 Bracelet to monitor physical activity

Most of the participants demonstrated a superficial awareness of technologies and bracelets for sports tracking, but don't currently use them. This is valid both for those participants playing team sports or individual sports.

In general, the most relevant important requirement of the wearable technologies should be the capability to organize and facilitate activities (especially sports) that they are involved in.

Functionality and ease of use were important: balance between number of functionalities (level of complexity) and its real efficacy (importance of reaching the personal objective).

The context of use is seen as a limit. As an example, schools' and clubs'

regulations could be conflicting; e.g., school regulations may not allow students to wear items such as jewellery, smart watches or have their mobile phones accessible.

Physical aspects are important for a wearable device and should be taken in account: particular personalization and personal expressivity, the choice of colours, gender differentiation and compatibility with existing technologies.

14.3.4.4 Garments - Wearable sensors in clothes

User requirements were quite conflicting. Some of the participants considered this sort of wearable sensors as useful only during exercise, and expressed doubts related to the fact that (this was more evident for girls) that they prefer to choose clothing, in addition some sports clothing that is quite revealing would show up the sensors (e.g. leotards).

Other participants, on the contrary, demonstrated a great interest about wearable sensors in clothes, considering them among the most innovative features of the PEGASO system. They demonstrated interest for price, its availability on the market, and information about materials. They would prefer that the electronics on the T-shirt could be visible but indicated that a good design would be required (although they weren't able to specify what they intend for beauty or preferred aesthetic qualities).

Throughout the focus group discussions teenagers expressed the importance of choice and personalization of device and the 'look' of products, whereby individual users wanted to customize not only the aesthetics of a product but also personalize their interactions to suit their requirements.

Teenagers place value on efficacy of products. They need to feel able to trust the data they are being provided from the technology. It was also stated across the countries that the results of the monitoring activity is important to influence duration of use per day and longevity of use over time. In addition, branding of the products was mentioned in relation to wearables.

14.3.5 Summary of Requirements from Phase 1

The requirements listed in the table below are the results of the first phase of PEGASO. The list provides an overview of what teenagers are aware of with respect to health and technology and prospective views about what they think they might want from the PEGASO system.

This preliminary study also provided insight into some topics, which have elicited quite specific requirements such as: the need for a storyline in the game; the preference for music and non-textual information; teenagers concerns about cyber bullying and requirements that the system protects them from this negative aspect of technology.

Theme	Name of requirement	Description/Details
Teens & Health	Creative Terminology	The system should propose only positive messages
	Gender split	Gender split needs consideration.
Health & technolo gy	Lack of relevance	Evidence of a 'lack of relevance' to a young user group. Consideration must be given throughout the development of the PEGASO system in order to make it relevant to the user groups
Health & Gaming	Make it real!	Gaming and technology should promote 'real' sport and activity and not virtual/ 'unreal' versions
Health & Social Networks	Control & Privacy	The PEGASO system should provide a cyber bullying report system

Smartph one	Centrality of the smartphone	The Smartphone is confirmed to be the centre and the most important device of the PEGASO platform
	Use of Multimedia	Limited text for communication
		Visual elements preferred to text. The PEGASO communication system has to be based primarily on that.
		Music is relevant for teenagers
	Usability & Ease of Use	The PEGASO main user interface should appear as a single app
		Multi OS compatibility
		High level of personalization
Wearable Sensors	Functionalities vs. ease of use	Balance between the number of functionalities provided by the wearable device (level of complexity) and its real efficacy (importance of reaching the personal objective).
	Modularity	All the PEGASO functionalities should be provided with the Smartphone. Additional sensors should be optional.
	Physical aspect (fashion)	Opportunity for personalization and personal expressivity through different design
		The possibility to choose colours is important for personalization
		The PEGASO system must be compatible with

		the existing technologies
Garment s	Conflicting statements of need	Needs further investigation
Question naires & Multimed ia Diaries	Convenience	Participants wanted developers to have an understanding of their everyday lives so that the use of the system could 'fit in' and compliment their daily activities.
	Routine with diversity	The system should facilitate the development of routine and positive habits and behaviours whilst engaging the user through diversity and a dynamic interface.
	Avoid boredom	The system should be used as a tool within the app e.g. diary functionalities to plan in active days, lazy days, good diet days, and days when they can relax the healthy eating
		Calories counting should not be implemented, after it has deemed to be a negative way of achieving healthy eating due to inflexibility and control
	Economics	The possible costs of wearable's is a concern
		The PEGASO system should be cheap for the end users. They demonstrate scarce willingness to pay
Gaming	New gaming experiences	The game experience should be linked to the real world, involving teenagers in real activities with real people (community)

		Innovative game experiences. The game should not try to replicate what already is present on the market.
		Augmented reality tools are a solution for innovative game experiences.
	Challenges	Challenges increase the teenager's engagement in the game. This is true particularly for male users
	Story	A well-structured story can be engaging for playing the game, especially for the female user population
Role of Expert	Real people	Teenagers express a great interest in the possibility to reach experts for suggestions. They expressed the need to contact real people
	Expert reputation	The PEGASO platform should propose a list of expert of certain reputation, to be contacted by the teenagers in the real world. Teenagers can rate the experts to improve their reputation inside the platform.
Social Networks	Information sharing	The PEGASO social platform must communicate only positive messages. The social environment must protect teenagers from cyber bullying. The user's social reputation must be protected from attacks or being rated in a negative way
		The social aspect of the PEGASO platform is

	very relevant. Teenagers strongly associate
	the idea of Health with the idea of Social life.
	The PEGASO platform should utilise visual language to communicate with teenagers, avoiding text messages.
	The social aspects of the PEGASO platform should be based primarily on the personal network of the user. Teenagers should be free to create their community and decide whether or not expand their activity to the global community.
	Balancing act to ensure that information sharing does not get to a "tipping point" where users disengage e.g. if information being shared is off putting or (enables negative comparison between users?) makes users feel inferior against others
Control & Privacy	'Permissions control' in relation with experts through specific platform, where users & experts can decide to make their identity public or not in contrast with the purpose of the system for sharing

14.1 Along the project duration: Pre-pilot phase and system co-design

The second phase of co-design was conducted during the curse of prepilots that took place during the project development and that allowed a continued interaction with different set of students over a period of almost two years. While in the first phase co-design sessions were conducted using drawings and other visual aids, during the pre-pilots, the students had the opportunity to work with prototypes of the different elements of the PEGASO solution and give feedback on different aspects of the proposed solution.

The pre-pilots followed a three-iteration approach where the system was improved according to the feedback of the users. Figure 28 below illustrates the iterative process for the system improvement and development during the pre-pilot phase. The objectives of each iteration were influenced by the findings and co-design progress of the previous iteration.

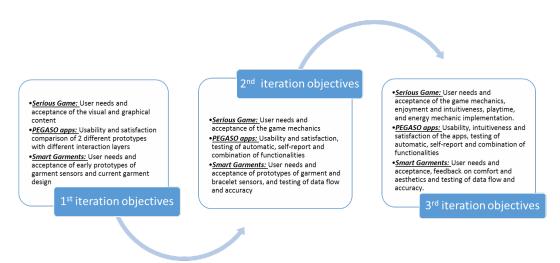


Figure 28 – Pre-pilot iterative process

The co-design sessions have contributed to the definition of the usability and acceptability of the proposed technologies and services. Following this co-design phase that has validated the initial assumption and determined which modifications are needed to develop a solution that meets the target audience' requirements, the integration of the prototype solution has started.

The main elements of the system tested consisted of:

- a set of apps under an umbrella app, the PEGASO Companion which collects user generated input (e.g. via the eDiary app, the profiling, etc.) and provides feedback to the user on actual behaviour based on a set of defined healthy behaviour targets and an analysis of behavioural data according to short term and long term timespans;

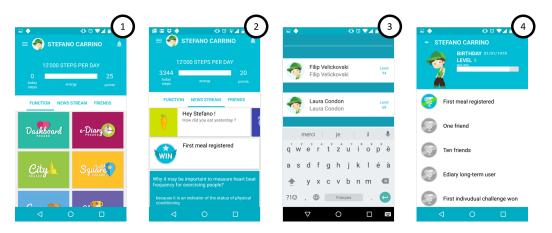


Figure 29 – Screenshots of Companion: 1) the screen providing access to all the PEGASO apps, 2) the screen collecting all the messages for the user, 3) the screen to connect with friends 4) the screen showing the user's achievements

- a set of wearable sensors (smart garment and bracelet) that seamlessly collect data on physical activities, sleep behaviour, etc.; and



Figure 30 – PEGASO Sensorised garments (initial design); PEGASO Data Logger (connected to the garments); PEGASO Bracelet (showing calories consumption)

- a serious game, which, in the form of a videogame, is education with respect to the principles of healthy lifestyles and supports motivation.

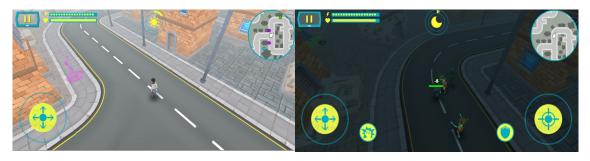


Figure 31 – Screenshots of the daytime and night-time game mechanics

Overall, the feedback from the teenagers was positive and there was interest in testing and trying the system. All of teens were interested in the devices and the potentialities of PEGASO. Unfortunately, due to some technical failures, they became tired after unsuccessful trials, bored and the experience turned out to be significantly less interesting. The overall feedback collected is summarized in the following tag cloud.



Figure 32 – Word-cloud showing the overall user perception during the tests

After the end of the pre-pilots, only 50% of the teens would recommend PEGASO to others (and 30% would recommend it after some improvements). The other half will not advise the use of PEGASO due to the technical limitations, but also because they feel it is not necessary. They felt that the system would be better targeted to university students that live on their own, and can make their own choices about lifestyle, in particular with regard to nutrition. Other targets could be people with particular health conditions, or a big amount of time to dedicate to use it. Students were also invited to create a ranking between the Serious Game, the Garments and sensors, and the APPs, to order their preferences (1-2-3).

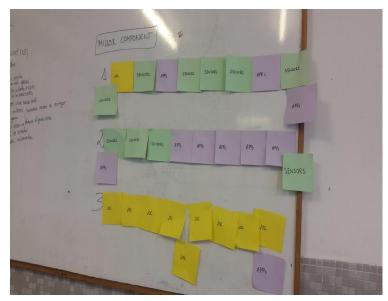


Figure 33 - Ranking of the PEGASO component

Sensors (in green) seem to be the preferred item, followed by Apps (in purple), although the distribution does not show a clear divide. The Serious Game (in yellow) was considered the worst component by 90% of the participants.

During the set of pre-pilots all the comments received were taken into consideration in order to improve the system and make modifications following relevant suggestion of the teens. At the end of the pre-pilot phase the final system integration was performed and the PEGASO system was produced in larger scale quantity for the final pilot phase.

14.2 Project end: Final Pilot and overall evaluation of the PEGASO system

In the final phase of the project, the pilot aimed to test the feasibility and acceptability of the system to adolescents. Given the exploratory nature and length of the intervention, the study was intended to provide a proof of concept and not evidence of effectiveness [Thabane 2010]. However, although this was not in the initial project plan, following a set of recommendation provided during the project reviews, the pilot was

organized in intervention groups and control group in a ration 2:1. An additional aim was therefore to understand recruitment and retention rates in preparation for a future substantive trial, the acceptability and utility of different outcome measures (anthropometric, behavioral, knowledge), and the variation of these in the population of interest.

The collection of information on participants at the start of study provided a description of a large sample of European adolescents, assigned or not to the PEGASO intervention, and enabled the exploration of potential outcomes within strata of demographic, socioeconomic, psychological characteristics and lifestyle related habits. A secondary, but nonetheless significant ambition of the pilot study was to provide insight into the state of the art to identify promising directions for future public health initiatives and interventions.

During the pilots, data were collected from four different types of sources: the PEGASO system (wearable sensors and PEGASO app), questionnaires, and focus groups observations. In addition, anthropometric measures were taken at different moments of the pilot duration (start, to set the baseline and end of pilot to evaluate the outcomes).

The following picture shows the scheme of the evaluation process conducted during the final pilot.

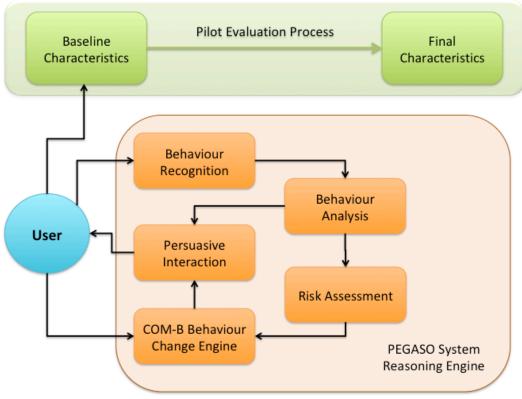


Figure 34 – Evaluation scheme of PEGASO intervention

In addition to the evaluation of the PEGASO system, the final pilot allowed us to reflect on the methodological approach and its efficacy. During the final pilot, no further modification to the design of the PEGASO system were introduced, but a continuous improved with regard to SW bugs was implemented. The issue with SW and the instability of the system had a significant impact of the overall evaluation of the system.

The final PEGASO system (as also shown in Figure 29, Figure 30, and Figure 31 provided in the previous section) consisted of the following elements:

- 1. <u>An Android smartphone</u>. To ensure that all student had smartphones with similar features, the devices where provided by the project. Due to the fact that the no single smartphone model was available in the different countries involved in the project and that even the same phone was subject to automatic updates of the operating system, there were problems with the stability of the system that behaved differently with different models and with different OS releases.
- 2. <u>A set of 6 apps</u> under an umbrella app, the PEGASO Companion with the

objective of providing a seamless experience to the user. The apps could be downloaded independently of each other, according to the project philosophy of providing a modular system. The apps of the PEGASO Companion are:

- eDiary. The eDiary is a food record application specifically targeted to monitor the dietary behaviours of adolescents, being based on food groups rather than the single specific kind of food, and focusing in the diversity and equilibrium of the diet rather than calories intake. The food groups have been selected on the basis of the nutritional characteristics of food. The app gives immediate feedback based on dietary data patterns introduced by the users.
- Challenges. The objective of the Challenges app is to motivate the user to achieve her/his target behaviour exploiting goal fixing and social elements. The Challenges app is another component of the PEGASO Companion allowing users per perform self-challenges and to challenge other users.
- Dashboard. The main goal of the PEGASO dashboard is to present to the user visual feedback and suggestions about target behaviours related to physical activity, sedentariness and sleep quantity and quality. In addition, the Dashboard is the sensors mate app. It allows for monitoring the sensors status and all the data downloaded from sensors.
- PEGASO City. The PEGASO City bridges the digital world of the PEGASO system with the real world. The app represented also the gamification in the PEGASO approach as healthy behaviours could be rewarded with badges that could be spent in the PEGASO ecosystem (e.g. food shops or swimming pools, etc.). Unfortunately, during the course of the project there were difficulties engaging external actors and setting up such ecosystem.
- Mobile Serious game to engage and motivate users and encourage positive behaviour changes.
- Report. This app provided a connection between the PEGASO ecosystem and the personal health folder in the EHR, in two pilot sites: namely Lombardy region and Cataluña. The connection is

established via the "BRIDGE" system. The BRIDGE allows extracting some significant data collected in the PEGASO ecosystem and to create a report to be shared with physicians into the personal health folder (PHF).

3. Wearable sensors, embedded in a smart bracelet and a smart garment, to keep track of physical activities.

Although not fully conclusive in its results, conducting the pilots has had a number of benefits in raising awareness about the health risks linked to lifestyle. Adolescents showed great enthusiasm towards ICT-based projects across all the Pilot sites. They were keen to use mobile phones and sensors in their daily routines. Although a number of bugs and malfunctions reduced the actual usage of the system, the students recognised the PEGASO project as trendy and well-fitting their needs. The capability to recruit and keep the students in the study was seen as a positive result; teachers were also very supportive and welcomed further work to educate teens on subjects related to wellbeing and health.

The PEGASO pilot was important for exploring limits and strengths of the ICT product, acquiring scientifically relevant information about lifestyles and capturing trends in a wide population of adolescents, paving the way for an advanced stage of study that can ground the final design on the optimal conditions identified in its pilot predecessor.

14.3 Conclusions and Lessons learned

The PEGASO project is among the first studies that applied the principles of a user-centred co-design of mHealth technology for adolescent healthy behaviour promotion at scale. Adolescents' design ideas and feedback for five PEGASO apps, a serious game and wearable sensors were implemented, where possible, following three iterative stages. With each iteration the participants were presented with further developed technology, which was then integrated in the final PEGASO system tested in a final pilot of six months duration.

This study demonstrated that it is possible to employ an iterative user-

centred design approach for development of a complex mHealth technology-based intervention to promote healthy lifestyle for adolescents in an international context.

The start of PEGASO took place at a key turning point in the history of the Internet, with the convergence of major trends driving changes in people behaviour and expectations. Many of these trends are still actual and have not yet expressed their full potential and impact in our society. mHealth is still in its infancy and the market of prevention is still largely unexplored; it is still unclear what are the real opportunities for companies, app vendors in particular, and the viable business models, but from the PEGASO experience and the research conducted conclusions emerge with regard to the facts that:

- Public-private partnerships are key for the success of mHealth and to promote prevention; social innovation approaches – among others should be explored;
- The role of Public Administration is quite fundamental and a number of sectors need to work together: in PEGASO we have attempted to bring together Education and Health, however more is needed; city planning, for instance, within the context of smart city projects should consider effects on health and plan for "active and healthy cities";
- Coherently with the above, integration of different disciplines is required, including human sciences; and finally
- The institutions of the European Union and the EU Commission, in particular, should take a leading role in promoting actions so that Member States and public administration initiate active policies for prevention, involving citizens in the discussion.

14.3.1 Considerations for follow-up "The Life Companion"

Through the work performed in the projects, we have come to the concept of a "life companion", a digital friend that provides the support and motivation for a healthy lifestyle.

The vision was partly introduced within PEGASO, limited to the concept of Companion and to the physical object embodying the Companion. Within the framework of PEGASO the Companion is the entry point to the PEGASO framework and in the frame of the PEGASO project, the smartphone embodied the Companion to guide the user's lifestyle. However, the Companion vision is not necessarily linked to a unique physical device but can be conceived as a ubiquitous intelligence, which changes form over time to accompany the user throughout life adapting to evolving needs and desires. The Companion knows the user's personality and will establish with her/him a long-lasting affective relationship. Different ages and stages of maturity have different requirements and the Companion has to be able to continuously adapt to novel needs and propose appropriate activities.

In this vision the Companion can be an interactive teddy bear when the user is a child and will become a smartphone during the adolescence; the Companion can follow also an adult to support his/her work as a laptop or will accompany him/her during the old age as a smart bracelet.

Such an evolution needs the design of a dynamic human-companion interaction able to evolve following the user needs and specificities over time. This is achieved with the constant understanding of the user's lifestyle, where the possibility to tailor the target behaviour and the interventions over time represents the capability of this system to adapt to an evolving user.

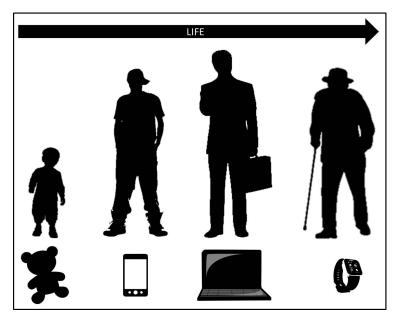


Figure 35 – Embodiment of Life-/Health- companion in different objects

In addition to the embodiment of the companion concept in different physical objects according to age, also the services offered through the companion will evolve and will be offered by different providers according to the specific needs.

15 Annex 2 - The project NESTORE

The project NESTORE was written in response to a European call during the last phases of PEGASO. From the requirements of the call, it was evident that the approach used in PEGASO could be adapted and used for the new target population. In particular remained valid the concepts of awareness, motivation and support to healthy behaviour. More important the methodological approach could be similar and co-design be used during the project development phase. In a different manner from the PEGASO approach, where we started from a specific architecture for the solution, here, the need to be less prescriptive on the solution was identified to allow for a more open choice of technologies, adoption or not of sensing technologies and type of sensing technologies, ensure that the solution meets requirements that might be very different as older people have the legacy of different life experience that will bear specific impact on the perception of the way they see ageing; there is a stronger need to leverage the "affective" dimension and this needs to be reflected in the solution that should be based on elements that have meaning and value for the people. Also, the concept of behaviour change needs to be adapted to the fact that older people have long established habits and tastes that are more difficult to change. The concept of "gentle nudge" should be considered in the development of the solution. In addition, older people are more sensitive to the concept of "health" with respect to younger people and ensuring, through good design practices, that the solution is something they can actually master and use, is very important.

15.1 Rationale behind NESTORE

Due to the longer life expectancy and the declining fertility rates, the proportion of people aged over 65 years is growing faster in most of the developed countries. Some forecasts indicate that the population of elderly people will almost double from 87.5 million in 2010 to 152.6 million in

2060³⁸. In general, we live longer and even though the ageing process entails more health complications, we all want to remain in the company of our friends and family, continue to live in places that are familiar and comfortable to us, and maintain our mental and physical autonomy. The emerging social aspect related to ageing population introduces some challenges to society and health care systems. Without adequate adjustments, i.e. social, economic and demographic policies as well as changes in people's behaviours, the process can trigger negative consequences in the long term. In order to maximize the wellbeing of older people and to reduce the economic burden of their care, the health systems should promote and actively support, as much as possible, policies for "healthy ageing"³⁹.

The challenge addressed by NESTORE has been well depicted in the following scheme:

³⁸ <u>https://ec.europa.eu/research/social-sciences/pdf/policy_reviews/kina26426enc.pdf</u>

³⁹ Healthy ageing is the process of optimising opportunities for physical, social and mental wellbeing to enable older people to take an active part in society without discrimination and to enjoy an independent and good quality of life.

⁽http://ec.europa.eu/health/ph_projects/2003/action1/docs/2003_1_26_frep_en.pdf)

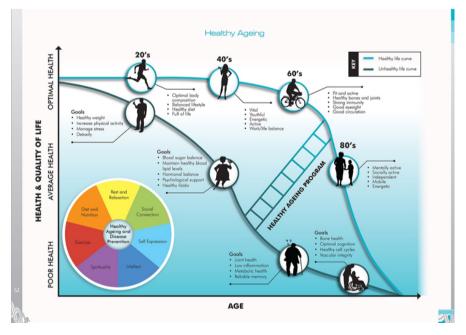


Figure 36 – Challenge of healthy ageing

Technologies, in particular ICT and in general the field of m-Health, can play a key role in support of the needs of the ageing population. Whilst technology can potentially have a significant impact on health and wellbeing, to date uptake of digital health technologies has been problematic in a number of wide-scale studies. Literature highlights that the reason for non-acceptance of health technologies is complex. Authors have cited confidence, the stigmatizing aesthetics of products, meaningfulness of technology in the broader context of the persons' life, ease of use and integration into everyday routines as important factors.

In the NESTORE project the objective is to overcome the limitations of current solutions. Taking "healthy" as the main keyword, NESTORE addresses healthy older people covering five key dimensions of wellbeing with an integrated approach. Leveraging participatory design, the focus is no longer on a single solution, but on solutions able to address the older population of tomorrow, open to integrate services provided by third-party and based on the design of pathways that according to user preferences and inclinations leverage existing personal capabilities to support healthy lifestyles and overall wellbeing.

The following picture provides the boundaries of the scope of the project, with a focus on primary prevention, where users will have an active role and will have to become managers of their own health and wellbeing.

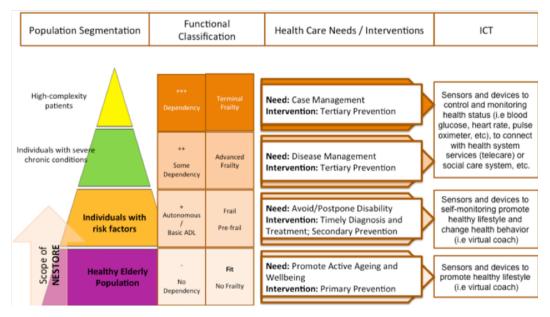


Figure 37 – Scope of NESTORE project

15.2 Model and approach

The model of wellbeing adopted by NESTORE in its design is based on five interconnected dimensions: Physiological status and physical activity, Nutrition, Mental and psychological wellbeing, Social interaction, and Cognitive capabilities. NESTORE acts as a coach monitoring older people behaviour along the different dimensions supporting the healthy ageing process based on healthy nutrition and adequate personalized physical activities, as well as social interaction, in order to prevent physical and cognitive decline and to preserve mental wellbeing.

The theoretical base for the design of the solution starts from the SOC model [Freund 2000, Schwarzer 1992, Sniehotta 2005] that outlines general-purpose processes of specialization by selection of developmental pathways, preferences or goals. According to SOC, the goal of NESTORE is to empower the latent reserve capacity of older people to limit the age-related loss of skills, in relation to the 5 dimensions addressed by NESTORE. To foster motivation, NESTORE helps the user to select and

identify a final purpose "the wellbeing pathway" (based on the risk perception, self-efficacy and outcome expectancies); it then facilitates the action planning and the maintenance of self-efficacy through the provision of a set of actions aimed at the achievement of goal. Finally, NESTORE monitors the user's progresses in order to propose recovery actions in case of impediments or actual loss of motivation.

Adopting SOC, NESTORE defines specific pathways that meet user preferences and whose aim is to allow reaching, by the older people, the maximum capacity of their latent reserve, that guarantees an active and healthy ageing. Such definition is related to the **Selection** component of the SOC model. It will then identify the building blocks that specify each pathway; this is related to the acquisition, application and integration of resources involved in attaining higher level of functionality (internal or external) in all the dimensions (**Optimization**). Such building blocks can be represented as possible actions that the user shall perform to pursue its pathway and that are suggested, monitored and provided by the Virtual Coach. Finally, NESTORE monitors the user's level of motivation and engagement and intervenes to restore and manage impediment or loss of motivation (**Compensation**).

According to the principles of participatory design, the methodological approach followed in NESTORE provides for users to be involved in the design of the solution throughout the project duration. The method draws on the value of 'thinking with things' as a means to build understanding of the factors end-users identify as being important in the design of digital health services and devices.

Literature highlights that the reason for non-acceptance of health technologies is complex. The role of the design is to better understand the broader physical and social environments in which services and technologies will operate and how they relate to the contexts of the end users' lives. NESTORE has adopted co-design methods that seek to engage and elicit information related to perception, acceptance and usability of technology to support healthcare. Such methods have been shown to be beneficial in the evaluation and design of health-care interventions [Schmittdiel 2005].

Participatory methods are centred on the principle that participant engagement can provide value throughout research planning and implementation [Lorenz 2009]. Participants are given an active role, allowing them to shape the direction and methods of the research itself. Multiple benefits are associated with the use of participatory methods in health-care settings including developing collaborative and productive partnerships with participants, providing participants with a voice and harnessing participant engagement to stimulate positive change [Jagosh 2011, Jagosh 2012] and the design of better products.

Multiple levels of engagement are possible at various stages in this paradigm and these will change and develop as the project evolves [Jagosh 2012]. Within NESTORE we adopt the definition of co-design, which is the *creativity of designers and people not trained in design working together in the design development process* [Sanders 2014]. Using the Design Council Double Diamond as a framework, co-design in the early phase of the project utilizes methods to better understand and interrogate the requirements of the product, the issues facing individuals. Methods here are more open (thinking with things, critical artefacts) as the design process seeks to ask questions rather than offering solutions.

This approach makes use of both divergent and divergent thinking during two different stages of project development. The first *Diamond* starts with divergent thinking – consideration of numerous ideas – then moves to convergent thinking – the refining and selection of ideas. At the end of this stage, a brief is defined, and the second stage begins. In the second *Diamond*, key ideas are selected, developed and tested before being refined again. *This creative process is iterative, that means ideas are developed, tested and refined a number of times* [Glaser 1967]. This paradigm can be repeated in an iterative way, (as it happens applying a Grounded Theory methodology), in order to identify, refine and integrate insights and requirements, and ultimately to fulfill users' needs and define a tailored solution.

The following table maps the NESTORE Co-Design against the Design Council Double Diamond Process

Phase	Co - Design intervention	Co – Design Participants
1. Discover	Exhibition in a box – critical artefacts	Participants (number x 80)
2. Define	Creative Probes - data capture translated through creative medium to form research tool kit.	Selected older users Researchers Stakeholders
3 Develop	Prototypes – product iterations	Stakeholders
4. Deliver	Pilot project - evaluation	60 persons recruited to engage in the pilot study across the country partners in IT, ES, NL.

Phase 1 – First collection of data from older people through a series of workshops, first with selected users to kick-start the co-design phase and then in the three pilot countries: Italy, Spain and The Netherlands. The workshops engage with representatives from the target populations and adopt an iterative cycle utilizing a grounded theory approach [Glaser 1967]. The workshops have the objectives of:

- Build understanding of user requirements of the technology: factors that promote and inhibit the use
- Identify priorities regarding health concerns of this population
- Explore potential contexts where technologies will be used
- Consider how data collated by the technology can be visualized in such a way to support health change

This phase focuses on activity to develop cultural and behavioural insight related to technology and specifically health technology.

Phase 2: 10 participants selected from Phase 1 will create a new working group with the partners and stakeholders and focus on the materiality, interaction and usability issues related to the NESTORE system. Participants will be recruited to create three co-design groups (6-8 in each) in Italy, Netherlands and Spain to extend cultural insight and test transferability of methodology.

Phase 3: will support the development of prototypes and product iteration through.

Phase 4: is the pilot study: 60 participants will be recruited across the pilot sites in IT, NL and ES.

The project, started in September 2017, has now concluded the first phase and the findings have been reported in the project documentation.

15.3 First phase methodology and findings

The methodology "Exhibition in a Box" used in the first phase of NESTORE has been developed by researchers of the Sheffield Hallam University [Chamberlain 2012] and uses objects and artifacts as methods to stimulate and structure ideas and thoughts. The nine objects (keys, pencil, glove, post card, stones, dice, wrist watch, soap, plastic spoon) that form the exhibits have been defined through the experience of several earlier projects earlier and can be transported to different environment that can trigger different reactions and generate different ideas in the people. The different objects invite individuals to express ideas and opinions in a freethinking process that allow people to describe what is important to them and which are key values in the context of the research theme.

The first set of workshops took place in the UK and involved people in the age range 58-65 (i.e., people still at work, but looking at retirement in the mid/near future). The workshops were located in several physical contexts, such as university labs, homes, etc. as different contexts may trigger

different feedbacks and ideas; the discussions allowed the researcher to identify some set of key values and relevant concepts with regard to the research theme, i.e., the use of personal technology for health. Based on this first categorisation additional workshops were held in the three pilot countries to confirm approach and add perspectives from different cultures.

15.4 Preliminary findings

The results from phase 1 of the co-design process have been categorised as follows:

- 1. Hobbies, work and leisure; this categorisation helps in finding the dimensions along which NESTORE should be developed in order to take into consideration what people are interested in. As NESTORE should propose wellbeing pathways according to people's interest, there should be enough flexibility to allow for very diverse interests.
- 2. **Technology**: barriers and enablers to engagement and adoption; this category is a core for the system design, as understanding motivational factors and potential barriers will avoid making obvious design mistakes. Understanding fears and expectations people have from technology, in particular, given the target age range, is important at the very early stage of the system development to eliminate factors that may lead to a scares use of the solution or to abandon the solution soon.
- 3. Design considerations to promote adoption: following the identification of barriers, this category was elicit ideas on product and service design to overcome such barriers and encourage adoption and sustained use.

The following tables provide an overview of the main results for each of the category.

Hobbies and activities	As expected, the range of hobbies and activities
	people described as being important was very
	broad and included cultural activities such as
	listening to music and playing instruments,

Table 7 - Hobbies, work and leisure

	visiting musea and exhibitions, as well as more manual activities such as gardening or drawing and sport activities, including walking. Older participants also talked about the importance of spirituality and faith in relation to their emotional and spiritual wellbeing.
Physical activity	Physical wellbeing is of course important and many of the participants engage in activities such running and walking. Physical activity also provides an opportunity for relaxation and for the maintenance of mental wellbeing.
Social dimension of activity	The social dimension of activity is a motivating factor and is key to maintaining mental health. Engaging in activities with other people and the importance and value of interacting with family, engaging in intergenerational activities, was a significant theme throughout all workshops.
Creative activities	Across all also workshops individuals identified creativity, art, writing and drawing as ways of keeping mentally and cognitively well and as a way to retain a sense of curiosity and new learning.

Table 8 - Technology: barriers and enablers to engagement and adoption

Perceptions	and	As the initial stage of discussion, an in order not
attitudes		to bias the discussion, technology was
		understood in very broad sense, although it
		became evident that most people associate the
		word technology with digital technology,

	mobile phones, computers, tablets, etc. and, with few exceptions, people had access to and could make use of digital technology. Most people have a positive view of technology as a facilitator for daily tasks, and to easily access information. Some people see the technological progress in a positive way, although most people indicated that they only use basic functions and are not interested in more technology. Some people saw technology as a threat to the current way of living, referring to the way communication has changed and how easily information about people can be collected, and how people can be influenced.
Barriers to engagement	Barriers to engagement were discussed at general level where, for instance, lack of encouragement was seen as a key factor, in particular when attempting something new. The cost in monetary terms as well as in terms of time to dedicate to activities was also seen as a barrier. In terms of technology related issues main barriers were identified in Speed of change and cognitive demands – people find frustrating having to constantly keep with updates that require the need to master new devices and programs. This is an issue, in particular at an age when people struggle to retain information and learn new things. Having to remember multiple passwords was also identified as a strong barrier. On the other hand people see the risk

of the technology divide and the risk of potential exclusion, so it is important that technology should be easy to use for adoption in the long term.
Costs and infrastructure People expressed concerns about the cost of technology and also to network coverage and speed. So there is a difference whether you can afford the technology and whether there is good access to Internet and fast mobile network in the areas where people live. Also, these factors could lead to social exclusion.
Security, privacy and trust There were, of course concerns with regard to these aspects, in general, but specifically in the case of health and health information. The concept of trust has many nuances: trust in terms of reliability first of all, that the technology work well and collect info (e.g. in the case of wearable sensors) in an accurate manner. Trust on the fact that products are well designed and do not lead to errors or misuse.
With regard to security and privacy concerns were expressed, as expected, on access to data and information and on the permanence of the digital footprint and the consequences of making mistakes, which were difficult to erase from the digital domain.

Personalisation	The possibility to personalise the technology was by far the most desirable design consideration expressed as this feature can create a sense of identity and ownership.
Consistency of instructions	If personalisation and the ability to adapt and shape the technology to reflect the owners personality then the opposite was true in relation to the operation of digital devices. Participants identified the need for consistency in design, in the symbols used and controls across products.
Portability and ergonomics	Portability was another design consideration: this reflects in size and weight, but also on connectivity, if needed for the functioning of devices. Capability to operate the devices in an independent manner is a minimum, in particular as the solution is supposed to support independent living. Ergonomics of the devices was also a key factor, as well as the capability of adaptation to people's changes as they age.
Features to promote control and self- efficacy	A key feature here is to have the choice and option to disconnect from technology. People also indicted that being continuously monitored can induce stress and questions on the ethics on constant monitoring were raised (this links to the privacy element, and who is able to read and act on the collected data).

Table 9 - Design considerations to promote adoption

Single	or	multiple	There were mixed views in terms of whether
functiona	alitie	S	devices should have multiple functions or
			whether a single piece of technology should
			have a single function.

15.5 Transfer of user perspectives towards technologies and solution development

This first round of focus groups allowed identifying main fears and expectations that people may have interacting with technology for healthcare. Although the focus of the discussion was not on the specific solution, the co-design sessions made evident some key general requirements in terms of capability to personalise the solution, easy and clear user interaction, respect for privacy and capability to switch off, flexibility and adaptation of the solution to meet personal preferences in terms of lifestyle, capability to sustain socialisation and sharing with friends and family.

The following steps have focused on the co-design of the specific solution. Based on the requirements a set of persona's and scenarios have been developed to design specific services. The solution has been developed in small steps according to prioritisation of requirements. At each step the solutions have been tested and validated with sample users to ensure that requirements are actually met, that user feel comfortable with the technology so that the NESTORE pioneers can become champions towards others. A second set of workshops was therefore conducted involving also technical experts with focus of the different parts of the NESTORE systems, so that user requirements could be correctly transferred to technical experts for the development of the technological solution.

The project is now in its final phase; pilot leaders are responsible for coordinating the installations in the users' homes. Results of the overall evaluation of the system and feedback from the users are expected in the fall 2020.

16 Annex 3 - Other project proposals

In the same field, still responding to European calls, I had the opportunity to coordinate the submission of two proposals (SHARP@Work and COMETA) and participate to the drafting of a third proposal (IdealAgeMode). In the three proposals we have tried to understand how to best use design strategies to develop approaches and solutions to improve wellbeing of people in two different cases: Sharp@Work and IdealAgeMode, within the scope of the H2020 framework, were two proposals addressing the issues of healthy ageing in the workplace. COMETA was a proposal in the ERASMUS Sport framework and aims at understanding how design methods can be best used to develop equipment and activities for disabled children, so that they can increase autonomy in performing sports.

Although the proposals were not funded, they can still be relevant (in particular SHARP@Work) to the discourse on health-design binomial, as for their preparation research was made in the use of participatory design for the definition of novel organisational policies in the workplace for the wellbeing of workers across the ageing process, and novel tools were identified for the implementation of the research, such as the use of living labs as playing and experimentation fields for analysing novel policies, and the impact of digital transformation on the wellbeing of workers.

16.1 Wellbeing at work: Sharp@Work and IdealAgeMode

Sharp@Work and IdealAgeMode aim at developing approaches and solutions for healthy ageing and wellbeing in the workplace. The field of research addressed is close and complementary to the one addressed in NESTORE. Although the envisaged specific solutions are different both projects adopt as research method co-design and participatory design.

Sharp@Work aims at an infrastructural solution in terms of a multistakeholders platform that, exploiting and integrating a digital technologies and enablers, is able support the development of novel organisational frameworks empowering best practices in "age management⁴⁰", able to recognise and negotiate roles, values, and priorities in order to sustain workers' health and motivation and provide them with practical support to remain active. Specific user services can be provided by third parties and can be negotiated between workers and employers to ensure that work can be adapted to workers as they age; focus is on ageing in general terms and services should provide support both on motivational aspects as well as on capability aspects.

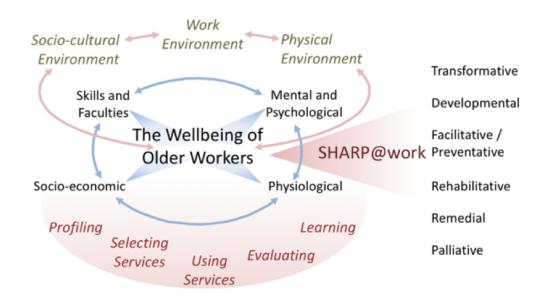


Figure 38 below shows the overall scope of the Sharp@Work proposal.

⁴⁰ Age management refers to the various dimensions by which human resources are managed within an organisation with an explicit focus on ageing. Age management includes age-related factors that should be taken into consideration in daily management, including Work arrangements and individual Work tasks, so that everybody feels empowered in reaching [their] own and corporate goals (Promoting active ageing in the Workplace, Prof. J. Ilmarinen, 2012)

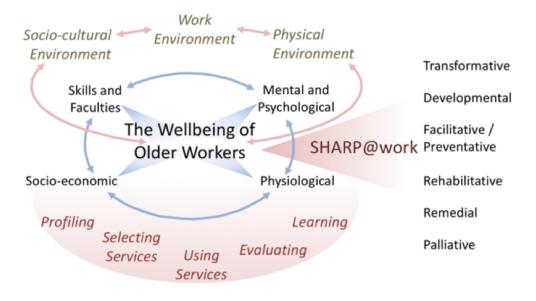


Figure 38 – Scope of Sharp@Work

IdealAgeMode aims at the development of a service platform and focuses on stress management. The solution is based on different sensing technologies, environmental, as well as wearable, able to recognise the stress levels in the individuals and take appropriate actions. Figure 39 below shows the conceptual model adopted in the proposal.

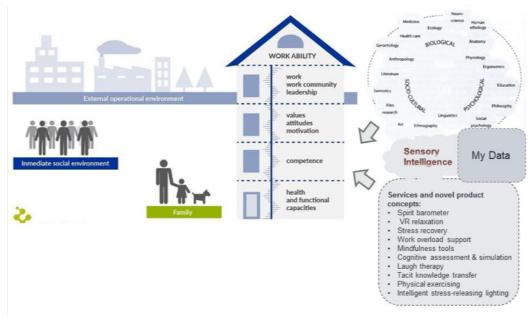


Figure 39 – The conceptual model of IdealAgeMode (based on the concept of work ability house)

Both projects base the proposed intervention on the concept of workability, as elaborated by the Finnish Institute of Occupational Health [Ilmarinen 2009] and also adopted by European Agency for Health as Safety at Work ⁴¹.

In the following section, details on the approach followed for Sharp@Work are provided, as I lead the definition and the approach of this project, while researchers in VTT (Finland) coordinated the drafting of the IdealAgeMode proposal, with some contributions from Politecnico di Milano.

16.1.1 Methodological approach in Sharp@Work

Work is not only a source of income, but it is also a relevant determinant of our personal identity, social integration, and wellbeing. Motivational factors therefore are a major determinant of staying active for longer. In late career, multiple facets of work motivation are distinguished, including *motivation at work* (the effort and persistence invested in one's work which can vary day-to-day), *motivation to retire* (intentions to exit from the career job), and *career motivation* (the direction and persistence of career-related behaviours) [Kanfer 2013, Fried 2007]. Figure 40 depicts the workflow adopted in SHARP@Work and gives on overview of the relevant predictors and outcomes of work motivation.

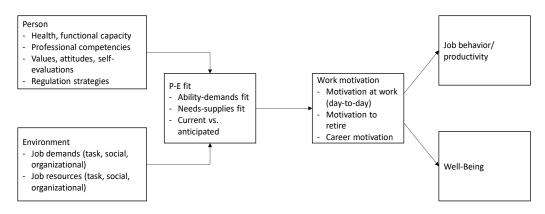


Figure 40 – Workflow adopted in SHARP@Work

⁴¹ https://osha.europa.eu/en/tools-and-publications/publications/articles/promoting-active-ageing-in-the-Workplace/view

In general, high levels of work motivation result from a good (current and anticipated) fit between person (P) and environment (E), in particular the fit between personal needs and abilities with the supplies and demands of the work environment [Zacher 2014].

On the side of the person, work motivation is driven by the resources and values that older workers bring to the workplace. Personal resources include basic functional capacities (cognition, physical strength, socioemotional skills) and health, professional competencies (job knowledge and tacit skills acquired over the course of one's working life), and self-regulation strategies (behaviours to regulate goals and emotions). Older workers also hold certain values and attitudes that define their self-concept. For example, the self-concept of being an older worker – and the negative attitudes associated with being old in our society – diminish older workers' daily cognitive engagement with their work when confronted with cues of aging or ageism [Armenta 2018].

The work environment is defined by job demands and resources. Job demands define the direction and magnitude of workers' goal-driven behaviour at work; job demands drain workers' energetic resources. Resources can be physical in nature (e.g., demands to work in painful positions, repetitive movements, lifting weights) or psychological (e.g. working under time pressure, high workload, social conflicts, managing other people). Job resources help workers to fulfil demands, recharge resources, and maintain high work ability over time. These also can be physical (ergonomic equipment and tools) or psychological in nature (social support, job autonomy, high leadership quality). Job demands and resources can further be divided into those concerning the work task, the social context, and the organizational context [Keller 2017]. Age diversity climate – a positive attitudes and valuation of workers of all ages, and the accompanying Human Resource practices – for example, can be a major organizational resource for older workers.

The critical issue related to the ageing workforce is ensuring a good fit of

the changing personal needs and abilities with age and the work environment (i.e., high P-E fit). A lack of P-E fit will result in lowered work motivation and ultimately diminish job performance and wellbeing and increase the risk of early exit from the workforce. Because occupational sectors involve different work demands and resources, the perceived sustainability of work varies across sectors, as the European Foundation for the Improvement of Living and Working Conditions (2010) survey shows (see Figure 41). In general, white collar workers – who face fewer physical job demands and often higher levels of job autonomy, expect to be able to carry on their activity longer than blue-collar workers – who face high physical demands and lower resources. The more workers are exposed to ergonomic risk (e.g. working in painful positions, repetitive movements, lifting weights and so on) the less likely they are to expect to be able to carry out their duties at 60.

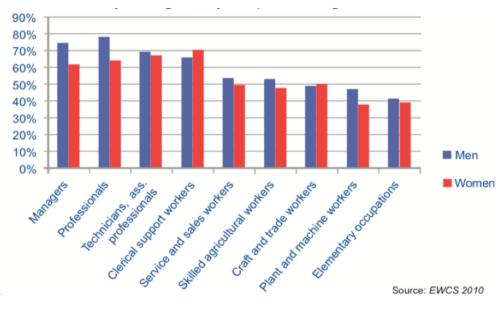


Figure 41 - Percentage of workers expecting to be able to carry out their job at age 60, by occupation and gender

Importantly, person and environment are not fixed but can be influenced through interventions. However, interventions need to be individualized to persons and work contexts to match the physical and psychological evolution of the worker and the specific work conditions to keep productivity, work-life balance, and job satisfaction at optimal levels. Older workers are a heterogeneous group and there are large inter-individual differences in how workers' abilities and needs develop across their career. Likewise, occupational and organizational environments differ widely in their demands and resources. One form of interventions that may be well suited to deal with this heterogeneity are bottom-up work redesign approaches such as I-deals [Rousseau 2006] (i.e., personalized arrangements that benefit employees and organizations and are bargained by employees).

The design approach adopted by the SHARP@Work project is based on the Double Diamond, also adopted in NESTORE, accompanied by experimentation in a Living Lab to test different services. As the scope of SHARP@Work was very wide, ranging from services for the individual worker to definition of policies for ageing in the workplace, we felt that there was a need for the involvement of the entire ecosystem of actors in the definition of the solution, as in the working environment there is a stronger mutual influence and any new intervention, even having as object a specific need from a subset of individuals, may affect the larger community of workers and the company as a whole.

The following picture, Figure 42, gives an idea of the complexity of the ecosystem that, centred on the worker, needs to consider other roles in the company and outside the company when designing the solution.

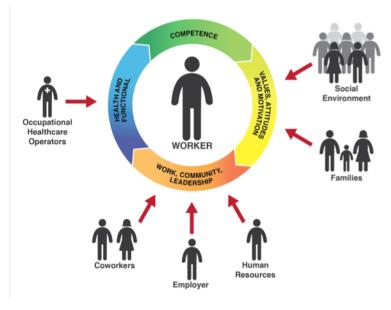


Figure 42 – The ecosystem of stakeholders in Sharp@Work

16.1.1.1 Double Diamond application

SHARP@Work makes use of co-design methods and tools to engage users and elicit information related to their perceptions, behaviours and attitudes concerning their daily working activities and the related environment. Design guides and eases the interaction among workers and the involved stakeholders, to better understand their needs and requirements and the broader physical and social environment in which they spend their working time.

The Design Council *Double Diamond* is again adopted as a methodological framework.

The different phases are organized as follows:

Phase 1 - Discover: During this phase, researchers will investigate the working conditions and the related environment, including all multifactorial, multifaceted aspects (cognitive, psychological and social aspects, workplace and furniture, activities and tasks), trying to understand and gather insights, useful to define the project's requirements. Final users and multi-stakeholders will be involved in Co-design activities and workshops. Their long-term engagement will be useful for tailoring the system and for its iterative implementation. Elderly Workers will be recruited from the different involved

countries, taking into account that working with people in their environment provides a better opportunity to gather rich insights. Elderly Workers will be recruited with a good gender balance and diverse ethnic representation. Pilot studies' leaders will attend the Co-design workshops phase, to experience and learn the methodology.

- Phase 2 Define: soon after the divergent phase, a convergent one is needed. All the insights, expectations and requirements identified will be used for developing personas and scenarios, useful to define the SHARP@Work platform. Personas create a strong focus on users and working contexts through the fictionalized setting. They represent a medium for communication and utilize the power of narrative and storytelling to enhance attention, memory, and organization of detailed user data. Scenarios will be constructed around personas. They are useful for engaging people and promoting reflection and discussion among team members and involved users. Personas and Scenarios represent a method for enhancing engagement and reality that enable design, product development and testing to move forward more effectively. The engagement of real users doesn't end in this phase: Personas and Scenarios evolve in response to ongoing observation of, and feedback from, the real people who inspired them. Personas and Scenarios represent a powerful design tool for generating new possibilities and solutions. At the end of this phase, a Brief will be defined, summarizing requirements and insights, to let project partners begin the development of SHARP@Work platform.
- Phase 3 Develop: the third phase is addressed at the platform development. It represents a new divergent phase, in which solutions or concepts are created, prototyped, tested and iterated. This process will engage users, supporting the researchers in the platform development and its implementation. This is an iterative process, during which solutions are continuously tested, improved and refined. To engage users, to drive their participation in the process, and to let them use the SHARP@Work final platform, a gamification approach could be adopted. Gamification taps into human desire and its natural attraction for gaming and can influence employees' behaviour in the workplace. Gamification triggers people's curiosity about work tasks, keeps people intrinsically motivated to continuously engage, enhances internal collaboration, promotes commitment among employees, increases motivation to learn and grow at every age,

provides insights for future areas of product/service applications, increases the willingness to take risks, educates on how to accept failure, promotes openness to new ideas and technologies, among many other behaviours. Gamification can also be a powerful way to involve different stakeholders in knowledge acquisition and sharing practices by leveraging analytical capabilities and establishing ties and commitment amongst employees. At the end of this phase, the platform framework and its features will be defined.

• Phase 4 – Delivery: The final step is the Delivery stage, where SHARP@Work platform is finalized and launched. During this phase, the designed platform framework will be tailored according to the final users and the pilot study's participants. Direct observations and interviews will be carried out at this stage too, for further implementations of the platform.

As stated, this is an iterative process, during which insights, ideas and concepts should evolve throughout the project lifespan thanks to the engagement of final users; it allows to overcome researchers' bias and assumptions and to develop responding solutions, tailored on users' needs.

16.1.1.2 The Living Lab Approach

The Living Lab platform and method play an important role in the user engagement, participative design and evaluation in SHARP@Work. This approach has been developed and employed for over a decade in the development of complex socio-technical platforms and environments particularly those that involve multiple agencies, disciplines and interests related health and welfare services.

The core objective of the approach is to create and juxtapose sets of exhibits as boundary objects which encourage and support processes of mutual engagement and sense-making, leading to co-design and coproduction, among sets of participants who represent different interests, disciplines and roles. Its objective is to support the innovation of relationships and the creation of shared visions and intentions among them. At the initiation of the process, the boundary objects take the form of "windows and mirrors" representing the different worlds of the participants, provoking and assisting the processes of mutual sensemaking, understanding and exploration. The process then moves on to the design of technical, organisational and individual processes and practices. This includes the specification of services and the creation of shared structures, processes and resources. In a third phase, data from the systems that have been implemented and deployed is used to visualise and animate the uses that are being made of the system. The sorts of platforms and service collections we are considering must remain open to creativity and innovation and this may produce unexpected outcomes. Whether such emergent uses are to be publicised and encouraged or steps taken to prevent them being repeated in the future represent the processes of governance through which learning takes place, within the system and the community, and the platform evolves.

The living Lab provides a mechanism for linking the work of the Pilots, the SHARP@Work Architecture and the Policy Modelling activities of the project.

In the first phase of the projects, the SHARP@Work pilot contexts will be investigated and mapped to produce an initial set of Living Lab exhibits the purpose of which is for the pilots to understand the contexts in which they operate. As SHARP@Work represents a multi-service infrastructure, specific use cases and user pathways are potentially extremely complex and varied: the standard application-oriented approach to use-cases and business logics cannot cope with this complexity and a more iterative and incremental approach is required. The Living Lab creates the contexts and occasions for the required conversations and co-construction to take place between the range of participants and interests represented in the pilots.

The Living Lab approach is also the basis for the proposed approach to policy modelling to be adopted in SHARP@Work. It provides a framework for organising and supporting the relationships between policy exploration and formulation, targeting, capacity and resource analysis, implementation/delivery and impact analysis and clarifying the disposition of roles and responsibilities among these activities.

16.1.1.3 Validation of Solution through Pilots in Real-life Settings

SHARP@Work was planned to be tested in different environments in order to demonstrate the feasibility of the concept. Pilot sites were planned in three countries, in a real environment with a sample of users, both employer organizations and workers.

Pilots were planned to be organised following three phases

- Preparation phase
- Execution phase
- Monitoring and Validation phase

The following table provides an overview of the tasks to be performed in each of the phases.

Phase	Action
Preparation phase	Contacting employers to get their participation and signature of a collaboration agreement;
	Field visit to the company to assess the current situation at work and potential situations that might require intervention;
	Participatory design workshops with all stakeholders (separately and jointly) to understand key cultural values determining the potential service offering and approach to the solution;
	Design services that might tackle the detected issues. Services co-design session with workers and other stakeholders involved in the service definition phase (stakeholders should have different profiles: doctors, managers, HR managers, technicians, psychologists)
Execution	Presentation of selected co-designed services that the

nhaaa	platform can offer to tackle the problem
phase	platform can offer to tackle the problem.
	Provision of specifications and guidelines for use to
	employers and workers.
	Validation by at least two interventions by each
	company. The length of each intervention would
	depend on the type of service and should be sufficient
	for a meaningful assessment of the intervention.
Monitoring and	Verifying that the proposed measures were satisfactory
Validation	through the proposed KPI.
	through the proposed Kri.
phase	Reporting to the employer and worker about the
	Reporting to the employer and worker about the
	outcomes of the pilot.
	outcomes of the pilot.
	outcomes of the pilot. Preparing a report with corrective measures in case, to improve the service.
	outcomes of the pilot. Preparing a report with corrective measures in case, to improve the service. Applying corrections to the services used in the
	outcomes of the pilot. Preparing a report with corrective measures in case, to improve the service.

16.2 Empowerment for disabled people: Project COMETA

COMETA is a project proposal submitted in the programme ERASMUS Sport, which aims at actions to promote sport and inclusion at all levels by means of sport. Within the frameworks our proposal focuses on better inclusion and participation in sport activities by young people affected by disability. In our approach design is central as the aim is to develop tools and instruments to perform sport activities in a more independent manner. Specific sport activities, currently adopted for therapeutic approaches, such as swimming, climbing, and horse-riding are analysed through Codesign and Participatory Design approaches, considering activities and tools as an integrated system (service/product design) to foster increased independence in the practice of sport by disabled people, in particular children and teens. The project wants to explore relationships between children with disabilities and sports/physical activities through design methodologies and co-design practices. This creative practice and codesign experience will enable an increase of the motivation and ownership of the final outcomes among all key stakeholders.

In relation to the role of design, the main outcome of the project was defined as:

• A design-based methodological approach to assess current practice, understand the different stakeholders' needs, and specifically needs and expected benefits of the people with disability.

The aim was that sport associations, sport equipment manufacturers, etc., could use the approach developed in their work practices to tailor activities, equipment and tools to the specific disability and therapeutic requirements.

16.2.1 The methodological framework

This project proposed a multidisciplinary methodological approach, coming from the Design Research field.

The methodological approach applied in COMETA provides engagement for users (children with disabilities, their relatives and therapists in charge of recreational sport activities) to be involved throughout the project duration. Through such engagement in the design of the integrated product-service-system-policies, COMETA partners can understand the factors that users identify as being important in the design of sports activities, health services and aids.

COMETA adopts Co-design methods and tools that will seek to engage users and elicit information related to their behaviors concerning sport activities (their perception, acceptance and, regarding aids, usability).

In COMETA, the role of Design (with its methods and tools) is to facilitate the interaction among end users, their caregivers (relatives and therapists) and all the involved stakeholders (non-profit organizations, sports equipment manufacturers and policy makers), to better understand the broader physical and social environments in which aids and services operate and how they relate to the contexts of the end users' lives.

Co-design in the early phase of the project applies methods to better understand the requirements of the product-service-system-policies solutions, facing individuals' issues. Methods here are very open (thinking with things, critical artifacts, etc.) as the design process seeks to ask questions before offering solutions.

COMETA is articulated into 4 different phases, as illustrated in the following picture.

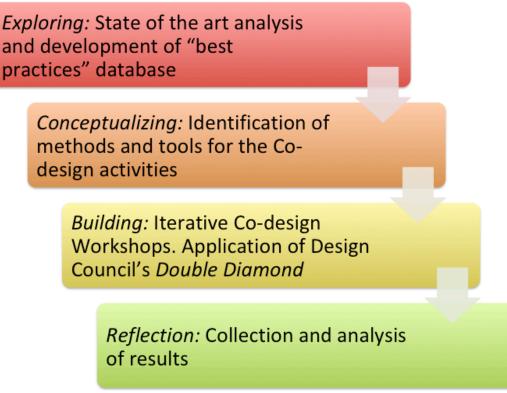


Figure 43 – Overall design approach in COMETA

The definition of the methodological framework and the identification of the best practice regarding the promotion of physical and sport activities among children and teens with disabilities represent the beginning of the project. This phase is shaped as an *Exploring Phase*, during which the state of the art will be investigated and a database of "best practices" in the selected fields will be created.

After the Exploring Phase, a Conceptualizing phase takes place. This phase

is related to the identification of the proper methods and tools to be used during the Co-design activities, to better involve end-users and the stakeholder network.

Selected methodology, methods and approaches will be applied in real case studies linked to Co-design Workshops. This phase is organized as an iterative process, in which the outcomes of each step represent the input for improving the approach. This phase can be defined as a *Building Phase*.

During this phase, the Design Council's *Double Diamond* will be used as a framework for the Co-design process and workshops. Accordingly, the four steps are organized as follows.

- Discover during this activity, involved users and researchers try to look at their sport experience in a different, fresh way, notice new things and gather insights;
- Define after this step, there is a definition stage, in which users and researchers try to make sense of all the possibilities identified in the Discover phase. The goal here is to develop a clear creative brief that frames the fundamental design challenge. The definition of the brief represents the intersection of the 2 diamonds.
- Develop The third step is addressed at the development of solutions or concepts that are created, prototyped, tested and iterated. This process of trial and error helps users and designers to improve and refine their ideas.
- Delivery The final step is the delivery stage, where the resulting project (products, services, policies) is finalised, produced and launched.

At the end of the *Building phase*, a *Reflection phase* will follow during which results are collected and analysed.

The innovative aspects of the project lie in its **process**, the **approach**, the **outcomes** and the **experience** of all stakeholders involved.

• The process: This study brings together academic researchers and practitioners from the fields of design and sports, which rarely collaborate with each other. This collaboration enables valuable knowledge exchanges across different disciplines. Moreover, all data will be captured in an engaging and

meaningful manner through suitable applications of co-design activities. In this way, the team can ensure that the needs, concerns and aspirations of all parties are properly investigated;

- The approach: The project focuses on children with disabilities and develops all work programs based on their needs in a bottom-up manner different from traditional top-down health agendas;
- The outcomes: This project offers a complete package of the methodological framework and the practical guidance offering solutions suitable for the needs of other disadvantaged groups;
- The experience: The active participation in Co-design activities throughout the project can benefit all parties in many different ways, such as building selfconfidence among children and carers and fostering creative thinking among sport practitioners. This creative experience differentiates this study from other similar studies without design/co-design inputs.