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IGITAL HEALTH ▲ CADEMY



Patients' Advice for a H.U.M.A.N Digital Health

A New Humanism for Digital Health

Patient Associations' recommendations for the Development of Digital Health - July 2020



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INTRODUCTION

Why prepare a vademecum of the Digital Health Patients' Associations?

The global health emergency, due to the spread of **COVID-19** has demonstrated very clearly the growing need for digital health solutions. In the historical moment we are going through it is important to rethink organisational models and relational models in digital care processes. What effects will the pandemic have on digital health and its evolution?

We are no longer at the stage where we have to think about the benefits of digitising health, we are already beyond that: immersed in a world that is now **phygital**; a world that combines physical and digital processes, in which we are all called to do our part to become the leaders and protagonists of new paths.

Patient Associations clearly want to have an active role in the development and construction of a new digital normality.

For nine years now, the **MSD Foundation** has developed multidisciplinary projects involving all actors in the health system - health management, institutions, patient associations and journalists on key health policy issues. Through the Patient Academy, in particular, the MSD Foundation has been working alongside Patient Associations in empowerment and engagement projects, with a particular focus on the opportunities and challenges offered by digital health, well aware that innovation - for it to make a concrete contribution to improving the quality of life and health - can only start with people and be tailored to their actual health needs.

In this context the Patients' Digital Health Award has been conceived, a true one-of-a-kind, in Italy and Europe, this year at its third edition which, with the collaboration of the Digital Health Academy and the unconditional contribution of the MSD Foundation, involves over 40 Patients' Associations to scout and reward those digital innovations that can make a difference in patients' quality of life. For the first time, Patient Associations are choosing, evaluating and rewarding digital health solutions. The prize was an opportunity to increase the **digital empowerment** of the associations and also to collect feedback from members with two surveys involving more than 800 patients. (see in the appendix, the results of the 2018 and 2019 Patients' Digital Health Awards surveys).



In this multi-year comparison, the Patients' Associations have debated the concept of **digital and technological humanism**. This calls into question the stereotype that technologies are associated with depersonalisation and dehumanisation.

From this long training and experience, enriched also by the direct evaluation of hundreds of projects and ideas, the need was seen to set some rules that can guide from the point of view of patients who work in digital health.



INTRODUCTION

Patient Association Recommendations for the development of Digital Health set out a **H.U.M.A.N.** approach to digital health:

H: health literacy U: uncomplicated M: meaningful A: authentic N: natural

The **Digital Health H.U.M.A.N Recommendations** aim to offer direction to all those who invent, develop and apply digital solutions, from start-ups to public organisations. They serve to keep the person, both the patient and the caregiver, at the heart of the technology.

The Recommendations were developed by the Digital Health Academy team on the basis of structured feedback from 40 patient associations.

DIGITAL HEALTH ACADEMY

The Digital Health Academy was created with the aim of spreading an authentic digital culture in healthcare and offering highly specialised training courses with innovative contents and formats.

It has developed a wide-ranging training offer, which meets the needs of the main players in the co-construction of health: pharmaceutical companies, doctors, patients, associations and industry managers.

The Digital Health Academy is the reference point for all those who think of Digital Health as a new paradigm of care and who want to be an active part of this process of digital health transformation. Further information can be found on the website: www.digitalhealthacademy.com



FONDAZIONE MSD

The MSD Foundation was established in 2004 by MSD Italia, which wanted to create an entity independent and autonomous from an organisational point of view, able to contribute to the growth of culture and the dissemination of knowledge in the health, scientific, industrial, social and cultural fields.

The MSD Foundation supports and develops both directly and through authoritative. independent third parties - initiatives and projects aimed at increasing knowledge in the health sector, with a specific focus on topics such as health literacy, health economics and health/social policy. In particular, for ten years through the annual initiatives of the Patient Academy - MSD Foundation has been promoting empowerment process Patient the of Associations

Further information can be found on the website: www.msd-italia.it



PATIENT ASSOCIATIONS

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CHAPTER 1: DIGITAL HEALTH





CHAPTER 1: DIGITAL HEALTH

What are Digital Health's keywords for Patient Associations?

Telemedicina Aiuto concreto Eco-sistema Fondamentale Accessibilità Semplificazione Opportunità per la salute Necessaria Supporto terapeutico Risorsa Accelarate diagnosi Informazione Strumento aggiuntivo Personalizzazione Sostegno

Health opportunities is the common denominator of different ways of thinking about digital health.

It is accompanied by essential, concrete help, therapeutic support, resource, necessary and simplification.

Digital Health can be told or imagined in various forms, but it certainly represents an important opportunity for everyone.

At the time of writing these Guidelines, we are experiencing a global health crisis that will affect the future of each and every one of us; on the one hand, the pandemic, on the other, the major economic changes have and will have an impact on all sectors of the market. Healthcare is not exempt from all this and digital health is an opportunity to rethink organisations and processes, to identify new treatment models, to accelerate research and development of therapies and diagnostics, to cope with the growing health crisis, to expand the capacity of our health system.

Patients have a great many positive expectations.

These must include being able to obtain through new digital solutions an improvement in quality of life and relationships (with the doctor, other patients and caregivers).

Then there is the desirable prospect that, through the use of innovative solutions, we can increase adherence to treatment and therapies, as well as achieve greater personalisation in the management of living with the disease and greater engagement: that is, to feel really take a leading role in the management of one's own health in order to improve the course of treatment.





CHAPTER 1: DIGITAL HEALTH

What features must digital technology have according to patients to meet these needs?

Let us start with the first letter of HUMAN: **H** for **Health Literacy**, or digital health literacy. This dimension refers to the ability to obtain, read, understand and use information related to digital technologies, to make appropriate decisions and correct use. What should digital health content be like to inform patients?

The keyword, according to the Patients' Associations, is semplify. Streamline, enable: life is facilitate. alreadv complicated enough for evervone. especially patients: this is whv information about technologies and their value must be clear and concise. Patients are willing to learn new things, to deal - if necessary - with digital fatigue, but they need appropriate pathways and instructions.

Technology must also inspire confidence: the associations attach great importance to the whole issue of the reliability and verifiability of information and authoritativeness of sources. The increasingly wide range of digital services on offer requires the sharing of reliable information and easily accessible institutional guidelines, which make it possible to understand what, for example, differentiates telemedicine from a remote monitoring system or digital therapy.

U for uncomplicated: what makes technology easy to use? Certainly the intuitiveness, immediacy, speed in the registration process, as well as a useraraphical friendly interface. But. if appropriate, patients ask that not everything be left at the mercy of the digital device and that, by contrast, "real" forms of assistance can be provided, with individuals ready to intervene for remote support.

M for **meaningful**: what gives a technology "meaning" for the patient? In other words: what does a technology need to be valuable to patients? Clearly, it must be able to simplify life and facilitate the management of the disease, streamline bureaucratic procedures, wait times for visits and bookings and access to hospital. But meaningful technology must also increase patient engagement and compliance, facilitate relationships with caregivers and other patients and reduce human error. Last but not least, a digital health solution is also expected to solve what has not been solved to date, or to find more effective answers than those identified so far.

A for **authentic**: how can a digital solution be "authentic"? What processes should inspire the development of new digital health solutions?

Developers and start-uppers should, first of all, think like a patient, analyse the problem from their perspective.



CAPITOLO 1: LA SALUTE DIGITALE

Only by putting yourself in the patient's shoes will it be possible to design any solution with the real difficulties and needs in mind. Patients are willing to be involved in the design phase. And they suggest that carers and caregivers should also be involved in this process, so that the quality of relations between all players remains at the centre.

for natural: how can N digital technologies fit more naturally into the path of life? First of all if they are easy to use, as is the case with the smartphone: today we turn on our telephone to perform multiple functions that previously seemed complicated to us; in the same way patients expect to be able to manage new digital solutions for health





In the following sections we will see, specifically, **10 rules for each letter of the acronym H.U.M.A.N.**, ten indications on how to make digital health more humane, from the patients' point of view.

On the one hand, the Patients' Associations seem to be asking digital to do better than man: reduce errors, reduce the time and complications of the current health organisation and find new solutions to problems that are as yet unsolved. There would appear to be a sometimes futuristic (and optimistic) expectation in which scenarios that have not yet been fully imagined are hypothesised.

On the other hand, digital technologies are asked to be "human", to resemble the best part of ourselves, not to abdicate all the empathic, experiential and social skills that characterise human beings.

Ultimately, a technology must go beyond man, yet be "human", it must not forget what only we humans can do: reassure, support, assist, eliminate distances, improve relationships and, above all, make us feel safer, stronger and more aware on life's journey, especially when we live with illness along the way.

CHAPTER 2: Health Literacy





pazienti premiano 'innovazione digitale



CHAPTER 2: H HEALTH LITERACY

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Communicating with each other, exchanging information is nature; giving proper consideration to information we are given is culture.

Goethe

The evolution of digital technologies in healthcare is shaping a new healthcare model. Digital health solutions are constantly growing. Tools such as medical apps, telemedicine and digital therapies are increasingly improving disease prevention, diagnosis and treatment processes.

In this context of innovation, the first real challenge becomes the cultural one: how to adopt a new vision that is really based on the sharing and transparent management of information? It is clear that, first and foremost, patients need to be properly informed about the opportunities, risks and requirements of digital solutions.

What features must communication on digital innovation have in order to correctly inform patients?

1. Clarity: information must be clear, simple, straightforward; digital content must be expressed in comprehensible language.

2. Concise: the information must be short, essential and to the point.

3. Multimedia: the textual content must be accompanied by images, illustrations, infographics, icons, photos, videos and anything that can help understanding.

4. Reliability: the contents must be reliable, secure, validated and verified. They must come from authoritative sources. All data must include official sources (WHO, Ministry of Health, ISS, etc.).

5. Accessibility: the information must be in Italian, without the use of odd English words here and there, accessible to all and understandable to every age group. Technicalities should be avoided, but without trivialising the specific themes and references to the therapeutic area and the pathology.

6. Relevance: the contents must respond to a concrete need of the patient. The information must be high quality, i.e. relevant to patients.

7. Uniformity: content must be accompanied by tools to support digital patient literacy, such as keys and digital vocabularies. A list of vocabulary and standardised definitions are very important to simplify the information.

8. Update: information must be updated in a timely manner, whenever new elements and needs arise. Even if present in official sources, outdated information may no longer be valid.

9. References: content must include references to studies, projects, activities carried out in health care facilities or in partnership with associations and scientific societies.

10. Testimonials: information told is more usable. The involvement of authoritative scientific experts and speakers is recommended to make the information more understandable and accessible.

CHAPTER 3: Uncomplicated





CHAPTER 3: U UNCOMPLICATED

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Everything should be made as simple as possible, but no simpler.

Albert Einstein

The process of the digitisation of healthcare must be able to ensure greater ease of access to technological solutions for all. For change to be real, democratic and rooted in the population, digital health must become "open health": a model of health accessible to all: patients, caregivers, doctors, health workers.

Accessibility does not only mean the necessary technical equipment and internet access, with a reduction of the digital divide (the gap between those who have adequate access to the internet and those who do not); accessibility also means the quality of such access and the reduction of differences between individual digital literacy levels.

What features make digital technology easy to use?

1. Intuitiveness: must be able to be used even without an instruction manual.

2. Immediacy: the user must be able to make immediate use of it, with a few clicks to perform actions and commands.

3. Ease of use: must have a simple graphical user interface and easy functionality, with the use of buttons and menus that accompany the finalisation of the prefixed task.

4. Quick registration: must require just a few steps for registration and privacy consent, which, in turn, must be clear and understandable.

5. Assistance: must provide a helpline also on the telephone with the possibility of receiving support from an actual operator and not only from automatic systems.

6. Customisation: must allow you to choose your preferred and most useful basic functionality.

7. Integration: digital health solutions need to be as integrated as possible to reduce the levels of fragmentation and overlap between different solutions that can lead to confusion, disorientation and avoidance of use.

8. Multi-device: must be designed taking into account the different possibilities of use and access from different devices.

9. Multi-ability: must be designed with people's different abilities in mind.

10. Multilevel: must provide a set of basic functions and services easily accessible to the less experienced user, but also more advanced functions and services accessible to the more digitised user.



CHAPTER 4: Meaningful





CHAPTER 4: M MEANINGFUL

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Culture' is a finite segment of the meaningless infinity of the world process, a segment on which human beings confer meaning and significance.

Max Weber

A new technology, an idea, an innovative solution, an intuition, can be of great help to meet the real needs of those who are sick and significantly improve their existence.

But when does a technology become truly relevant in a patient's life? Only when new information, devices and solutions are added to an already complex routine does digital translate into meaningful support. A new digital culture must make sense and have meaning for patients.

What does a technology need to have value from a patient's point of view?

1. Simplify life: technology must facilitate the management of the disease for the patient, simplify the bureaucratic procedures of the care path, reduce the time given to the patient for his life and to the clinician for the relationship with the patient.

2. Ensuring security: the technology must be secure, tested and meet the required scientific and service standards.

3. Protect your privacy: digital technology must guarantee the privacy and protection of personal information, taking all necessary measures to protect sensitive data.

4. Increase engagement and empowerment: digital solutions must facilitate the active, informed and aware involvement of the patient in the treatment process

5. Increase compliance: thanks to the use of technology, the patient must be able to improve adherence to therapy and disease management.

6. Reassure: the digital solution must reassure the patient, make them feel happier in disease management and relieve the psychological burden of the disease as much as possible..

7. Facilitate the relationship with the caregivers: technology should facilitate contact with their doctors and help to improve the doctor/patient relationship.

8. Facilitate the relationship between patients: technology must foster sharing with people living the same condition and with the associations of reference. It can help to overcome loneliness and help learning from others.

9. Reduce human error: a technology acquires particular value if, through its use, the reliability of a diagnosis/care/therapy is improved and the potential for human error is reduced.

10. Innovate: a new digital technology needs to be developed either to respond to problems that have not yet been solved, or to find more effective solutions than those already existing.

CHAPTER 5: Authentic





CAPITOLO 5: A AUTHENTIC

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Who should live your life if not yourselves? So live yourselves.

Carl Gustav Jung

Digital innovation in health is recording increasingly encouraging data in investments, job opportunities and the development of start-ups. Digital health is a globally evolving market sector that will continue to grow.

In this context in great ferment, the flip side of the coin - from the patients' perspective - may be that sometimes technologies respond more to market logics and fashions of the moment than to the actual needs of those who have to use them, of those looking for the best ways to live themselves.

What are the processes that should inspire the development of authentic technologies?

1. Start out from real needs: to develop a truly patient-oriented digital solution you need to think like a patient.

2. Analyse the difficulties: before proceeding with the development, it is advisable to have a clear analysis of the difficulties that the patient has to overcome in relation to his disease.

3. Involve the patients: patient associations need to be involved in the process of developing the technology, in order to draw on a wide and varied wealth of experience.

4. Include: technologies must be developed with the most fragile people and all age groups in mind, including the elderly.

5. Involve doctors: health professionals must be involved in the design of the technology.

6. Involve caregivers: for a better management of everyday life and to evaluate the effects of technology on the patient's life, solutions should also be designed together with family caregivers

7. Measure: the development and use of a solution must leave room for the collection of input and feedback from users/patients so that the solution is always aligned with their needs and opinions, as they change over time

8. Cover new needs: study deficiencies in the social-healthcare structure in order to find new solutions to the problems.

9. Broaden horizons: study examples and technological solutions already developed in the world.

10. Ensure independence: the content of the technologies must not implicitly convey commercial indications about medicines and services.



CHAPTER 6: Natural





CAPITOLO 6: N NATURAL

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We are nearing the point where computers and robots will be able to see, move and interact naturally, unlocking many new applications and empowering people even more.

Bill Gates

Patients' lives, chronic and otherwise, can be very complicated. If technology fits naturally into a patient's life, if you get a real lightening of everyday complexity, digital can really be an added value.

How can technologies fit more naturally into the path of life by improving everyday life?

1. Use on smartphones: technologies must be usable through the digital tools most commonly used in everyday life, such as the smartphone.

2. Customisation: technologies must be able to increase the possibilities of customisation of care for the patient.

3. Accessibility: the solutions must make available the consultation and organisation of your medical records, your personal history, to have full access to them at any time with a click. For example, when checking, all information must be at hand.

4. Everyday management: solutions must support the day-to-day management of the disease for the patient.

5. Lifestyle: technology must provide support even beyond the illness, to improve a patient's daily life as a person with suggestions regarding nutrition, physical activity and psychological wellbeing. **6. Caregiver support:** digital solutions must support the patient's daily routine, replacing the functions of a caregiver as far as possible and facilitating communication and the patient's relationship with family members

7. Coaching: digital solutions must remind, stimulate, accompany, facilitate the management of complexity and mitigate the fatigue of care.

8. Facilitate contact: digital solutions should facilitate consultation with the caregiver and the specialist and ensure this in the shortest possible time.

9. Decrease movement: digital solutions should help the patient to be followed as much as possible at home, strengthening telemedicine, avoiding access to the hospital, as well as long waits for both bookings and visits.

10. Emergency support: digital solutions must allow to launch an alarm every time vital parameters deviate from the norm and record the patient's parameters daily in a simple and intuitive way.



PDHA 2018 Digital Health at the service of patients

The survey was conducted in May 2018, involving 40 patient associations. A total of 740 patients took part, 63% women and 37% men, aged between 18 and 75 years.





PDHA 2019 How human is the technology?

Between July and September 2019, a survey was carried out involving the **43 Patient Associations** of the **PDHA**: the results offer an interesting insight not only into the use of digital technologies but also into the importance they take on when, without losing sight of actual needs and requirements, they become more 'human' and thus improve people's lives.







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