

Transdisciplinary Communication Lectures | on Health

The Role of Intelligent Technology in Healthcare

Donald Norman

Report of the lecture

November 19th, 2019

Firenze, Gabinetto Scientifico Letterario G.P. Vieusseux, Piazza e Palazzo Strozzi

edited by

Viola Davini, Eugenio Pandolfini, Lisa Capitini

Table of contents

1. Institutional Greetings and Introduction Luca Toschi	2
2. Innovation and Healthcare: Best Practices in Communication	4
2.1. Background: Looking for a New Health Literacy Viola Davini	4
2.2. What Communication for Healthcare Eugenio Pandolfini	7
2.3. A strategic Area: Beyond Earth. New Frontiers of Space Communication Lisa Capitini	10
3. The Role of Intelligent Technology in Healthcare Donald Norman	11

1. Institutional Greetings and Introduction | Luca Toschi

The Transdisciplinary Communication Lectures are high level scientific conferences that involve researchers and experts to discuss about the value of a communication able to build transdisciplinary research projects. The first edition of these lectures is focused on Health Communication.



Luca Toschi at Gabinetto Vieusseux, introducing The Transdisciplinary Communication Lectures

Transdisciplinary Communication Lecture #1

The first Transdisciplinary Communication Lecture on Health took place in October, and it was titled *Health research WITH the community rather than FOR the community. Two experiences of excellence in Canada and Australia.*

The lecturers were **John Challis** - University Professor Emeritus in Physiology, Obstetrics & Gynaecology, and Medicine at the University of Toronto, Founding Executive Director of the Western Australia Health Translation Network - and **Nicky Lewis** - 20 years' experience in senior management and executive leadership roles in public health and health research administration, before Executive Director of the Canadian Breast Cancer Research Alliance and now CEO at the Kids Brain Health Network.

They shared with us their experiences in medical-health research, highlighting the role of communication in sharing knowledge oriented to both scientists and researchers and citizens.

Today's event

The second Lecture features Donald Norman, Director of the Design Lab at the University of California, Co-founder of the Nielsen Norman group and Honorary Professor at Tongji University (Shanghai) in their College of Design and Innovation. He has also worked in industry as Vice President of the Advanced Technology Group, Apple's research arm.

Today Norman's emphasis is on helping technology companies structure their product lines and businesses, concentrating on design thinking to help drive both incremental and radical innovation.

He is one of the major experts in ergonomics and design, authors of fundamental books in these fields, such as *The Design*

of *Everyday Things* (1988) and *Living with Complexity* (2010), focusing on the complexity of our technology (that mirrors the complexity and richness of our lives).

The last article in his website, starts like that:

How did we reach the point where our technology is more important than people? And most importantly, how can we reverse this trend in order to ensure that our technologies are designed with people in mind, more humane, more collaborative, and more beneficial to the needs of people, societies, and humanity. To me, these are some of the foremost issues facing the world.

The Role of Intelligent Technology in Healthcare

This morning Donald Norman will lecture about *The Role of Intelligent Technology in Healthcare*. His point of view is very important, because he teaches us - as a scholar and as a man - how important it is to try to see things with different minds and eyes, to get out of the enclosures of the definitions that are considered valid forever, respect the theory because without it there can be no application, useful use; but it also teaches us how much doing is born from free thinking, from imagining the impossible.

His vision is not only interdisciplinary but above all transdisciplinary because he is not looking for the simple collaboration among different disciplines, but he is drawing a radically new scholarly profile. This unpublished scholar is attentive to the specialty of his work, but because he is proud of his own diversity he tries to communicate with the differences, the specializations of others, scholars and professionals and workers in the conviction that today specialization means diversity profoundly, structurally involved and participant of other specializations, of other diversities. A scholar hostile to all conformism, especially if he is winning, if he finds success, consensus everywhere; indifferent to any definition, especially if universally known, accepted. He is a scholar who has the courage to think what in everyday life few believe is convenient, political, economic to think; he is motivated by the passion to try to do what many, often most of the consider impracticable, is not achievable.

Its prestigious history, in fact, has not only been a story of success, of recognition from the academic world, of research, of business. As every new man had to fight to try to win his idea of humanity and technology, of research and social commitment.

Donald Norman never forgets his history, the long phase of a cultural and scientific battle in which if you are really new, innovative, revolutionary at the beginning you are really - not alone, this never - but isolated yes. A story where you find walls that are hard to overcome, and even when you get over them, they tell you that we invented them, that they weren't there. A story of resistance expressed or, even worse, denied, hidden.

Maybe that's why Don Norman is here in Florence today. Perhaps, by overestimating the activity at the Center for Generative Communication, he sees in the battle that these young scholars are carrying out a sense, a value, a commitment that with its mere presence can legitimize, helping to move it on.

The young people are naturally transdisciplinary, hostile to definitions valid forever, to the prepared solutions, to defend the past mummifying it. Young scholars are the present which is already the future. You can isolate young people, you can try to frighten them with the threat of a crisis that never seems to end, you can try to stop them in their most revolutionary needs. But what you can't do is ignore them, because they never give up.

That is why today they are paying the highest price for this crisis that seems never to end: the price of not recognizing them the fundamental role they have in changing a world that is just not right. From no point of view: a world that did not build them but that found themselves already realized.

Donald Norman will speak for those young people engaged in the world of research, which does not mean only academy. Today research is an activity that characterizes the life of anyone who wants to change this world. Who is concerned with the health of this world: not only physical but moral, cultural, immaterial, the health of the human spirit.

2. Innovation and Healthcare: Best Practices in Communication

2.1. Background: Looking for a New Health Literacy | Viola Davini



Viola Davini is a research fellow at the Center for Generative Communication (CfGC), directed by Luca Toschi, and a PhD student in *Management of Agricultural, Forestry and Food Resources* with a curriculum in *Wine Economics and Rural Development* from the University of Florence. Within the CfGC, she carries out research activities related to communication strategies to strengthen a transdisciplinary design of innovation, favoring the relationship between the University and local stakeholders.

As head of external relations at CfGC, she is also in charge of coordinating public engagement activities both on national and international scales.

Viola Davini had shown the Center for Generative Communication approach to **innovation in Healthcare through the presentation of data and statistics.**

Studying communicative processes, what are we looking at in the wide field of innovation and healthcare? Surely, we are studying the relationship between innovation processes and the needs of people, that is the role of scientific research and the sociocultural and political project behind the present innovation in Healthcare.

Italy has reached a life expectancy of 83.6 years, 22.6 of those lived not in good health. The current state of health of Italian citizens is threatened by a series of phenomena: the progressive ageing of the population, the increase in risk factors and chronic non-communicable diseases, the phenomenon of vaccine hesitation, the threat of antimicrobial resistance, the difficulty of access to innovation, the shortage of doctors, regional differences and the delay in digitising the health system.

Currently, **75% of health costs are concentrated in the over-60s.** Obesity and sedentary activity are among the most alarming risk factors for our country, almost 40% of young people are overweight/obese and only 8.3% of young people exercise moderately, placing themselves in the last place among EU-15 countries¹.

Vaccines

Vaccine covers are still in many cases below the optimal thresholds indicated by the WHO (World Health Organisation) and **it is estimated that 16% of Italian parents are hesitant or against vaccines.** Delays in the process of evaluating and adopting innovative therapies, medical devices and digital technologies are increasing at regional level where inequalities are becoming increasingly marked, increasing the North-South gap.

Older and not in good health

In Italy, in fact, life expectancy at birth has increased significantly in the last 100 years, mainly thanks to advances in medical, scientific and technological research. However, in view of the healthy years from 2004 to 2016, there has been a decrease of 2.5 years. A trend in sharp contrast to that of other European countries: in Sweden, for example, the number of years lived in good health (in the same span of time) has increased by 11.7 years.

Obesity

In Italy about 2 million 130 thousand children and adolescents aged 3-17 are in excess of weight and almost 2 million do not practice sport or physical activity. 74.2% consume fruit and/or vegetables every day, but only 12.6% get to 4 or more servings.²

Declining births

The birth rate has been declining since 2008. Already from 2015, the number of births has dropped below half a million and in 2018 there is a new negative record: in the birth registry, they were registered only 439,747 children, the historical minimum from the unit of Italy (1861).

What *kind of innovation can face this scenario? But, above all, what kind of communication can guarantee an effective innovation of the system?*

¹ XIV Rapporto Meridiano Sanità (2019), *Le coordinate della salute*, online: <http://eventi.ambrosetti.eu/forum-meridiano-sanita-14/wp-content/uploads/sites/107/2019/11/reportMS14.pdf>

² ISTAT (2019), *Stili di vita di bambini e ragazzi*, online: <https://www.istat.it/it/archivio/234930>

Innovation in this system can provide a useful solution by improving citizens' quality of life. It is not only a question of access to health services, but of a **new culture of health**. At the Italian level there is certainly an increasing commitment in the **digitization** of the health system.

Public Digital Identity System, which allows citizens to access online public administration services with a single digital identity and is a key element in the development of digital transformation, reached 5,049,614 citizens, up from 838,000 in 2016. But this number still represents only about **8% of the Italian population**³.

The percentage of citizens who have activated the **Electronic Health Record** from the total number of National Healthcare System beneficiaries is only 21%. The latest figures from the **Observatory for Digital Innovation in Health at the Polytechnic University of Milan** confirm the still inadequate diffusion of the Electronic Health Record with only 21% of citizens who have heard of it and only 7% who claim to have actually used it. The main barriers to using the Electronic Health Record are the **difficulty of access and lack of knowledge about its existence**.

In everyday life, instead, more digital tools are used to communicate:

- 85% of doctors and 81% of medical specialists use **emails** to send communications to their patients;
- **whatsapp** is used by 64% and 57% respectively to schedule or move appointments and to share documents and clinical information;
- 41% of citizens use a coaching application or a **wearable lifestyle monitoring device**; the percentage increases to 55% among young people under 35.

In most cases, the amount of data and information collected by these devices is not shared with doctors and often remains unused from the National Healthcare System point of view. Therefore there is an **urgent need to overcome the current fragmentation of digital health innovation** so as to integrate and capitalize on the potential of these technologies and the data they collect.

We think that is essential to think about new technology **not as a product to impose** to passive users but as a **tool to create communities of interests and values** in order to rethink and to optimize **the whole system**.

Is this delay in innovation also due to a weak involvement of the citizenship in the design phase?

Thinking of an active role of citizens, it cannot be forgotten another important issue that deals with communication: **health literacy**. In 1988 the World Health Organization (WHO) inserted the term **Health literacy** into the *Health Promotion Glossary*, defining it as “the cognitive and social skills that determine the motivation and ability of individuals to access information, to understand and use them in such a way as to promote and maintain good health”.

The **Ottawa Charter for Health Promotion** defined **health promotion** as “the process of enabling people to increase control over, and to improve, their health. To reach a state of complete physical, mental and social well-being, an individual or group must be able to identify and to realize aspirations, to satisfy needs, and to change or cope with the environment. Health is, therefore, seen as a resource for everyday life, not the objective of living. Health is a positive concept emphasizing social and personal resources, as well as physical capacities. Therefore, health promotion is not just the responsibility of the health sector, but goes beyond healthy life-styles to well-being”.⁴

According to **European Health Literacy Consortium (2012)**, “Health literacy is linked to literacy and entails people’s knowledge, motivation and competences to access, understand, appraise and apply health information in order to make judgements and take decisions in everyday life concerning health care, disease prevention and health promotion to maintain or improve quality of life during the life course”.⁵

Health illiteracy has consequences:

- Studies from the *Health Literacy Center Europe* estimate between 7% and 17% of health costs due to insufficient levels of health literacy in the population⁶;
- In the United States, it is estimated that about 90 million American citizens (more than a quarter of the entire population) do not possess a correct medical-health literacy⁷;

³ AGID (2019), *Piano Triennale per l’Informatica nella Pubblica Amministrazione 2019 – 2021*, online: https://www.agid.gov.it/sites/default/files/repository_files/piano_triennale_per_linformatica_nella_pubblica_amministrazione_2019_-_2021_allegati20190327.pdf, pp. 159 - 166

⁴ The first International Conference on Health Promotion (1986), online: <https://www.who.int/healthpromotion/conferences/previous/ottawa/en>

⁵ WHO (2013), *Health literacy. The solid facts*, WHO Regional Office for Europe, online:

http://www.euro.who.int/_data/assets/pdf_file/0008/190655/e96854.pdf?ua=1

⁶ HLCE (2015), *Costs of low health literacy*, online: <http://healthliteracycentre.eu/costs-of-low-health-literacy/>

⁷ Biasio, Luigi Roberto; Corbellini, Gilberto (2017), *Morire di ignoranza*, *Il Sole 24 Ore*, online:

<https://www.ilsole24ore.com/art/morire-ignoranza-AEnJqng>

- 56.5% of citizens believe that they cure themselves on their own;
- 1 Italian out of 3 search information on specific diseases online;
- Health illiteracy may double the risk of death in patients with heart failure⁸.

Unfortunately, these are **not fake news**. Too many citizens do not have adequate levels of health and medical literacy, and this has an impact on their lives and on the health system as a whole, with huge costs, especially in terms of human lives, but also at an economic and social level.

In this scenario, how can we work on a new Health literacy that promotes processes of innovation first of all human, cultural and technological?

We need a new alliance between the world of institutions, businesses, citizens and citizens. But first of **all we need a change of communicative paradigm** that puts at the centre of any innovation process those needs of knowledge, those questions that come from the everyday life of ordinary people whether these experts or ordinary citizens.

⁸ Healthdesk (2018), *Scompenso cardiaco: l'analfabetismo sanitario può compromettere il successo delle terapie online*: <http://www.healthdesk.it/medicina/scompenso-cardiaco-analfabetismo-sanitario-pu-compromettere-successo-terapie>

2.2. What Communication for Healthcare | Eugenio Pandolfini



Eugenio Pandolfini is a research fellow at the Center for Generative Communication (CfGC), directed by Luca Toschi. Within the Center, he develops research related to governance and territorial marketing, the landscape and the third mission of the University, working closely with institutions, associations and businesses of the territory. Eugenio Pandolfini introduced the CfGC and the main features of the generative communication paradigm, talking about the idea of innovation and the areas in which CfGC is working with its research projects, concluding with a focus on the Health and Healthcare area and the detailed description of two projects in progress.

The Center for Generative Communication, directed by Professor Luca Toschi, is a group of researchers working together at the University of Florence. The CfGC is a research and development center of the *Political and Social Sciences Department* which is focused on communication, favoring interaction between knowledge and expertise in various areas of research and innovation. The main Features of the CfGC are:

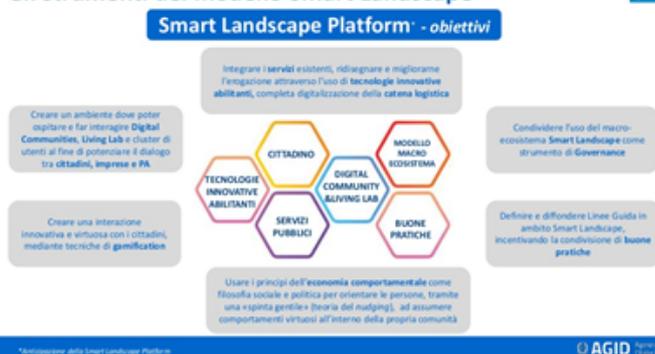
- **an operational approach to research**, in order to find effective solutions to the problems of institutions, associations and companies that are the **expression of social, economic, cultural and political needs**;
- the idea that complexity is not an additional problem to manage: **the complexity** of the society in which we live - if you face this challenge in terms of strategy and not in terms of program as suggested by Edgar Morin⁹ (1993) - **becomes an incredible resource in terms of diversity, quantity of aspects and opportunities**;
- an idea of communication that goes beyond the traditional paradigm that is transmissive, hierarchical and - in brief - *top down*. We are talking about **a new communication model that generates relations between people and other resources, working on aggregation, mediation and on the sharing of knowledge**. A process that we call: **community building**.

All CfGC research projects are based on the generative communication paradigm¹⁰: **a model of analysis and design of communication** with a strong organizational value, **able to aggregate different stakeholders around common objectives**.

In the generative paradigm, projects in complex context are faced by exchanging and sharing knowledge, skills and competences with the subjects involved and developing a systemic innovation, **without boundaries given by a-priori established hierarchies**, geographical limits, areas of influence. We are talking about an innovation - in the form of new processes, tools, etc. - aimed to identify common solutions that are the expression of the infinite resources available in the context under investigation. The CfGC work consists in bringing these resources together and enhancing them by generating relationships among stakeholders, also considering those aspects which are usually kept apart.

The idea of pursuing a systemic innovation is recently spreading even at the level of Italian digital agenda: this year (in August) the *Agency for Digital Italy (AGID)* has launched a new paradigm for innovation - the **smart landscape**¹¹ - that **overcomes the idea of smart city** as it is excessively linked to the geographic boundaries of the urban fabric.

Gli strumenti del modello Smart Landscape



a. Smart Landscape model - Source: AGID

⁹ Morin, Edgar (1993), *Terre-Patrie*, Paris, Seuil, 1993. Trad. it. *Terra-Patria*, Milano, Raffaello Cortina, 1994

¹⁰ Toschi, Luca (2011), *La comunicazione generativa*, Milano, Apogeo

¹¹ AGID (2019), *Piano Triennale per l'Informatica nella Pubblica Amministrazione 2019 – 2021*, online: https://www.agid.gov.it/sites/default/files/repository_files/piano_triennale_per_linformatica_nella_pubblica_amministrazione_2019_-_2021_allegati20190327.pdf, pp. 159 - 166

The Smart Landscape concept introduces a new research perspective, in which the community and the landscape are regarded as a **complex system of relations between all the smart dimensions** (economy, mobility, environment, people and governance) which can't be limited to the urban context. The whole process is supported by a digitalization that facilitates relations and exchanges between all the subjects and element involved.



b. Smart Landscape model - Source: AGID

In the dynamic model of the smart landscape, we recognize **the need for a communication close to the generative paradigm**, a communication that:

- goes beyond the idea of translating research activity (*scientia*) into interventions and concrete applications in the territory (*usus*) in *top down* terms;
- generates and manages relationships, legitimizing knowledge, skills and abilities of different subjects in non-hierarchical terms.

The main activities of a CfGC research projects aim to:

- detect and understand the needs expressed by stakeholders;
- analyze these needs to bring out the unexpressed criticalities and real needs;
- monitor perception and imaginary with respect to the identified issues;
- create synergies between different stakeholders by activating community based projects;
- involve the experts of the identified sectors to provide authoritative answers to the needs of the territory;
- coordinate the design of joint solutions to the problems identified by exploiting the resources that have been recognized and aggregated.

And we do that in **different areas**:

- Agriculture and rural development
- Beyond Earth. New frontiers of space communication
- Cultural Heritage
- Governance and participation
- Healthcare, health and well-being
- Landscape and complex places
- Mobility
- Robot and automation process
- Sustainable behaviors
- ...

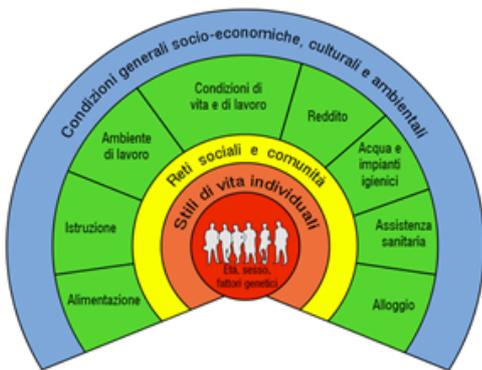
In **agriculture**, for example, CfGC have recognized the need to re-establish relations between the Institutions and the entrepreneurs at the level of intermediate bodies, working for the Tuscany Region to create a network of sensors in the territory in the context of the Rural Development Program.

Focusing on **Cultural Heritage, Agriculture and Landscape**, CfGC started a project on the **recovery of the culture of olive oil as an engine for culture-based territorial development**, involving and reactivating relations between inactive resources: the small cultural realities of the territory and small oil producers.

The CfGC approach to Health and Healthcare area

Health and healthcare are strategic sectors for social, economic, and cultural development, as well as for citizens' well-being. The World Health Organization's definition of health is *"a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity"*.

There are various conceptual models based on different determinants (and on the relationships between them) that are able to affect the state of health (these models are then associated with the different public health policies). In Europe we are using a model that distinguishes between modifiable and non-modifiable determinants, represented in a scheme of concentric circles corresponding to different levels of influence.



c. Model of Health Determinants. Source: Dahlgren G, Whitehead M. *Policies and strategies to promote social equity in health*. Stockholm: Institute of Futures Studies, 1991

The non-modifiable determinants are the biological characteristics such as sex, age and genetic heritage. The modifiable elements **have to do with the lifestyle, with the relationships that people have in the communities where they live, then with the socio-economic and environmental conditions** (level of education, income, quality of health assistance, living and working conditions, with the environment): **health is a complex field**, in which there are many aspects to consider, plus the relationships between them.

The fact that health has to do with agriculture, with food, with the territory, with the environment, with cultural heritage makes us understand how necessary it is **to reflect and intervene on the communication model that distinguishes health communication**. It is not possible, in fact, to promote "good information" without **a specific communication environment in which the various actors involved** in the health macrosystem (doctors, health personnel, journalists, communicators and, last but not least, citizens. But also entrepreneurs, politicians, etc.) **can interact and dialogue** on the many determinants of health and their importance for people's health.

This is the only way to legitimize the demands of men and women and make health operators aware of how citizens perceive risks that could compromise their health and, consequently, their well-being.

2.3. A strategic Area: Beyond Earth. New Frontiers of Space Communication | Lisa Capitini



Lisa Capitini is master degree student in *Theory of Communication* at the University of Florence. She is currently working on a thesis about communication from space to Earth with professor Luca Toschi, director of Center for Generative Communication (CfGC) entitled: *Beyond our Planet. An Overview on the Next Frontiers of Earth/Space Communication*.

Two Communications

In the last decades, **we saw great developments in the field of space research and exploration**, sectors that have always been attracting social, political and economic interests of the nations involved. The main point of the thesis, is to try to **understand how these scientific discoveries and relationship with an unusual kind of space, are changing the subject of communication** from a transdisciplinary perspective.

How we can communicate in or from different places and what are the peculiarities of this type of communication - in terms of means and contents - when we are able to communicate from a place outside of planet Earth.

It is possible to consider **two opposite ways**:

- one of absolute continuity, where we still emulate the **same kind of communication we are used to on Earth**;
- one where we **try to design a new communication paradigm**, because we recognise that communication on outer space is totally different from the Earth and represents a brand new situation for humankind.

A New Documentation Centre at CfGC

Center for Generative Communication is opening a new Documentation Centre, an interest-based community where there will be made available all the findings and research material discovered on the subject of space communication on a national and international scale: for this purpose, CfGC has been involving university departments, research centres and the major Space Agencies.

There are **three major topics of interest for the Centre**:

- (1) The study of **individual/collective Imagery about space exploration from media representations** (TV, cinema, literature products for example); how communication is influenced by the horizon opened with the metaphor of the "Space Age" in the 50s.
- (2) The analysis of the **real experiences and communication practices** of astronauts on the space environment.
- (3) The study of **the relationship between this and outer space imagery**.

The Relation Between Health and Communication in Space Environments

Discussing the topic of **communication for innovation in healthcare**, the *Center for Generative Communication* is activating new contacts in this field, and health is one of the areas included in the studies. We can approach **the subject of health in space** in three different ways:

- (1) **How communication changes when our body is in space**; what are the relevant psychological and physical factors that influence the way astronauts communicate with their relatives and Mission Control Center on Earth.
- (2) Studying **Astronauts as objects and patients** for medical experiments.
- (3) Making **research experiments on space contexts**; for example, inside the *International Space Station*, astronauts do experiments that are impossible to do except in those specific conditions, for example in microgravity or exposed to cosmic radiations.

This thesis will contribute in generating knowledge in this direction and through the *Center for Generative Communication* and the new *Documentation Center* it is possible to keep up to date with the progress of this study.

3. The Role of Intelligent Technology in Healthcare | Donald Norman

Donald Norman is the director of the [Design Lab at the University of California](#), Co-founder and principal of the User Experience/Usability consulting firm, [Nielsen Norman group](#), and Honorary Professor at Tongji University (Shanghai) - College of Design and Innovation. He serves on numerous boards and as an advisor to companies and organizations. He is an [IDEO fellow](#) and a member of the Board of Trustees of IIT's Institute of Design in Chicago.



Donald Norman at Gabinetto Vieusseux

Healthcare, Medicine and Ageing

Everyone wants a longer life. Nobody wants to get old. But how do you stay healthy? Now that we are living longer lives, science has to face some more challenges to optimize the quality of these lives.

The Health community has never thought about staying healthy: the main approach has always been to deal with illness or injuries. **The science of medicine and surgery is becoming always important to “repair” people.** In this sense, science has produced a lot of specializations for each type of health issue. Those specialists often do not even know each other (even if they are in the same University of maybe even in the same Department).

If we talk about “Healthcare”, in USA you mean two different areas:

- **Public health** (quality of lives, well-being, enjoying our lives etc.);
- **Medicine** (pills and surgery).

The point is that public health is almost ignored. In American science world, the research is focused on Medicine where a pill can cost billions of dollars, giving two more months to a person who is sick and paying all the attention of media and newspaper. **If there is a research dealing with “public health” able to change habits of a population in ten years, no one is interested in it.** That is the first problem of communication.

This is not related to a lack of knowledge. For example everyone needs to exercise, everyone knows that is better to take the stairs and not the elevator, that we should eat better. But there are not always the conditions to do that, because, following

the last example, businesses of fast food know exactly what people like and decide to make their food good and tasty even if it is not healthy.

This is just an example to explain that **everyone thinks that the solutions in healthcare will come from science, experts and from technology, but it is not true.**

Innovation in Healthcare: the wrong centrality of technologies

Regarding the *Electronic Medical Record System*, Americans would love the fact that in Italy no one uses it, because in the US they have extended the use of this record and it has caused a damage of the whole system. The technology - "invented by technologists that love technology" - usually do not understand people life.

Automation is not bad, **problems start when an entire system is automatized without thinking about the people.** For example, inside hospitals you can always hear the sound of some medical alarms or signals (like a continuous "bip" signal): each of them is made by a machine, built by different companies that measures different parameters and they actually do not talk to each other. Signals that create rumors and noises: nobody has thought that all these signals are annoying for the medical staff or patients who have to stay in those rooms and who are supposed to sleep.

In other words, **we have focused our lives on technologies, but they do not understand people.**

All the technologies that we have in Healthcare - more than 'Robots' we have to speak about machines, artificial intelligence etc. - are born from good ideas and to solve problems, but in the most cases they are not done in the proper way. signals in hospitals come from sensors that measure parameters of the human body, but they will never be able to measure what people feel or care about.

Self-Care: The Example of Continuous Glucose Monitor

In San Diego patients are building their own technologies regarding diabetes disease. Patients dealing with this illness have to be very careful with their high blood sugar level, monitoring it several times a day. To overcome this problem, there is a **wearable device called *Continuous Glucose Monitor***, which is always sampling the blood sugar level: the patient who use it can decide what to do, guided by the results of measurements. If sugar level is too high, maybe they have to take some insulin or, if it is too low, some sugar. If someone has diabetes - especially type 2 - he or she has to live the entire life thinking about that parameter, which is not a comfortable life.

This new technology is supposed to help those people, but there are some problems:

- People that wear it, **do not always trust it.**
- People do not know what to do **after the measurements.**

Some people got very tired of waiting for the technology to come down, so they built their own technology. They found the company that made *Continuous Glucose Monitor* and they figured out how it worked, they took the signals from the devices and searched for them on the web by themselves. Someone else found the company that made the insulin pump, and discovered a way to connect the two technologies: they called it an artificial pancreas. When the blood sugar level is too high, the new system automatically corrects it.

The important fact is that **people are developing it, not a company. They put together a method to control diabetes.** The healthcare community is encouraging people to do the same and understand how to take care of their own life.

This is a good case of people taking control of their own health: it is not perfect but it works, because people care about their daily lives and they are ready to learn more. In this case, **people building something for themselves they do not need permission, people are learning how to do that.** Companies are watching people how they learn to build them and they doing a lot of research involving normal people in everyday life.

What can we do to make people more aware, to let them know more about medicine and to develop their own solutions?

Medicine as a Complex System: beyond the war of specializations

Medicine should be a system. The whole body is a complex system where almost every part is connected: instead, in medicine, there are too many separate specialists who only understand their own specialties. On the opposite side, there are general practitioners who know a lot of things but not in great depth: their objective is to provide preventive care and to send the patient to a certain specialist. Here, the problem is **that the specialist sees the patient as a set of diseases, not as a real person** and this situation can become a sort of chain: the patient will be sent from one specialist to another one, and each one does not know what the other one has previously seen or done. And the same thing happens in the hospitals: why are nurses giving

pills by night when patients are supposed to sleep? Because it is the easiest way to schedule treatment, without any regardment of the patient as a person who has to rest, but only as a disease to treat.

This is a **communication problem**, that starts from two aspects:

- (1) **The lack of trust from the patient, who does not recognize the authority** - caused by the confusion generated from opposite answers from specialists in the same - or different - field;
- (2) **The division of science into little, narrow departments and specializations** that do not have systemic approach.

The problem goes back to how universities are organised. Every single field is separated here: there are schools and, in each school, there are departments with all experts. **Specialists do not necessarily communicate with each other** - they often compete. A second problem related to academic world, is **the way faculty member promotes him/her self**. He/She needs to be published in journals, in order to gain public attention. In fact, the more a journal is difficult to be published in, the more estimated it is. Researchers may find procedures to save a thousand lives but they are not certain to be accredited if they will not be published. **So trying to find practical solutions in the academic world is not rewarded**. On the contrary, in the outside world, people need solutions and generalists who look at the whole system. This is a problem on how our societies are organised.

The Role of the Designer in a Community-Based Healthcare

Designers must build things that people use. For this purpose **they need to understand people**. But there are a lot of things that they do not know, so **they have to call experts**. This lack of knowledge for the designers is an extraordinary resource because they have to collaborate with specialists. Every specialist gives his own contribution and a good designer must find a solution putting all the aspects together.

There is a problem in how designers work: they find solutions proposing them to people as the perfect products, trying to convince people. Designers tend to understand people and the system but **they do not understand how to make a wonderful life for the world**.

It is necessary to start thinking about a community-based healthcare. In 7 billion people, many millions are very clever and creative: it is important to find those people, helping them by being inventors and facilitators, not by telling them what to do. This is what happened in the eastern parts of the United States: in the mountains, where people are living isolated, they also have travel difficulties to get to a good healthcare system because of the condition of mountain roads. It is not that far away, but It takes many hours and, in winter, they get very slow until they cannot travel at all. Actually, these people have the highest level of lung cancer in the entire country. the *Central Communication Commission* - which is in charge to control radio/television signal and internet access - has done a study and they discovered those people have almost no internet connection. Physicians working for them had thought that resolving the internet issue, could have helped those people: with remote medicine, in fact, they could have measured and advised all of them over the internet. But without talking to them or being there in person, it is impossible to determine the real peculiarities of the situation.

Researchers found out that people who live there:

- are used to drink very much. Those locations are famous for *Bourbon* and home-made whiskey;
- used to smoke a lot;
- do not get much exercise;
- eat unhealthy food.

More than cancer, those people have heart diseases, diabetes and they are drug addicted.

A good designer, at this point, would have tried not to understand the symptoms but to look for the major reasons behind those diseases: the problem was that those people knew they weren't having the right lifestyle and, telling them they were acting bad, would have not resolved anything. The real issue, in fact, was their job: they did not have one. This is an area of the country where the money comes from coal industry, which is really dangerous for the atmosphere and for the environment, so the industry is not working anymore.

Here if the problem: the most evident problem is cancer, but making an analysis and understanding the socio-economic conditions, they found out that people needs a job to make their life better.

Politics and Communication

A problem which appears obvious - such as internet connection and remote medicine to treat the cancer - indicates a behaviour that privileges **treating the symptoms, not the cause**: to treat the cause is difficult, and it is necessary to understand **how the**

entire system works (economic conditions, political conditions, etc...). Systems, in the end, involved all the people, societies, organisations and politics together: for example, if we want better education or healthcare, we have to become better politicians. **Politics - ideally - is a necessary component of our lives** because it is about different people who have different values systems: they look at the world with different eyes and, therefore, they tend to emphasize different things. **Good politicians may disagree with each other but good politics have to compromise and find a solution that works for everyone**, which is an aspect that concerns communication and the way we are used to relate to our values. So in this world where everyone thinks to know the truth there are polarized positions but should be mediated.

Do we really want a better Healthcare system?

Let's see an example, coming from a recent work experience at Philips's company, related to healthcare and medicine. The company has 400 designers working in healthcare, spending years to understand a problem before doing anything. They work with premature children: in hospitals, nurses usually put them in a sort of incubator made of glass or plexiglass from which is possible to see through and to maintain the temperature under control. The designers thought this was a problem, because most premature babies tend to have difficulties in this critical period. This had risen a question: what is the difference between the incubator, which keeps the temperature constant, and the mother's womb which does the same thing? The answer is almost everything: for example, the difference is in the light that penetrates the womb and arrives to the baby or the sounds from the outside, that the baby can hear inside the liquid, along with the heartbeat of the mother. From the little incubator, instead, the baby can see the switching of the lights of the room and the nurses that take care of him/her during the day. They handle the baby but he/she is not handled in the womb: this is a problem because babies can be injured by people considered the fragility of their skin. **From this perspective, designers thought that incubator was wrong and made a new one which is covered, providing lights and sounds similar to the ones in the mother's womb.** Nowadays, **parents are allowed to visit a few times a day their baby, but they are not really involved in the care routines.** The team has put together a solution: parents can stay in the same room as nurses and they are allowed to watch the treatments or take part in them; in order to do this, there is a big video screen on the wall to constantly monitor the baby in the dark using a video camera. **It improves the understanding of the parents on what was happening and the learning of how to take care of the newborn baby in the near future.**

This last example represents the way we must work in the future and doing the healthcare: **trying to focus on all the people who are involved**, not just the patient or the physician, but even the families, the nurses, the technical staff or the people who clean the hospital. It is important to start thinking of all of this as a system, and it is necessary to bring everyday people together in order to find new solutions.

Technology is an essential tool, but only if it is designed by the people, for the people, with the people.