

Antonio Gaddi · Fabio Capello  
Marco Manca *Editors*

# eHealth, Care and Quality of Life

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Forewords by Sergio Bertolucci and Gianfranco Gensini

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## Foreword 1

There is no doubt that the Internet has been the most influential enabling technology of the last 20 years, possibly comparable to the introduction of electric power at the end of the nineteenth century.

Beyond its economical impact (recent studies show that it has accounted for 21 % of GDP growth in mature economies over the past 5 years, with a continuing positive trend), the Internet has shaken all the pre-existing paradigms on information generation, elaboration and fruition, introducing epochal changes, which encompass all levels of the society.

Nonetheless, the necessary emergency of new paradigms, redefining the roles (and the rules) for the different stakeholders, has been a far less linear process and, *vis-à-vis* of many success stories, one can find several near-failures or unconvincing propositions.

For its own nature, the Internet greatly favors the introduction of innovations based on the vision of talented individuals or small groups (think of Google, Facebook, Twitter, etc.), but it is much less efficient in promoting organized changes in already structured social environments, like education or health, where the presence of a plethora of stakeholders with widely diversified obligations and rights, of country-wide governmental policies and often of colossal economic interests originate the phenomenal challenges proper to any complex system.

Health at the times of Internet, or eHealth, is the perfect example of such an environment: it is the second most popular topic on the Web (as a small helper to the reader, the first one is not sport, nor climate), it has enormous potential in terms of quality, efficiency, and cost of healthcare systems, it could bring transformational changes in medical research and practice, it is technically mature. And despite that, all the attempts to extend very successful pilot projects to a general framework have not met the promised results or they have to a large extent failed.

The book edited by Gaddi, Capello, and Manca is a refreshing novelty in the debate on eHealth: barely past the index, you are confronted with their overarching conviction that complex problems have often a solution, which is simple, elegant, and wrong. The ensuing exploration of the different dimensions of the problem offers several interesting cues for a more holistic approach, underlining the priority of rethinking the fundamentals, and refusing the miracle solution of an automatic adoption of the technology.

It is a book on the method, addressing the challenges in a non-consolatory way, and yet it is an optimistic book, which never misses the view of the fantastic opportunities to bring transformational changes to the healthcare system for a better society. Enjoy it!

Sergio Bertolucci  
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## Foreword 2

Terrific progress in medicine, which has brought personalized healthcare in reach, and a tidal change in welfare expenditures, have created an unprecedented opportunity for eHealth adoption, and this acts both as cultural *humus* for the medical community and the administrators/politicians.

However, many challenges still lie ahead, as most (if not all) implementations so far have fallen short of the promises which backed up their adoption. The book edited by Gaddi, Cappello, and Manca comes at exactly the right time, and with a thorough and in-depth reflection on the nature and motives for the current healthcare's engagement in eHealth, it sets the stage for a much needed paradigm shift. Through the book we learn about the constraints posed by the purposes of medicine to the design of eHealth solution, and how this dictates where and how disruption is possible or incremental innovation is required. The reader will look at the healthcare/eHealth ecosystem through the eyes of the different stakeholders, discovering where the untapped value and the pitfalls lie in wait, and will become familiar with the interpretation of the promises and shortcomings as read by the parties so far. Without ever sitting on a "*cathedra*" or assuming the tones of a guideline, the authors of this book offer pragmatic and instrumental directions to think of an eHealth which is not a closed niche, but a new large and bright node in the environment of care and in the life of the citizens: the legal implications, the economics, the sociology, and the psychology of being explicitly part of a networked ecosystem are all analyzed issues, and without ever hiding behind one finger the book suggests sometimes otherwise uncomfortable reflections on the need for governance and education which arises from connecting our societies in new ways.

A must-read of our times, this book will be remembered as the map which navigated us from the pioneering times of the early Internet age, to the maturity of a connected health and wellness care ecosystem.

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## Preface

The development of a new era in medicine and in human technology has started since the 1980s a chain reaction that is producing today a switch from the traditional view of health to a new and multifaceted scenario. The traditional approach to illness and diseases, and the same idea of well-being is changing as the new world is evolving. The same vision of the society and of the way people live, interact, and move around the world is different today.

Nowadays people can count on tools, electronic devices, and software that expand their five senses potentially to the extreme. We can use computers to increase the capacity of our brain, switch on mobile phones and tablets to connect people from different continents, and exchange information and complex data in real-time, use electronic agenda to schedule our daily life, store our memories or entire libraries in gadgets smaller than a nail, or travel from one place to its antipodes in a matter of hours.

But this is only one possible face of the new society as long as the same perception of life is changing. The cultural constraints that limited the fusion of people coming from different cultures are fading out, while the division among developed and developing countries is changing as well. It means a new awareness that goes beyond the physical limits of a country or a nation. People all around the world are starting to understand that life can be lived in several ways, and that what was considered an absolute restraint in the past, now is not anymore.

It is deeply affecting society and political choices worldwide. Human beings know and understand that they had rights. Moreover, people have realized that everyone can be the master of his own fate, and that opportunities are in reach, even for those who come from extremely rural and undeveloped areas.

In this scenario the same health, which is more and more connected with the idea of quality of life, rather than absence of illness, is changing.

It is a natural consequence, as long as no improvement can be really achieved if a more sustainable and equal distribution of what well-being is, is not established.

In such a transformed picture, eHealth—the application of electronic tools and technologies to health—has a crucial role.

If the information and communication technology, also known as ICT, has revolutionized every aspect of human life today, health—as a supreme ideal—cannot be untouched to this change. We can see it everyday, if we go to a doctor's

clinic or to a hospital. Computers store information about our life and our state of health; send requests for medical investigations or referrals; process data that come from laboratory analysis, instrumental investigations, and medical imaging; give information about therapies and side effects; remind appointments and treatments scheduled.

This is only a first step toward the evolution of health, but probably the less important one.

In fact, hideous hazards can mine this process. The contribution that ICT can bring to health indeed can be extraordinary provided that proper rules and methodologies are followed.

This new approach to care can be considered useful only if it can demonstrate itself able to produce benefits for patients, doctors, and all the other actors involved in the process of care. It implies governments, enterprises, developers, researchers, and caregivers at every level.

Patients have to find their central and active role in the management of their own health, in order to achieve the best possible quality of life, both in healthy or unhealthy conditions. Doctors need to find precious tools that do not affect the quality of trust and relationship with patients but can enhance the level of their work and consequently the outcomes of their interventions. Researches can exploit the incredible amount of information that came from medical practice, integrating the data that come from their study with live and real data and with those that come from simulators. Decision-makers can use the information produced, monitoring in real-time the outcomes of their policies. Enterprises can find optimal solutions that can combine the profit they are after with the needs of the population. Health workers can count on advanced tools that could help them deliver the best possible care to their patients.

Besides, the same promotion of health and of healthy behaviors, the medical education, and the management of a quality life, can take advantage from informatics and from communication technologies, reducing the chances of disease onset and improving the lifestyles.

On the other hand, the developing and implementation of unsuitable models in eHealth can retard the achievement of these goals, or even impede their establishment. This is a clear and present risk, as long as the systems currently under development are missing the focus of the problem, and are producing models that do not take into account all the complex variables that compound eHealth.

Two are the possible results of such a reproachable approach.

First, the creation of systems that do not exploit the real potentialities of eHealth, in a world that is moving toward an electronic setup; it would finally result in a lack of opportunities and a delay, with a waste of resource that would bring to the collapse of the entire system. It also could mean: the development of models that—in a rapidly changing scenario as the ICT is—could be outdated at the same moment of their implementation, or could be unsuitable for the technical

solution to come; the implementation of models that cannot fit the rules for health worldwide, creating non-communication systems; the production of redundant solutions that produce and incredibly waste resources; the creation of disparity among people that can or cannot access to the electronic health, whereas eHealth is intended for all.

Second, the dehumanization of medicine. People are already complaining because of the deterioration of the doctor–patient relationship, while the trust in the former is going significantly down. Most patients are experiencing frustration as most of the time spent during a medical encounter is passed with the doctor staring at a computer monitor rather than at a patient’s face. On the other hand, the use of electronic algorithms and devices, together with the use of strictly and sometimes controversial guidelines, is already creating a gap between the singularity of every patient’s life, and the standardization of the practice. People are becoming numbers and files, losing their identity and switching to their virtual alter-ego, also in the management of their care.

In addition, eHealth is part of a modern society, with its social, political, ethical, and economic constraints.

The bottom line is that electronic solutions designed for health cannot track the path that other fields of human activities can follow. Human beings are complex and so are their relationships and interactions with the world. Besides, what can be considered extremely good for an individual, can be the worse possible solution for another. We are indeed part of an extraordinary reality, made of spiritual feelings, cultural models, taste and distaste, insignificant details that are instead vital for people, able to change the perspective and quality of someone’s life.

It also means that commercial models created for the management of data cannot apply to the complexity of health and human life. But this is instead the approach that government and hardware or software enterprises have used so far.

In this book we will explore the potentialities of eHealth, trying to understand how it can affect and improve people’s life, and how the best possible solutions can help to achieve the best from the design of working models. We will explore all the possible constraints that could limit the expansion in a real world of modern technologies, also taking into account the legal, ethical, and economical restraints that could jeopardize the entire process. We will point out as well the known and the unexplored issues that could expose the implementation of eHealth, underling as well why most of the systems produced so far for eHealth have failed. We at least highlight the real scenario in which those system are supposed to work today and in the future, both in high- and in low-income countries, and in rural versus high-density areas.

But above all we would like to emphasize and sponsor the centrality of the human being, as a person with his beliefs, his dignity, his individualities, and peculiarities, that either in healthy or unhealthy conditions have to be treated with humanity and respect. This is not something that an electronic tool can achieve on

its own. But it is something people who handle electronic solutions have to have constantly in mind, in order to give a human response to humans asking for help or simply for a better life.

Besides, this is the same nature of health. Or, better, the heart of the human nature.

Antonio Gaddi  
Fabio Capello  
Marco Manca

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