

Research beyond the Labs: Responsible Research and Innovation applied to Active and Healthy Ageing Research.



Introduction

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introduction

Research beyond the Labs: Responsible Research and Innovation applied to Active and Healthy Ageing Research.

Today, ageing is neither a disease nor is it considered a health problem; but, it could become a social problem, if we do not put forth efforts to research and innovate in order to address this new facet of society. From my point of view, it is the society at large which must take responsibility for the change, and this must occur at all levels.

On one hand, I believe a change must occur in terms of social justice, that is, policymakers should be held accountable so that they are in better touch with people and create social policies in line with the actual needs of today's society, particularly those relating to ageing. In terms of researchers, they should be empowered to direct studies and research on ageing more toward social benefit and not only toward scientific benefit.

Lastly, in my opinion, it is also essential for the population in general to adopt a view of the elderly different from the one which currently exists, in which older people tend to lose authority, both in the family and in the community, due to the fact they cease to perform economic activity, which is one of


Why has this paradigm shift with ageing occurred?

Analysing our history, we find a paradigmatic change in vision with regard to ageing. Thus, in the most traditional societies, there was great respect for the elderly, who were seen as a source of wisdom and experience. Nonetheless, it is also true that few people reached 'old' age. So, **how do we currently define old age**, given that this term is an eminently modern concept (like 'childhood' and 'youth')?

Returning to the analysis of our history, we can say that ageing was traditionally associated with a series of physical changes which necessitated a series of habit changes. Thus, an elderly person was a person who, due to physical wear, could no longer perform normal labour activity and who therefore began producing less or became financially dependent. Since the Mediterranean society is eminently a family-oriented society, it was mainly the family who took responsibility for caring for and supporting the family member.

Although this habit is not far different from the one we currently have, there has been a number of significant changes that have contributed to a new view of the elderly.

The first is related to the family model. Families used to be more extensive, and it was common to find three generations living together in the same household. Moreover, the traditional model assumed that the oldest man was the person responsible for taking household decisions, affording him an authority which has now been lost. The change in the family model assumes the emancipation and separation of young people from the home, hence causing the father, who will later become an old man, to lose authority in the home, since children are living in a different home.



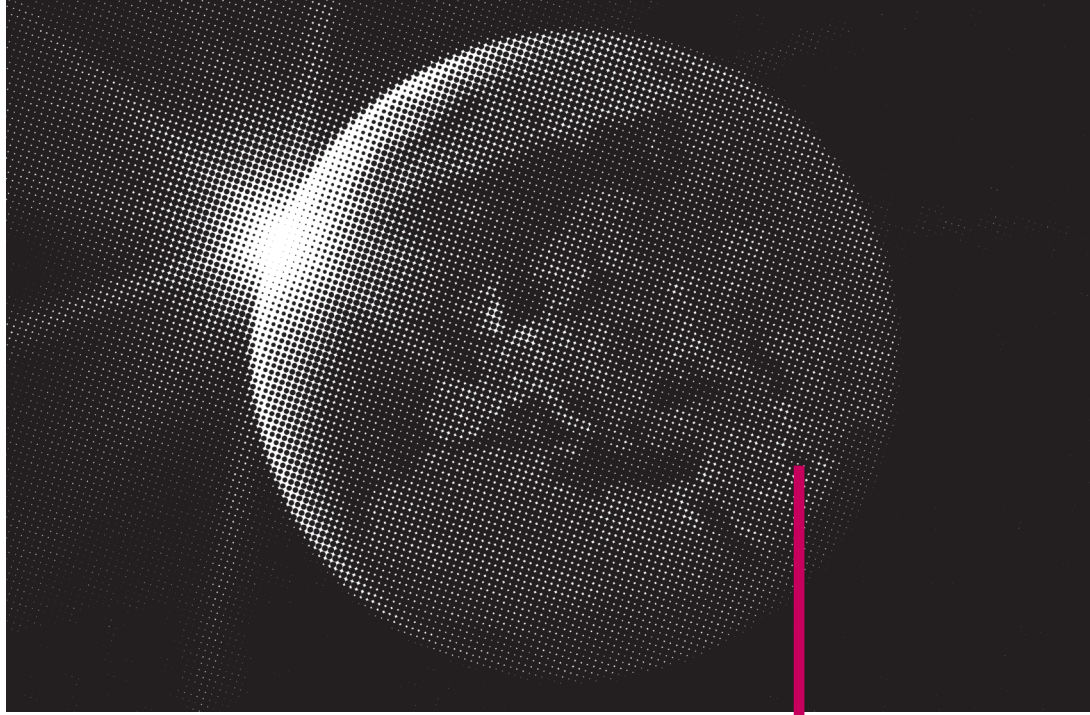
The second is related to the expansion of education and the division into branches and specialisation of employment. Thus, it used to be much more common to receive job training at home, with children learning the trade of parents. Consequently, the oldest man was the greatest source of experience in the household and the person from whom advice was sought by the rest of the family in case of doubt or need. However, this transfer of knowledge is currently less common, and, as a result of the great technological revolution of recent decades, there is a general view that the most traditional work is no longer worthy – or, in other words, it is outdated.

The third –but no less important– factor relates to the prevailing economic model. Thus, the household economy was what once ruled, and there were none of the current social and economic policies, contributions to social security and, therefore, retirement payments. Today's economic model, however, is based on the economic production of the working population, who must assume payment for the nonworking population, including the retired.

As a result, nowadays old age is legally defined as 'the age at which most people retire from work and begin collecting social benefits', social benefits which must be paid by the working age population. This fact prompts society to place enormous value on youth, on vitality and, in short, on the working population, while elderly people, who are no longer contributing financially to society, tend to become 'invisible' socially speaking.

Nevertheless, despite these considerations, the prospects are not as negative as they seem. Today, the elderly have not regained the authority and prestige they had in traditional societies, but they have regained the RESPECT and care of the welfare state and of policymakers, to a certain extent, since the elderly represent a percentage of interesting votes. Meanwhile, there are currently groups of activists who fight against 'age discrimination' with the aim of promoting a more positive image of 'being old'. These groups also have their influence.






What is the picture of our country?



A total of 95% of the elderly lives in private households (not in convalescent homes or hospitals). Senile dementia affects 7% of those over 80 years old, and attendance and productivity at work of people over 60 remains high; in fact, the retirement age is getting older and older. However, having said that, young people and adults have a virtual monopoly at work and in fashion, as well as in education and in power.

What have we learned from research and official reports?



In their published research, healthcare professionals, sociologists and anthropologists alert us to the need to plan leisure activities for a specific segment of elderly people, namely, the segment of the population that has had a form of special education before retiring, people that have realised their potential through leisure, and in this segment this may represent the fruit of their former working lives.

Even early retirement (55 to 60 years old) provides us with the chance to research and innovate in the design of new life plans, which are currently self-imposed obligations. These obligations include things such as crafts, hobbies, volunteer work to feel creative and useful to society, 'grandparenting', travel, social clubs, day centres for the elderly, etc.

We can say that there are differences between the elderly and the extremely elderly, as there are also differences based on the elderly person's sex, if he or she lives in a rural area or in an urban area, if he or she has an academic education or not, his or her specific family situation, his or her financial situation, and if he or she is in good physical and cognitive health.

For example, elderly people living in rural areas who have worked all their lives on a farm never retire; they continue working after age 65 and are healthier than elderly people who suddenly stop working when they reach retirement age, as they stop being useful to society.

Therefore, what we propose is to promote active leisure activities to force the elderly to socialise, including cultural activities, lifelong learning (such as public lectures or university attendance for the elderly), games and recreation to foster diversion and entertainment (such as dancing, clubs), in short, everything related to social education.

If we take into account that the ageing of society has occurred for various reasons, including an increased life expectancy, a decrease in birth rates, a number of changes in the structure of current families, and the rising changes in the status of women (such as women entering the workforce), what we have is a society where more and more people reach advanced age healthier and with greater likelihood to become disabled or have some type of disability (because they live longer, more years).

Since science and technology empower policymakers to take decisions, then governments have an obligation to combine educational, healthcare and social care policies with each other and combine them with the country's economy.

This requires responsibilities to be shared among the state, family and individual, both in the public sector and in the private sector, and thus necessarily entails social and family support and the need to adapt to the new condition of women, who traditionally took care of and take care of the elderly.

For this to occur, it is necessary to develop policies that promote quality of life for the elderly and the dependent elderly. This is a challenge for social policies, for the various services and for healthcare services. This quality of life is closely linked to the economy, to financial security, to social inclusion, to knowledge transfer between generations, and if this is done, society will learn to age, changing stereotypes like beauty, old age and fashion.

For society to learn to age, different aspects like retirement, socio-economic structure, former lifestyle, accumulated experience, etc. must be a priority in the policies of each country in order to change the values of this society. For example, retirement should not imply a loss of status of the individual, but rather it should afford the individual the ability to rediscover free time, thus seeing it as an opportunity and not a threat.

This learning should be LIFELONG

throughout people's entire lives, as it is a key factor in active and healthy ageing. And all lifelong learning is inseparable from society, because society progresses inevitably, and to progress means to 'overcome stereotypes', to accept, for example, that finding happiness has no age, as we can see in the most recent report by Fundació la Caixa. To progress also means to stop associating STATUS with AGE and to provide learning opportunity to retirees while we learn from them. This progress may occur through programmes that promote intergenerational transfer, with the younger generations helping the elderly incorporate new routines in their lives.

Alas the fate of most of us here is to have a long life.

DOING all this is RESEARCHING RESPONSIBLY.

The progress of medicine and technology at the same time has increased people's life expectancy, which is causing the population pyramid to flip. For this reason, healthcare professionals must conduct research on anti-ageing medicine, in terms of living longer with a better quality of life, thus enhancing prospects for life. Hence, while technology and medicine advance, social policies and education should be integrated, and all these processes should be globalised, because we live in a globalised society.

A recent study (2009) conducted in Lleida



by primary care physicians reported that caring for grandchildren causes stress among the elderly; however, if we analyse this study in depth, we find that 30% of those surveyed (113 people with an average age of 71) also stated that because they care for their grandchildren, they are ageing in good physical and mental health thanks to this stimulus, so it is a rewarding part of their life cycle. These self-imposed obligations help a high percentage of the elderly to age healthily. As a result, social policies could be designed to stimulate the elderly with strategies for learning, training and even leisure, as laughter has been proven to prolong life. The ultimate political and social goal is to promote active and healthy ageing.

And all LIFELONG LEARNING is inseparable from society, because society progresses, and to progress means to 'overcome stereotypes', to accept, for example, that finding happiness has no age and to stop associating status with an individual's age. It is for these reasons that we think it necessary to provide learning opportunities to retirees, even though we know that the elderly learn slower, and that we should also consider the possibility of learning from them through intergenerational transfer programmes where knowledge is transmitted both ways.

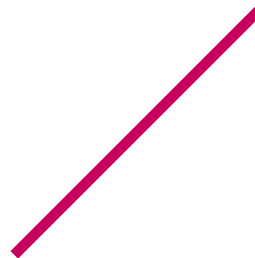
And finally, I remind you that THE FATE OF

MOST OF US is to have a long life; therefore, it should also be IN THE INTEREST OF MOST OF US to ensure that this long life be as healthy and as quality-filled as possible. To achieve everything said so far, we need COMMITMENT (in capital letters), as commitment is the key element to HAPPINESS. This commitment must be assumed and addressed at all levels of society. And I conclude with the reflections of Elaine Fox, a neuroscientist from Dublin who published an article in the newspaper La Vanguardia two years ago. In her article she discusses some elderly people who were responsible for taking care of a plant in different conditions. One group was responsible for deciding when to water the plant with complete freedom, and the other group had no responsibility, since the watering guidelines were not free for them to decide. The group that was committed to its task lived happier and longer (more and better), that is, presumably more active and healthier.

Eva Barallat Gimeno (RN, PhD)

Some Remarks about the Responsibility of Science

The relationship between science and society has undergone profound transformations. These changes could be summed up by considering the new complexity that stems from the weakening of the limits that guided traditional science. A range of circumstances is making us redefine the difference between facts and values, between experts and laypeople, between knowledge and non-knowledge. I am going to examine this new situation beginning with some of these distinctions, namely: 1) the distinction between the laboratory and the outside world; 2) the distinction between science and other social systems which has led to the establishment of traditional scientific autonomy; 3) the distinction between scientists and everyone else or between experts and non-experts; and 4) the distinction between scientific truth and public opinion.



1. Experiments on Ourselves

Some years back, a series of themes and problems that were unusual for the political agenda began appearing on the public stage: nature conservation, food security, the global climate, the genetic code, pollution, illnesses, health in general. Our greatest concerns currently stem from gas emissions, olive-residue oil, atmospheric temperatures, riverbeds and sea levels, genes, and cattle; the protagonists are veterinarians, doctors, farmers, and firefighters. Governmental agencies related to science, nature, and biology—which used to be considered less important—now stand on the forefront of public awareness. There are political negotiations over issues that barely merited attention until now or, if they did, only technical specialists paid attention. Biological matters have become central to politics; one of the fundamental political issues these days is agreeing on a clear definition of what has come to be called nature politics or bio-politics.

These issues all reveal the increasing frequency with which society addresses the concerns, risks, and potential consequences of scientific knowledge and its technological implementation. What is unusual about these problems is that they ignore the divide between laboratories and the rest of the world. We are immersed in collective experiments that reject the relatively manageable limits of the lab. These social experiments are not performed inside a lab, and they lack established rules.

Science has traditionally tried to avoid external interference as much as possible and detach itself from specific contexts. Many scientific techniques used to involve specific isolation; we can see this in the traditional idea of the laboratory. Traditional scientists worked with models and simulations that could be repeated, proved, and certified. It was possible to experiment first on animals, materials, or software. Knowledge was produced at a concrete, specific location with scientific controls, and, from there, it expanded—once sufficient time had elapsed and other requirements had been met—to the rest of the world. The classic experiment based its success on the possibility of reducing and simplifying nature to a size that could be controlled in the laboratory. The practical application of knowledge obtained in this fashion was better when the conditions of the world more closely resembled the reductions and simplifications that could be controlled inside the lab. Until the time it was applied, science was a private affair. The scientist's responsibility was relatively easily definable, as long as there was a clear distinction between research and application, between what Graham called knowledge's "contexts of justification" and "contexts of relevance" (1981, 379). These two areas currently overlap to an extent that requires us to reconsider our traditional way of thinking.

The separation between basic research and technical application is no longer valid (Schmoch 1996). Nowadays, “knowledge is increasingly *produced* in the context of application” (Krohn 2003, 111). The distance between our theoretical knowledge and its possible practical applications is decreasing, and the uncertain consequences of its possibilities are increasing. When the amount of time between theoretical innovation and technical application is shortened (in some fields, this gap is almost non-existent), the relationship between research and practice narrows. Scientists are thus forced to anticipate the way their research can be applied. Science is now under greater pressure to justify itself since the determination of risks can only be proven through practice. The experiment and its practical application tend to go hand in hand. When we talk about nuclear energy, the financial configuration of the world, genetically modified organisms, or the use of certain chemical substances, we can barely separate the methodically controlled production of scientific knowledge and how it is applied in open social and ecological contexts. To the extent that society and nature become laboratories, scientific autonomy is a principle that needs new legitimation.

While the laboratory works with a smaller model, current collective experiments are carried out on the original scale. We become concerned as we observe the complications of using the entire planet as our laboratory. Experiments are done on a one-to-one scale, in real time, with no possibility of repeating or minimizing the experiment or of gaining knowledge about the causes and consequences of our actions. There is no way to reduce the collective experiment, nothing to replace it, which means it has to be carried out without sufficient certainty. Extending the laboratory in this way turns society into a general experiment. That is why it makes perfect sense to describe the knowledge society “as a laboratory” (Krohn / Weyer 1989, 349). That is also why scientific questions interest everyone now, generating concern and hope, or requiring participation.

The collective learning processes that have been called “true experiments” do not take place in a laboratory according to methodologically determined rules. Instead, they are carried out in an open environment in which social, technical, and environmental processes cross paths, integrating the participation of many stakeholders with different interests, values, and objectives (Weingart / Carrier / Krohn 2007, 139). True experiments are carried out in a setting that cannot be completely reduced to theoretical models or isolated into an ideal research environment, making it so uncertainty is particularly great and backtracking is practically impossible.



These difficulties are best perceived in the problem of side effects. If there were no side effects, if processes were reversible, science could rely on absolution for its failed experiments. These parameters were assumed when scientific autonomy and freedom of research were configured. But the scientific system is increasingly aware of the fact that it has to anticipate its effects on a world from which it is no longer comfortably separated by the boundaries of the experimental arena. Science must remain cognizant of issues, keeping in mind what it cannot fully resolve or what it can scarcely repair. That is why it must develop its own way of managing uncertainty. One of the paradoxes of science is that the sooner the reflection about consequences begins, the greater the uncertainty about the knowledge of those consequences will be, while the later the reflection begins, the greater the inefficiency will be when it comes to avoiding or correcting those consequences. The decision about whether or not to continue a scientific process is always made under uncertain assumptions. It is not possible, not even financially, to prove systematically and ex ante all the imaginable synergies that could lead to side effects. It seems as if we can only choose between decisions that are practically blind or knowledge that comes so late that almost nothing can be changed. Many health norms, for example, stem from this paradigm of security and precaution that is not applicable to current problems. This explains the perplexity of government agencies or of public opinion concerning decisions that we might consider either hasty or opportunistic, an abuse of power or an exercise in responsibility.

Current collective experiments cannot wait until absolute certainty is attained. Global warming, the design of the world economy, and food production are eloquent examples of this type of experimentation. The special concern or irritation these experiments produce results from their uncontrollable size, their lack of regulation, and the difficulties of backtracking. With these experiments, we cannot give ourselves time for a learning curve after we make mistakes, because these are not simply preposterous hypotheses or practical failures; they are potentially fatal errors from which society must be properly protected. We have gone from a consistent manner of solving problems that arose from the development of science and technology to the reduction or prevention of unwanted consequences. The politics of knowledge cannot afford to act indifferently, limiting itself to a posteriori repairs. We can no longer put everything off for later intervention.

For these experiments that we make with ourselves, there are no protocols. Protocols would have to come from the mediation between science and the desires of society, from those “hybrid forums” (Callon / Rip 1991) in which scientific and political controversies take place. Until now, we have lived with a clear distinction between science and politics. The unusualness of our situation is that we combine the precise and exact criteria that control scientific tasks with the political space where they attempt to generate confidence and make a choice (Latour 2001).

The comfortable distinction between people and things, between facts and values, between the two cultures (the sciences and humanities), has been broken. The most interesting part of it is now found in connecting political realities to science and technology. We can assert that scientific fields where there are not too many outside factors to be considered are less creative, while those that are more “contextualized” are more relevant (Nowotny / Scott / Gibbons 2004, 211). It is obvious that scientific objectivity is possible, but objectivity is greatest when the project is more abstract and holds less practical significance.

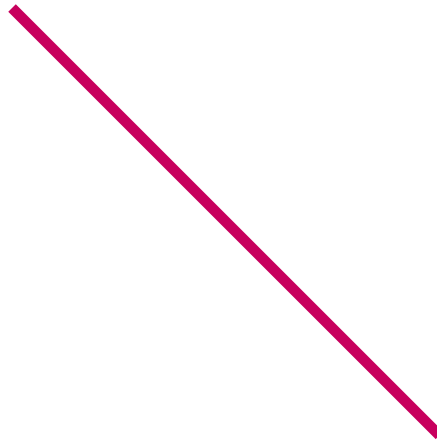
At the same time, although science has achieved a monopoly on explaining the natural world, it does not control all interpretations. Other types of knowledge continue circulating, making claims of validity. The desire for meaning, for example, cannot be satisfied by science alone. This would lead to the paradox that science is more successful than common sense when it comes to discovering and explaining reality, but less so when it comes to interpreting what it all means. The greater the extent of meaning that resides in science, the greater the involvement of other social players. Scientists are in charge of science, of course, but many other people intervene in interpreting it, which –ultimately and to varying degrees– makes it a collective task.

2. Science as a Task for Everyone

The process by which the ideal of scientific autonomy was built has been accompanied by a process that separates science from society. The value of autonomy relates to the fact of the differentiation of science. Although today we can and should distinguish that value from this fact and redefine the relationships between science and society, there is an indisputable logic to that process. The sciences were formed at a certain distance from society. They allowed us to gain access to a new territory, and the rules that produced this new knowledge did not allow any type of external control. This distance in relation to society is of a systematic nature, given in part the dynamic of differentiation inherent in science, which even affords it its own language and a preferential interior audience. This fully justifies its goal of autonomy and the related establishing of the radical difference between experts and laypeople. There is even a scientific “class” that Derek Price (1965) compared to an estate, understood as societal groups that demanded financing but were not prepared to submit to any control of responsibility. This situation has changed radically in a democracy of knowledge which demands that we rethink the relationships between science and society in the context of new realities and new responsibilities.

What has recently made it necessary to come up with a new definition for the traditional relationship between science and society and the classic version of scientific autonomy? Essentially, there has been a complex process leading to a “dedifferentiation” of science and a certain degree of reintegration of science into society, basically in the heart of related social and political responsibilities. Some people have discussed a “delimitation” of science or a loss of its institutional exclusivity, that is, a reflexive questioning, which has weakened the cognitive and institutional separation of science from other social environments, players, and forms of knowledge (Krohn 2003, 111). The rising social relevance of science has been accompanied by society’s growing intervention in science, which is something that demands that we review the traditional ideal of self-regulation. Science is a social business that influences and also depends on its social context. As an organization, it needs to be assigned resources; as a social institution, it requires legitimacy.

We can now say that the scientific “class” has lost the unlimited authority it originally enjoyed. For some time now, there have been excessive public controls on a social group that receives funding for an activity whose achievements are often invisible and whose quality cannot be judged only internally. “Self-regulating science” is, alongside the myth of the self-regulating economic system, the latest scandal of democratic society (Weingart 2005, 49). In fact, since the 1990s, science’s social contract has been renegotiated. Social responsibility, the demand for accountability, and public obligations are some of the concepts through which public institutional weight is given to controls, external assessment, and competitive rankings. Everything indicates that this is the end of a particular scientific establishment and that there is a demand for the democratization of expert knowledge.



Discussions on the conflicts attached to risk (and similar conflicts) have revealed that the influence science exercises over society has been modified considerably. With the impression of the technocratic theories of the 1960s and 1970s, the original assumption was that science would provide clear, unique direction for political and social action. Since then, it has been shown that “scientification” is a more complex and tense process; it not only includes the influence of scientific knowledge on social relationships, but also the effects uncertainty and scientific non-knowledge have on society. The fact is that society is brought face to face both with “true” knowledge, which is scientifically certified, and with a fundamental uncertainty about the scope of that knowledge and how it is applied in different contexts and the presence of latent non-knowledge that is found within knowledge. Awareness of this new knowledge constellation is what has made us move “from a culture of scientific autonomy to a culture of accountability” (Gibbons / Limoges / Nowotny / Schwartzmann / Scott / Trow 1994, 119).

Alongside all these processes, science has lost the monopoly on unquestionable knowledge. Science cannot help but let down expectations of attaining trustworthy, certain, risk-free knowledge. Other social systems end up compensating this type of social inaccuracy. Advances in science have expanded political territory in that they have created new demands for norms and regulations. The criteria to determine the quality and relevance of knowledge are no longer defined by science alone, but also by those who apply knowledge. These criteria arise in the context of applying knowledge where social, political, and economic schools of thought are all-powerful. Producing, disseminating, and applying knowledge are reflexive processes which bear social debts; they are regulated by a series of social compromises in the face of some modified legitimacy requirements, thus making knowledge an eminently political question.

The perplexity with which we address these questions stems from the fact that there is now no validity in the traditional definition of a science that is only applied or of politics that is rational decision making as advised by experts. Our collective experiments are enormously complicated by the fact that consensus and certainty are more difficult to achieve with them than with the regulated exercise of science inside a lab. Increasing public controversies about scientific issues show that the traditional model of science or ideology scarcely meets our needs. The fact that there is always a compromise to balance political and scientific criteria means that knowledge is no longer irrefutable as an instrument of legitimation. Acting rationally in any field does not mean carrying out a preconceived plan but delving into the unforeseen consequences of a provisional and revisable project.

In a democracy of knowledge, there is no longer use for the strict division of labor based on the assumption that no perspective wants the responsibility of taking other points of view into consideration. New challenges will require continuous attention to be paid to various schools of thought that must be put into play in forums that can be rather tense. Social changes are not going to be produced at the initiative of a science to which society responds passively or by a social mandate directed at a science that is assigned specific tasks. Science has forced its way into society and society has forced its way into science. Our primary concerns must be identified and managed during the scientification of society and the related socialization of science.

In this way, society becomes a complex framework formed by players with different resources, interests, and realms for action. Society dramatizes the argument between diverse points of view to adopt the decisions of our collective experiments and thus configure our common world. We live in a world that demands that we be something like “specialists in contexts” who are capable of finding the relationship between different disciplines, of comparing schools of thought, of paying attention to unexpected causalities, and of contemplating risks and opportunities. The integration of various social systems, when it occurs, consists precisely of exchanging points of view to compensate one’s own blindness and find formulas that make different viewpoints compatible.

It would be a question of activating collective processes of reflection like those “hybrid forums” (Callon / Rip 1991) that work to incorporate changes in the criteria used to measure knowledge. They would also afford self-reflection and improved attention to social demands, or the idea of *agora* (Nowotny / Scott / Gibbons 2004), which is not the bureaucratic world of regulators, but a place in which to conduct a series of interactions between competing interests: diverse perspectives, economic limitations, global dynamics, political and legal regulations, budgetary priorities, etc.

Science, politics, and public opinion must find new and innovative ways to encourage science’s social role and manage the growing ignorance of science’s consequences in a productive, transparent, and democratically legitimated fashion. Our choice is not between controlling science (as if there were an institution capable of doing so without destroying science’s innovative capacity) or giving it free rein and “naturalizing” existence (which would mean believing that processes such as climate change or global economic tendencies, for example, are inevitable realities that allow no intervention). The democracy of knowledge is affirmed as a key example of mediation within the maze of controversies, stakeholders, and divergent cultures.



3. Science and People

Another distinction that is blurred within the current configuration of knowledge is the clear differentiation between experts and laypeople. The public presence of scientific ideas nowadays does not mean that scientific competition no longer makes sense, but rather that the distinction between those on the inside and those on the outside of the scientific disciplines has been weakened. Previously, when there were experiments, it was always under the scientists' control, while everyone else was relegated to the often unwanted role of spectator of something they could not judge. But we no longer live in a time when experts talk about indisputable data and use their knowledge to put an end to any controversy. In a knowledge society, people have more cognitive abilities. New organizations and interest groups appear and help weaken the authority of experts. What used to be an esoteric power of knowledge is now publically debated, controlled, and regulated.

The democratization of science does not mean abolishing the difference between experts and non-experts, but politicizing that difference. The democratization of knowledge is tied to the fact that scientific authority is not indisputable. This is best seen in the value we assign to expert judgment, which is also submitted to democratic demands. I am not trying to formulate a political imperative but to assert a verifiable fact: the government, opposition parties, and protest movements all have their own experts, and different experts have, of course, differing opinions. The legitimizing function of scientific knowledge has led to a paradoxical competition between experts. For this reason, we can say that the increase in knowledge in a given society does not necessarily mean greater consensus; instead, it reinforces dissent by providing reasons and the means for argumentation. The consequence is that political decisions are not adopted, as hoped, in a more rational, obvious, and consensual fashion, but in the midst of more intense controversies and with insufficient knowledge and greater awareness of risks.

The first condition for democratizing expert knowledge and its monitoring by society consists of clearly establishing who is to be considered an expert, a question that can in no way be answered in advance. The closer a question is to politics, the less important the distinction between layperson and expert becomes. It is not that there are no experts, but that the distinction between their competencies must be legitimized. We must justify the reasons why the experts are the leaders of their respective scientific disciplines. Expert status may be conferred on “normal” citizens or laypeople (as we can see with juries, for example, or with the universal access to public positions afforded in a democracy) or on those who are locally affected, who have been called “non-certified experts” (Collins / Evans 2002). What we would then have is a type of “extended peer communities”: the circle of those who can and should evaluate the quality and usefulness of scientific knowledge to solve certain problems is wider than the circle of experts in the relevant field.

In fact, there are already many texts that emphasize that non-expert knowledge should be taken seriously in numerous situations (Wyne 1989). This does not mean that we should vote on the truth of scientific matters or that all opinions are equally valid, but that we would do well to listen to non-experts, especially when expert authority is not always indisputable on every question and we have seen that laypeople sometimes know more than specialists. There are plenty of examples of the democratization of expert knowledge or citizen involvement in scientific issues. In Europe, there is a long history of the participatory governance of science and technology in the field that has been called “participatory technological assessment” (Joss / Bellucci 2002). The Danish “consensus conference” model is the one most cited. The European Union governance program, for instance, tries to involve civil society in various stages of research, especially in defining financial priorities (Commission of the European Communities 2000, 8). Along the lines of the democratization of expert knowledge, we could mention a willingness to facilitate access to knowledge, the limits imposed on administrative secrecy, the right to know who is assessing specific public decisions, and how positions of relative scientific significance—such as professors, juries, expert commissions—are determined.

The discourse of the knowledge society previously focused on the production of knowledge and, therefore, on the experts, while the account by the risk society, by emphasizing those who suffer that risk—consumers, voters, citizens—, places the distinction between experts and non-experts on a secondary plane. Laypeople lack specialized knowledge but may be affected by the decision being made or have first-hand experience with the matter being addressed, which sometimes gives them a broader perspective than politicians and experts. These non-experts can represent civil society, be competent when it comes to values, or have at their disposal “local knowledge,” i.e., that “disparaged opinion” that Husserl tried to save. In any case, and also for epistemological reasons, it is important that science not discredit “outside” impulses or irritations as if they revealed ignorance or hysteria. Especially in those research fields that attract a lot of public attention, a “sociologically sensitive epistemology” (Nowotny / Scott / Gibbons 2004) should not waste the opportunities for reflection and justification afforded by the non-knowledge produced by that very public attention.

Demands for democratization and participation attempt to integrate the perspective of non-experts and of those who are directly affected in order to put collective learning processes in place. This “cognitive politicization” (van den Daele / Neidhardt 1996) seeks to resolve the democratic contradiction suggested by a society of non-experts that is directed by an elitist group of experts. The objective of a democracy of knowledge is to treat everyone as citizens who bear equal responsibility for political decisions, without negating their differing degrees of competence. We are increasingly less able to use scientifically provable fact or the professional competence of experts to determine what knowledge and what normative criteria are relevant for resolving many of our major controversies, because these facts and competences themselves are subject to social controversies and negotiation. Participation is important when decisions have to be made in the midst of great uncertainty and when expert counsel is insufficient.

All technical/scientific innovation holds risks stemming from non-knowledge, and that is why the decision about whether a society wants to expose itself to those risks is a political decision also influenced by normative considerations. They must be considered expressly as political decisions and not defined as risk assessments derived from a scientific verification of facts. This bears at least two consequences. First, non-cognitive arguments and criteria—such as social utility, opportunity, economic costs, and the consideration of other alternatives—can and should be involved in political decisions. Second, we are dealing with matters that need to be negotiated politically which are not predetermined by the objective criteria of experts. The political conclusions deduced from expert advice are very rarely irrefutable.

Because of this, our biggest problem consists of how to carry out a social reintegration of science when we know that the issues at stake are too important to leave in the hands of specialists. In our collective experiments, it will not work to have the expert play the role of mediator between the production of knowledge and society. In the new knowledge society, experts are replaced by what Michel Callon has called “co-investigators.” No one in this society is satisfied to simply implement innovations without knowing their origins. The time when the application of scientific knowledge was unquestioned and necessarily useful is now gone. In a knowledge society, there is an increase in the number of organizations that are intelligent and investigative and that cannot limit themselves to being “consumers” of knowledge, but must also be “producers” of knowledge. That is why there is nothing strange about citizens having increasing aspirations to be heard and to participate in collective experiments. Of course, it is not an attempt to establish a type of customer mentality to science as if we had a right to comfortable truths; science in a democratic society still has the obligation to speak truth to power, in other words, to public opinion. In any case, the politics of science and democracies of knowledge are primary concerns of the new citizenship.

4. Scientific Truth and Public Opinion



If scientific knowledge can legitimize distinct positions and political decisions, then it is not easy to maintain the idea that knowledge describes a hard, objective, visible, and one-dimensional truth. Scientific knowledge cannot be as clearly separated from value judgments as the technocratic and decisionist model would have preferred. The relationship between knowledge and decision making is more complex. It presents many questions about how it formulates problems, its trustworthiness, its range of interpretations, the number of answers it allows, and the relationship that knowledge has to social values and political interests, in other words, to its context of meaning. The final distinction we will need to retrace assumes that scientific truth and public opinion are two absolutely different things.

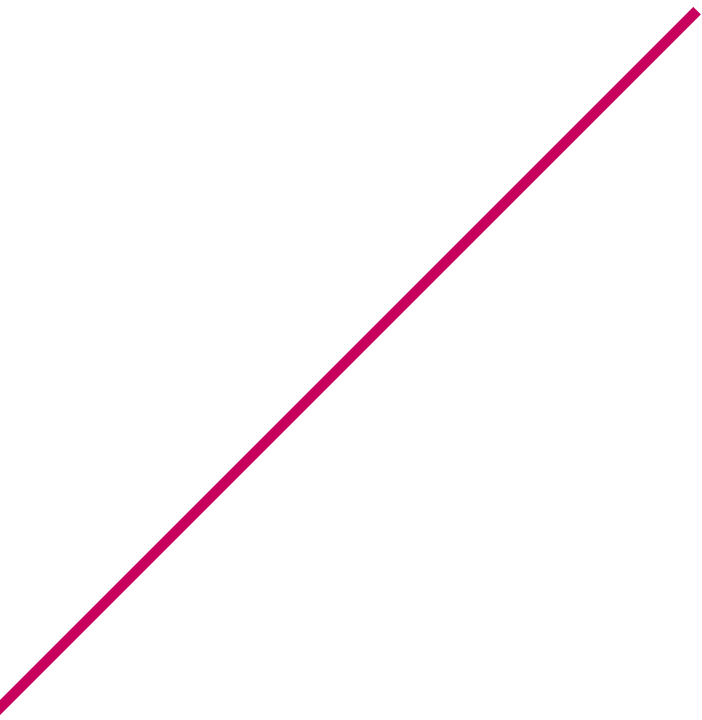
In a democracy, the application of knowledge is a “public” affair, i.e., it needs collective approval. That is why the observations that the media makes about science are very important in the knowledge society. Science has become a matter of public concern, since the media observes and informs on it, discussing its ethical implications or the risks of research. The media is a social institution that plays a part in configuring knowledge and its collective legitimacy. Of course, the media, like any social system, has a unilateral view of reality which must be balanced with other points of view. But its role, particularly its emphasis on the legitimacy of knowledge, is irreplaceable in a knowledge society. It has acquired an importance explained by the very development of democratic societies.

The relationship between science and the media should not be interpreted as the traditional popularity of some forms of hierarchically understood knowledge. According to that model, the scientific system produced truths that were revealed to public opinion, generally in a simplified and popularized form. The “Enlightenment model” was still being influenced by pre-democratic forms of public opinion. The public was generally passive and indistinguishable, unable to judge the knowledge it received. The communicative process only ran in one direction. Because of this asymmetry, mediation was not given any specific function. Many popular science programs were meant to attract attention through specific events or entertainment; they imagined a generalized and badly structured public. Allowing “the people” to return to science means something more than providing them with a closer, more humane, or more communicative image, even when that is very important. It is not a true democracy of knowledge if science is presented as a collection of facts whose origin either remains in darkness or is attributed to a few famous thinkers.

In contrast to this elitist vision of science, we have begun accepting the idea that knowledge is everybody’s business, a task that is supported not only by scientists in the strict sense, but also by every citizen. We have gradually begun recognizing the ability of all human beings to participate in research, in inventing, and in doing science, or at least in judging some of its conclusions. In the early 1990s, organizations like the American Association for the Advancement of Science (AAAS) and UNESCO popularized the slogan “Science for all,” which can be summarized in the following principle: “not only science in the service of everyone, but science by everyone.” There is no democracy of knowledge if we do not recognize the principle that everyone has the ability to participate actively in science, understood as a collective task.

This is the context in which the current “mediatization of science” should be considered: science’s focus on the media has increased considerably because of the importance that the media has gained in shaping public consciousness, political opinion, and, ultimately, world perception. There is also the fact that there is heavy competition both among the sciences and between the sciences and other social systems for scarce resources and public attention. In the space between science and politics, the media has the task of transmitting themes that confer legitimacy. The media can no longer simply be faithful transmitters of scientific knowledge or of any other event. By its very nature, it tends to question science’s legitimacy, relevance, timeliness, and compatibility with other social demands. The media has not replaced criteria for validating science, but it has supplemented them with a particular perspective that a democratic society cannot do without.

Present-day democracy demands some recovery of sovereignty over natural things and processes under today’s complex conditions. It must try to resist the preconception that there is no alternative (in other words, politics), because the world is unanswerable and is defined by privileged people. Hans Magnus Enzensberger (2001) recently claimed that our laboratories contain “coup supporters”: scientists who want absolute power and do not want to submit their decisions to the processes of public deliberation. In spite of their not infrequent contradictions, environmental or anti-globalization movements respond to this demand for participation with a reasoning that is very similar to the battle that was unleashed in the past against absolute monarchies: they want to stop being subjects and start co-defining the common world. What has changed least is that we find ourselves immersed in the same struggle to reduce authoritarian voices to the democratic conversation of rumors.



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La Ciencia, un asunto de todos.

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Entre sus últimos libros cabe destacar Un mundo de todos y de nadie; La democracia del conocimiento, Premio Euskadi de Ensayo 2012; La humanidad amenazada: gobernar los riesgos globales (con Javier Solana); El futuro y sus enemigos; El nuevo espacio público; La sociedad invisible, Premio Espasa de Ensayo 2004; La transformación de la política, III Premio de Ensayo Miguel de Unamuno y Premio Nacional de Literatura en la modalidad de Ensayo 2003; y Ética de la hospitalidad, Premio de la Sociedad Alpina de Filosofía 2011 al mejor libro de filosofía en lengua francesa. Algunos de sus libros han sido traducidos en Francia, Portugal, Estados Unidos, Italia y Canadá.



The Responsibility of Science.

The more we know the more responsible we are.

1. Expanding knowledge, expanding responsibilities

With the expansion of scientific knowledge and of the technologies resulting from it, our responsibilities also expand to the same extent. We cannot be held responsible for anything completely beyond our control or domain, such as many natural disasters. And of course, we also cannot be held responsible if when faced with an imminent danger or damage that is actually occurring, such as a disease or an epidemic, we do not have –usually because we are unaware of them– the means, such as drugs or medical instruments, to overcome this danger or avoid this epidemic.

But, from the time we have the knowledge to detect imminent dangers and the instrumental means to avoid them, then we can consider the responsibility of who could have or should have prevented the damage from occurring. And that is how in this advanced industrial society in which we live the increase in knowledge and the abundance of technical means we have are burdening us with new and complex responsibilities ¹. This is undoubtedly another of the formidable challenges that scientific and technical progress pose for the law and which not only extends to the realm of public liability with its marked compensatory component, but also to that of criminal liability or to that of political liability for decisions taken or, above all, for those not taken, when scientific and technical means enable effective decisions to be taken.

The responsibilities that doctors may face today, for instance, are much broader than those faced by their 19th century colleagues from the time that scientific knowledge and available means are today also much more effective than what existed then ². Knowledge that makes it possible to diagnose diseases which were completely undetectable at the time and fully overcome others that then were considered incurable. What is reasonably expected from a medical professional or from a medical centre today far exceeds the expectations placed in them 30 years ago. But there is no need to go back to the 19th century: medical advances in recent decades have been phenomenal.

These advances in knowledge have occurred in all sciences. Hence, far from the field of medical or health sciences, we can focus on geology or seismology: seismic events, which were once enveloped in the most inscrutable mystery when not considered hidden forces of nature, are now well understood in terms of their causes and components. Seismic risk zones are also known with increasingly greater precision and future forecasts of these movements are more and more accurate.

All these advances are without doubt very positive and favourable for society as a whole, but paradoxically, at any given time, they can backfire on those who promote them. This paradox occurs precisely when we consider liability for damages that have occurred and could have been prevented with the scientific knowledge and technical means we have today. A critical and very significant point of this trend occurred when, after the tragedy of the tsunami in Indonesia 10 years ago and of Hurricane Katrina in New Orleans the following year, the idea, and even the conviction, spread that with current seismic knowledge, we could have foreseen the formation of the wave and evacuate the beaches and coastal areas in time in the case of the tsunami or reinforce the containment system with dams and other techniques in the case of Hurricane Katrina. In media debates, and not beyond this arena, people began insinuating potential liability, although without specifying those liable or the kind of liability enforceable. The case of L'Aquila three years ago confirmed these prognostications and marked the entry into the legal sphere: an Italian court sentenced members of a scientific advisory committee of the civil protection authorities for not giving the

¹ At the beginning of his work, Hans Jonas states that since all previous ethics shared one of the premises that the “range of human action and therefore responsibility was narrowly circumscribed”, now “with certain developments of our powers the nature of human action has changed and since ethics is concerned with action, it should follow that the changed nature of human action calls for a change in ethics as well” *Technology and Responsibility: Reflections on the New Tasks of Ethics*. The outlook for the law and particularly for the liability regime is also greatly transformed with the dramatic increase in the power that technology has afforded human action and its effects.

² This statement on the broadening of medical responsibilities in the wake of advances in knowledge and technology, which is deliberately generic in order to highlight the changing situation, should be expanded upon to provide much more accurate and realistic profiles of the liability of these professionals, which are used as an example because of the constraints and possibilities that scientific progress has on their otherwise age-old activity. In any case, this is not the place to analyse the complex regime of responsibilities of healthcare professionals or the regime applied in other sectors. I only wanted to point out some general features of the changes in responsibility in parallel with scientific and technological progress. On medical liability from different perspectives, AAVV, *Responsabilidad del personal sanitario*, Madrid, Consejo General del Poder Judicial, 1994.

right information to people living in this area in view of the projections of an earthquake which ended up causing the death of nearly 300 people who did not leave the town. The issue has yet to be finally settled in the legal sphere, as it is awaiting the decision of appeals to higher courts, but it is very telling of the pressure of demands for responsibility of scientific knowledge and how it is used.

Similar ideas can be formed about degenerative phenomena, the causes of which are being discovered by scientists and are attributable to our actions and not to natural phenomena which we cannot control. Climate change is a current and eloquent example.

This trend toward responsibility is clear in any case, and to the extent in which science and technology assure human dominion over natural phenomena, that is, over the prediction, prevention and avoidance of them, the community will raise the issue of political responsibilities to the parliament or to the political community itself and public opinion or the issue of public liability that victims can potentially demand in court.



2. The position of the law and its demands for accountability in the face of scientific and technological progress

How to handle liability linked to scientific and technological progress is, as can already be seen, a complex, delicate and hotly-debated issue. In any case, it is obvious that this controversial issue of liability primarily affects the agents and subjects most involved in scientific progress and technological innovation. Widespread criticism is constantly being expressed by these segments of the population regarding the attempts to adapt the liability regime by updating it. They tend to perceive as oppressive, contradictory and unfair the expansion of liabilities stemming from progress and ultimately from the advances in knowledge made by science. Those who in the long run promote progress in benefit of society would thus be burdened with pressing responsibilities. Hence it could be concluded, and this is an idea that is widespread in broad areas of the world of science and technology, that the law adopts a hostile attitude toward scientific and technological progress, burdening it with onerous responsibilities.

To a large extent this is true, but the law can in no way be said to have a hostile attitude toward progress. What is happening is that this scientific and technological progress is making us aware of and giving us the ability to act upon and take decisions in relation to industries and areas that until now were unknown and exclusively subject to the action of natural processes over which we had no control. We cannot demand liability for natural processes over which there is no capacity for human intervention. In fact, the law has nothing to say in cases where only natural forces are at work. The matter of law is human activity or behaviour and ultimately the most characteristic aspect of human beings: intelligence (which is knowledge, which is expanded with scientific activity) and will (which is decision, the effects of which are amplified with technological progress). Human decision is thus the main object of attention by the law. The decisions taken by policymakers, by judges, by public administration officers. And of course also decisions taken by private individuals: by he who decides to hire in specific conditions, by he who decides to commit a crime or by he who commits an act that, although not criminal, causes damage and turns others into victims of this action.

Insofar as we decide, we must be accountable for our decisions. Our liability thus extends as far as the effects of our decisions reach. The thing is that the formidable technological fabric that we have greatly broadens our capacity to decide and also substantially expands the effects of our actions. Science and technology have completely transformed many areas that before were totally dependent on the processes and rhythms of nature –and in which there was no place for regulation or legal liability of any kind– and which are now an industry subject to the complete dominion of technology and of the human intervention implementing and controlling it. With a transformation like this, these industries become a matter of law subject to legal regulation focused on the human intervention in them and on the potential liability that may arise from this intervention.

One of the industries (which is vital to others and to which we referred to by way of example) in which these profound changes are clearly visible is the food industry. Until just a few decades ago, food was offered by a nature that was subject to very slight human intervention or handling, especially through agriculture and farming. An intervention that focused on providing other natural elements, such as water for agriculture, or on defending against the dangers of nature itself, such as protecting livestock from attacks by vermin. When, as was common, there were natural phenomena with negative effects on agriculture

or livestock, such as pests, droughts, frost, floods, etc., there could be very serious consequences for humans, including deaths or malformations from starvation. But even when there were true disasters caused by famine or lack of food, there was no reason whatsoever to demand responsibility, since no human intervention contributed to this damage.

In developed countries today, food no longer comes from nature nor is it subject to the dictates of nature, but is provided by an industry, the food industry. All the technological development occurring in relation to food has had a highly positive result insofar as this industry is able to ensure food for the population, making it so food is not dependent on the effects and dangers of nature for agriculture and livestock. There is no looming danger in our society for the lack of food and even less so that this may happen due to bad harvests, when most people do not even know the seasons of the most common agricultural products and many young people have only seen cows and sheep on television. The food industry is completely removed from natural conditions, which no longer represent a danger, and ensures food supply with its extensive technologies for production, preservation, storage and packaging and now with the genetic intervention and manipulation of plants and animals used in the food industry.

However, alongside such positive results, with the revolution that has resulted in doing away with the traditional food system reliant on nature, the food industry has placed itself in the midst of the legal system from the time that an industrial process becomes entirely dependent on and comprised of human interventions and decisions that can be the subject or object of legal regulation. Regulation and authorisation, if the case may be, of certain products, additives, production processes, food preservation; controls and inspections; and, moreover, potential liability for damage that may occur as a result of human intervention and activity in food industry processes, since it is no longer possible to attribute this potential damage to the inscrutable designs of an untamed nature.

Extending liability to the space in which the food industry operates, and to many others won over by technological development, is in no way a penalisation of progress, but rather a basic expression of maturity assuming the consequences of what must be responsible decisions.

3. Does demanding accountability discourage scientific and technological advances?

Given the extending of liability, in parallel to the extending of our ability to control and intervene achieved for us by scientific and technological development, a discouraging and paralysing reaction may arise in industry and technological innovation. It could then be argued that while the effort for technological innovation benefits society as a whole, responsibility falls overwhelmingly on the shoulders of those who promote progress, who would subsequently have no incentive to put forth the effort and investments that innovation requires. A consideration and assessment similar to the one related to relevant incentives that are found in other regulations or legal formulas such as those offered in the system of patents on invention or technological innovation.

This objection, which clearly has its logic, helps us get closer to the core, to the crux of the relationships between science and law as regards defining responsibilities.

First of all, however strict the liability regime is, the truth is that technological development has not stopped because of it. This constant progress, which is never blocked by the burden of responsibility potentially imposed by the law, has two fundamental explanations. The first is that it is selective progress: when those responsible for advances come across high-risk industries where there could be large or frequent damage, which would be burdened with significant responsibility, then technological progress is directed toward industries with less potential risk and is only directed at high-risk industries when safe, very reliable technology exists.

Second of all, it should be noted that scientific and technological progress responds to a range of incentives and stimuli and not only, in fact far less so, to the selfless desire to improve the living conditions of society or to benefit society as a whole. The centres, organisations and companies fundamentally that drive technological development and promote scientific research that opens new avenues for them logically hope to profit from their efforts and investments, and the truth is that the results leave no doubt that these industries and companies that operate in innovative and progressive areas generally obtain growing profits. It does not appear that potential liabilities that may result from their technological innovation –and which occasionally are legally imposed when there are damages attributable to them– has stopped their activity or production.

The pharmaceutical industry, to cite an industry noted for its innovation and progress, knows that it has to deal with the liability that may result from damages caused by the new drugs it markets (and on several occasions it has been forced to pay substantial compensation for this reason), but this burden has not stopped the productive activity of this thriving industry and its constant offerings at the forefront of research and innovation.

Although the most prominent champions of progress include subjects and organisations motivated by profit, which in and of itself cannot be disqualified given that, among other reasons, this is the same motive moving any industrial and commercial activity, it is no less true that progress benefits large segments of the population. Which also does not allow us to establish the principle that progress is for the benefit of mankind, as repeated experience has shown that unfortunately this is not the case. So, to continue with the pharmaceutical industry, it is a proven and repeatedly criticised fact that its production could cover much of the drug needs of the Third World; however, the commercial interests of the industry stop it from achieving this objective. The verification of this fact invalidates the false allegation by certain sectors of the food industry which claim that with the spread of GM foods, which are already a lucrative business, the hunger problem in developing countries would be solved.

In any case, there are a wide range of public and private interests revolving around technological progress, and there are also associated benefits distributed –with different content– among different subjects and groups. Hence, it is understandable that the question of liability for potential negative effects and damage resulting from progress is an issue centring on how this liability, which is actually a cost, is distributed among the various promoters, participants or beneficiaries, if any, of this scientific and technological progress. In short, it is a matter of allocating and distributing a cost –liability for damage, with its compensatory component– among the various players. The solutions are varied and often controversial and may be full of nuances. There is no concrete responsibility, as one could initially and superficially think, that hovers exclusively over the professionals of science or over those who promote progress benefitting society as a whole. This responsibility should be adapted to the way progress occurs and how its costs are distributed.

Returning to the case of the medical professional and to the assertion stated a few lines above: a doctor's responsibility today is much more extensive than that of a 19th century colleague, as developments in the medical sciences require doctors to have means and knowledge not available last century. This is a statement that must be clarified and revised in terms of its consequences if we consider the way in which progress in medicine has occurred. One avenue of progress has undoubtedly been specialisation, which has resulted in the segmentation of knowledge and hence of responsibilities. An orthopaedic surgeon can in no way be required to have the knowledge of an ophthalmologist. And vice versa. In the current advanced state of knowledge of medicine, this knowledge is, necessarily, specialised.

Also, of course, so-called general practitioners or, as they are commonly known, family doctors can only be expected to provide an initial diagnosis and primary care, but in the face of a specific disease or pain, they cannot be required to have the knowledge of a specialist in the afflicted organ or in the disease diagnosed. By contrast, 19th century doctors were required to have more general knowledge but with less content and specialisation. In reality, it could be argued that the accumulated knowledge required of a 19th century doctor and of one today is quite similar, and it could hardly be otherwise if skills were similar and a similar amount of time was devoted to training and learning. The difference lies in the configuration of this knowledge: broader and more general in the 19th century, more specialised and, as a whole, much more extensive, with a much more powerful technical apparatus for implementation, today.



The debate on responsible research in active and healthy ageing research

From these general considerations on the responsibility of science, I allow myself to address the debate on Responsible Research and Innovation (RRI) applied to Active and Healthy Ageing Research (AHA).

Without doubt, the fundamental issue that these types of considerations raise is how to apply responsible research and innovation (RRI) in this field of research (AHA). One possible criterion is to consider whether this type of research seeks –or is able– to change the basic rules and references of nature. On this basis, we can distinguish between two fronts by the kinds of effects that scientific research and its technological implementation have on them.

The first front goes beyond nature and relates to our available means and instruments. Our means of communication, transport and nourishment. This also includes the means we have to combat our diseases which have been developed at the impetus of pharmacological research. If we want to highlight an industry that has undergone amazing development in recent years, it would have to relate to several closely-related industries like telecommunications, computer science, and the Internet, which have unleashed a true technological revolution. In any case, we are here on the same front of research and production of means and instruments in which the efforts of mankind have focused from the beginning, like the efforts in the early days to secure livelihoods.



But in recent years, a new front has been initiated that works not on means to dominate nature, but on nature itself, altering and reconfiguring her structure, which is given to us by nature and in which we intervene. As a mere example, we could focus on a significant, growing industry like genetically modified organisms. Intervention and genetic manipulation allow us to change nature, change what is given to us, and create new organisms used, for example, for food. This intervention in nature can also extend to human nature itself.

Thus, with regard to food, we can differentiate between two types of scientific research. One is traditional research that focuses on the means and instruments without altering the natural structure (for example, food freezing techniques, fertilisers, preservation, etc.). But the other focuses on altering the natural structure of natural products, which cease being so at that moment. And on this same front of intervention, scientists could focus on human nature, altering its processes so that we require less food or so food has a greater impact.

As for anti-ageing research, we need to consider if we want to or can use it to alter the natural processes, with their rhythms and seasons, of human life. If that is the case, we must assess the potential consequences, as this may change the balances on the planet, as noted in the second question: Ageing across the world. It is a process similar to the one caused by genetically mutated organisms: on the planet, there are different areas for growing each organism based on weather conditions and other kinds of conditions. The population has also been established based on these expectations for crop growing. However, if we insert a gene into a tropical crop to make it immune to cold, it could then be grown in very cold and arid areas, many of which had been unproductive until that time. The economic and social consequences for population settlements could be very significant, even traumatic in some cases.

There would also be an effect on the job market and on social justice, as noted in the third question, since the very structure would be altered and along with it the established expectations in the political and electoral order and in the distribution of benefits and obligations in the social state and the welfare state. These are effects to be explored and consequences to be assessed.

José Esteve

Responsabilidad Social de la Ciencia, Referencias Constitucionales.

José Esteve Pardo es Catedrático de Derecho Administrativo en la Universitat de Barcelona. En su amplia obra académica, destaca por su investigación sobre la relevancia de los riesgos tecnológicos en la regulación jurídica. Destaca su obra “Técnica, riesgo y Derecho” (Ed. Ariel) así como otros artículos y edición de volúmenes sobre “Seguridad alimentaria y regulación de riesgos”, “Auto-regulación en técnica y ciencia”, “Público y privado en el control técnico”. Ha trabajado y presentado ponencias sobre estas materias en diversas universidades y centros de investigación, especialmente en la Universidad de Munich (donde recibió formación como investigador de la Alexander von Humboldt Foundation) y en la Northwestern University of Chicago. Es el director del International Research Group of Risk and Economics Regulation y miembros del consejo asesor del “European Journal of Risk Regulation”. Este enfoque sobre el riesgo le ha llevado a profundizar en el análisis de la creciente interacción entre la ciencia y el derecho. Entre sus últimas publicaciones destacan: EL DESCONCIERTO DEL LEVIATAN: POLITICA Y DERECHO ANTE LAS INCERTIDUMBRES DE LA CIENCIA (2009), CIENCIA Y DERECHO: LA NUEVA DIVISION DE PODERES, junto al Dr. Javier Tejada Palacios y la tercera edición de su obra “DERECHO DEL MEDIO AMBIENTE”.



ETHICS OF REGENERATIVE MEDICINE

Ethical Aspects of Research at the European Level

I appreciate the kind invitation from professors María Vidal and Brian Worsford to participate in this roundtable on **Responsible research and innovation, ethics and ageing** and the confidence of the organisers, professors Ander Errasti and Elena Urdaneta, in giving me the opportunity to present my ideas in this area, ideas which have been shaped over 30 years of studying bioethics at the Borja Institute of Bioethics of Barcelona, completing the joint master's degree with the Autonomous University of Barcelona, taking part in workshops and European congresses and publishing various studies in the field as a professor of bioethics at my University of Lleida in conjunction with my position as the chair of surgery and surgical practice at the University Hospital Arnau de Vilanova in Lleida.

I commend the initiative of those who have created SIForAGE and the ethical issues that are part of your interests.

Ageing is a hot topic in research to which many resources are devoted - millions of dollars and euros. The aim is to find the “fountain of youth pill”, that is, the drug that prevents ageing, whether aesthetic or by curing and preventing diseases.

One of the most modern lines of research with a promising future is regenerative medicine. It seeks to discover treatments for diseases, prevent or slow ageing, repair damaged or diseased tissues and produce replacement organs and tissues.

I will try to respond to and create more questions about ageing research taking research in regenerative medicine as a paradigm of the practical application of research that can be done on healthy ageing. I will base my presentation on my recent talk in September 2014 at a workshop held in Poblet at the Integrated Cognition Institute (ICI): A New Vision for Promoting Humanity.

DESCRIPTION OF REGENERATIVE MEDICINE:

Regenerative medicine seeks to restore or replace lost cellular functions either by drugs to rejuvenate adult stem cell populations and stop ageing or by replacing lost cells with other cells of the patient which have been manipulated, reprogrammed and transdifferentiated in a lab to later be transplanted. It also researches the possibility of producing entire organs and tissues in a laboratory using three-dimensional scaffolds repopulated from various cell types. The vast majority of cell therapy is currently conducted with blood stem cells. Regenerative medicine has excellent future potential to restore damaged organs and tissues and dysfunctional or dead cells. It works by creating new cells, tissues or even organs that can replace the diseased ones, that is, replacement organs. This is all still experimental today, although some applications have already entered the **clinical trial** phase while others are already on the market.

Cell therapy, genetic engineering and tissue engineering are the three fields of regenerative medicine. It is hoped that by 2020, this medicine will be widely used in the clinic and lead to improvements in the injured, sick and elderly and in sports injuries and war wounds.

ETHICS AND BIOETHICS

All scientific progress, and even more so if it alters nature and more specifically human nature, creates ethical dilemmas that must be addressed to find reasonable proposals. Constant advances in science and technology raise the issue of “not everything that can be done should be done”, although there is also the belief that if man has a technology and the power to use it to his advantage, he will do so no matter how against the law or harmful it may be.

Ethics is the part of philosophy that deals with finding the rational basis of human behaviour, of morals (like the philosophy of science deals with the nature of science). It is the study of the customs and values that shape human behaviour. Ethics, as a philosophical reflection, is directed at the phenomenon of morality, which has always been an unavoidable part of people's lives.

The words moral and ethics are not the same, but they are interrelated. Moral reflection belongs to the world of life, and ethical reflection is identified with the knowledge of experts, like philosophy; hence, Aranguren calls ethics “thought moral”. At the same time, in the context of philosophical thought as a whole, ethics is part of the so-called practical philosophy sphere, since its task is to guide behaviour, while theoretical philosophy is not necessarily tied to action. This all stems from Greek philosophy.

Bioethics is a discipline that studies human behaviour in relation to life sciences and health; it is a part of ethics. I will address the bioethical aspects of regenerative medicine: the dilemmas, the potential problems to be solved, the dangers to overcome, its advantages for improving the life and quality of human beings and current and future societies, etc.





ANTHROPOLOGICAL AND ETHICAL BASIS

A person is a unique, indivisible being who has dignity for the mere fact of existing as a human being and who, as Kant says, is never a means, but rather an end in himself. No one person is “worthier” than another, regardless of whether she is a prime minister, a multimillionaire, a schizophrenic, a drug addict, a thief or an immigrant. This vision must not be lost. People, all of us, give meaning to our lives; we are not like bees in a hive or ants in a colony. That is why the culture of our country and of Europe is against the death penalty for the antisocial murderer; he must be isolated to prevent him from hurting again, but not eliminated; we must even try to rehabilitate him as a person belonging to our human species.

The universal human rights declaration reiterates this aspect of collective responsibility towards human beings and our equal dignity, and the great religious traditions go even further, like Jesus, who calls all people his brothers and sisters.

Our intelligence allows us to “dominate the Earth”, but not only with logical-mathematical intelligence; we must combine all the intelligences, and currently we could use the description by Gardner (1) in his theory on multiple intelligences (logical-mathematical, linguistic-verbal, spatial, musical, bodily-kinaesthetic, naturalistic, interpersonal or emotional [as popularised by Goleman] and intrapersonal or spiritual [according to Emmon]).

Emotional intelligence has been considered essential for some years now, and lately, particularly since 2000, spiritual intelligence is finding its place. We must then work on all of them, especially considering that experience shows us that people with a smaller degree of logical intelligence and a more evolved emotional intelligence that have given meaning to their lives have a more successful, happier existence. The meaning of our lives is what will give us happiness or take it away from us. Moreover, the lack of emotional and spiritual intelligences, with the predominance of logical-mathematical intelligence, has resulted and is resulting in great human disasters: wars, genocide, etc.

As forward-thinking beings capable of altering our natural evolution, we are concerned about tomorrow, we project it on today and we also remember yesterday. This means that we have questions about death. Do we disappear entirely? No relative or acquaintance has come back to explain if there's something afterward.

Therefore, we want to live longer and better, healthier. We use our intelligence to dominate nature, to study and treat diseases, to alter the environment to make it more hospitable and comfortable, more pleasant and cosier. All this is very good, because it allows us to live better and to live healthy longer. But we must be wary of the illusions that can trap us, of the deceptions we end up believing. Since "everything that is alive dies", the condition to die is to "be alive". The regeneration of the species means that we must make way for new, younger generations and the older generations must go. Generosity is needed so as not to waste and not to leave our descendents with an unliveable ecosystem that is worse than the one left to us. Here lies one of the bioethical problems of the new approaches in biomedical research that we will address.

There are **four** universally accepted **principles** in bioethics, which are: 1) Nonmaleficence – avoid causing harm; 2) Beneficence – do good; 3) Justice – don't discriminate, treat with equality; 4) Autonomy – show respect for people. There are other principles that are not as universal as in Europe that are accepted: 5) Solidarity – help those in need; 6) Prioritise the most vulnerable. When presenting the ethical aspects of regenerative medicine, I will bear these principles in mind as a reference whenever appropriate.

Overall there is a controversy among some scientists who demand total freedom to research whatever they want and they moreover believe that society should give them all the money they need to do so, and they claim that bioethics inhibits them, which they accuse of trying to slow progress.

We mustn't confuse "science" with "scientist". Science in and of itself is neutral; it is a tool without morals. But scientists are never neutral. They are people like anyone else who have their (legitimate) interest to earn money, to create a high profile for themselves, to earn and move up positions at their labs and workplaces, to build their curriculum, etc. We must remember that capitalism follows the laws of the market, and scientists are not exempt from these laws.

Bioethics by definition is a trans-professional interdisciplinary discipline. Progress in bioethical research is made with the contribution of a range of knowledge. It has gained paramount importance especially for research following the discovery of attacks on human dignity by researchers using human beings as a medium, causing suffering and death. Hence the need to regulate research, which began with the Nuremberg Code after World War II, the Declaration of Helsinki in 1962 and in the US the Belmont Report in 1978 (2), the foundation of modern bioethics principles, which in essence say that all research should have the appropriately informed consent of the subject of the investigation, for the subject there should be a favourable risk/benefit ratio, and certain particularly weak groups should be especially protected, such as children, the mentally ill, prisoners, etc.


BIOETHICAL CHALLENGES OF REGENERATIVE MEDICINE

Having briefly discussed the general principles of bioethics and of the ethics of research and the justification for regulating research in defence of people and society, I will now describe some of the bioethical challenges and problems of research in regenerative medicine:

1. Objectification of human beings:

We can, following Awaya (3), start by becoming aware that with regenerative medicine we are dividing human beings in parts, we are objectifying them, thus creating different bioethical problems by treating the whole as parts. The danger is to forget the meaning, the human being as a whole, that the entire body is a unit.

By subdividing the study of the body into many specialities, we are able to better and more efficiently treat its diseases; it is precisely this which has caused medicine to advance. This good aspect, like everything, has “side effects”. The problem medicine has today is forgetting about the person as a whole, the holistic view of human beings. The family doctor, the internist and the general surgeon have a very important role: they must direct the actions of super-specialists, or these specialists can end up doing more harm than good.



This “componentisation” or treating the human body as parts and the exaltation of the vision of these parts may be the initial stage in considering the human body to be “a set of components” before moving on to its commodification. The commodification of the human body follows four steps: objectification – being treated as a material object (first stage); componentisation – human body as a set of components (second stage); resourcialization – being treated as a resource (third stage); and commodification (fourth stage).

Transplant medicine and the development of artificial organs facilitates the treatment of organs and tissues as parts, and regenerative medicine plays a role in advancing the componentisation of the human body and promoting its view as parts. This componentisation of the human body is considered a challenge to the traditional view of the human body and the abstract value of “human dignity”, or being treated as resources and being commodified.

The danger in the near future is that tissues, organs and human bodies themselves will be perceived as available tools and “consumables” like syringes, contact lenses, etc. We must take this new bioethical challenge into account. As I will address later in the challenge of justice, medical attention and healthcare are not commodities. As noted by American bioethicist Edmund Pellegrino (4), considering health to be a commodity is detrimental to the ethics of patient care. Health is a human asset that a good society has the obligation to protect from market ethics.

Following this consideration, new technologies make it increasingly more possible to implant functional “prosthesis”, chips and elements in the human body that supplement defects in our organs and tissues or give us new capabilities that the human body itself does not have: “bionic” men and women are becoming a reality.

Another area of research being conducted is the alteration of cells and tissues to provide the human body with more capabilities: genetically manipulate it, thus creating new cells that have potentialities that their progenitors do not. It is a new way of doping, of creating stronger athletes to win the Olympics, by giving them animal gene extracts that give them skills, such as to high jump with flea genes, to run faster, etc.

2. Different sources of stem cells for regenerative medicine

In 2000, Francesc Abel (5) published an article about regenerative medicine titled *Human embryo and regenerative medicine: wonder of wonders*.

He reminds us that an embryo resulting from the union of a sperm and an egg will become a human being who, thanks to the uniqueness of his brain, will one day be conscious and able to think, communicate with words, project the future and know that one day he will die. A body's cells are renewed throughout life, constantly being replaced by proliferation, differentiation and genetically programmed cell death or apoptosis.

Abel said then that humanity in the year 2000 was still not aware of the greatest discovery: the ability to generate tissues and organs in a laboratory due to the potential of human embryonic cells to divide and differentiate. He highlights the discovery made by Vescovi in 1999 of the plasticity of adult stem cells, of their multipotentiality, with the ability to become certain specialised cells and tissues, thus becoming pluripotent cells (iPS), like embryonic stem cells (not the totipotentiality of the first eight or 16 cells of the embryo, which can make a complete individual). They can thus also transform into any other, opening up a new avenue of research that obviates the use of human embryos and the (actual or potential) ethical and legal problems of their personhood and exploitation.

Sources of stem cells grown in a laboratory are:

- Surplus embryos from in vitro fertilisation (IVF) or even created for research
- Germ cells from aborted fetuses
- Embryos cloned by nuclear transfer from an adult cell or an enucleated egg
- Reprogrammed adult cells
- Bone marrow cells
- Umbilical cord cells

According to Abel, from the point of view of ethics, there is no substantial difference between an implanted embryo and a “surplus” embryo and they should be equally respected. Those resulting from induced abortions also have ethical problems in how they are obtained. Those obtained by nuclear transfer, not for reproduction, cannot always be considered human embryos.

There are, however, no ethical problems with reprogrammed adult cells, or those obtained from bone marrow, as this is donor solidarity. There is also no problem with umbilical cord cells.

The ontological and biological reality is that a human being begins with fertilisation and therefore the embryo already has dignity.

I do not want to go into details on this aspect of the dignity and personality and inviolability of the human embryo: From when can a person be considered an individual and hence to have the same dignity as all adult human beings and until when does he or she have a special status as a potential generator of a person but has not yet reached the status of individual, although still requiring respect and consideration and a higher and different status than any other human tissue?

Although it is easier today to programme embryonic stem cells in a laboratory, it is very difficult to stop them from reproducing; hence, implanting them causes tumours, which is why their use in a clinical setting has had bad outcomes and is currently very slow. By contrast, it is more difficult to obtain stem cells of certain tissues from reprogrammed adult stem cells, but it is currently being achieved in the laboratory more and more easily, and these cells do not have such a pronounced problem when it comes to stopping or controlling their reproduction, so there is not as much danger of them becoming tumour cells. This aspect is providing impetus to research with adult stem cells.

Research is also being conducted on the bioethical, anthropological and human dignity related aspects of this entire area of research. Religions give their opinions, as do philosophy and other disciplines of human sciences, which has enriched the trans-professional aspect of bioethics; however, it is a mistake when one of them attempts to place constraints by encroaching upon the field of the other, where it does not belong. Each one of them should preserve its independence, with reciprocity, interactivity and distinctive character, and in this way help the other as a different dimension of a common human culture. Bioethics must be faithful to scientific principles or it will not properly exercise its function of seeking out the truth.



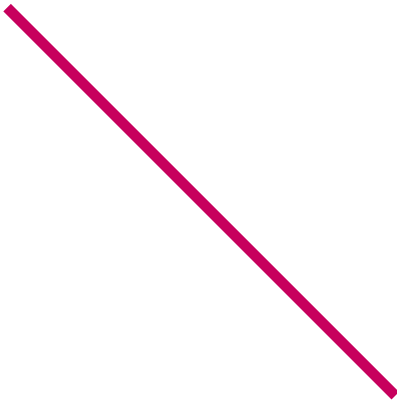
3. Ethical aspects of justice

It should be noted that all biomedical research requires enormous financial resources to make it possible. Obtaining and necessarily prioritising the allocation of limited resources is a very important aspect to address in relation to the principle of justice. Inexpensive discoveries, even those made by a single person, like that of Ramón y Cajal in the late 19th century, are history. Research today is done in teams with very expensive materials. Who obtains resources and from where?

i. If they are from public sources, then we must ask how they are prioritised: Which need of the population is most pressing? Where should resources be invested first? In the world: What is most urgent and necessary? To devote the resources to treat the thousands of children and young people who die every day in the Third World from diseases that have been eradicated in our First World or to extend the lives of people in our First World? Or should we devote resources to creating a fair world economic system? And in the First World: What is more necessary? To make it so couples are not sterile or to cure cancer, for example? Public resources do not reach everything; it is necessary to prioritise.

ii. And if they are from private sources: Should they be regulated so they don't contaminate and cause health and social problems for the rest of society? Can everything be freely researched if someone pays for it? Is everything patentable? Can you make money from living cells and tissues?

This raises another issue. The matter of the ethical distribution of limited resources in health and in research is very extensive to be covered here, which is why it is only touched upon.



4. Patents for tissues obtained: Profit making with human tissues and cells

Human tissues cannot be patented. The human genome is not patentable; it is ethical and common genetic heritage of mankind, as noted by Federico Mayor Zaragoza when he was Director-General of UNESCO. Only the resulting drug is patentable, the invention itself; if not, no one would investigate and we would not have new drugs that cure diseases, since it would not be profitable to do so and public systems do not have enough resources (in the current global economic system, which is terrible due to the high level of mortality that it causes in much of humanity) to do so.

Regenerated tissues are already beginning to be sold commercially, such as cartilage obtained from stem cells in which a lot of resources are being invested, both private – to make money, of course – and public, in hopes that large benefits will be obtained by 2020.

Given the crisis of the welfare state and the economic crisis we are suffering, which appears to be a cyclical change and not only a passing crisis from which we will recover and be better off than before, will public healthcare systems be able to cover the costs of these new and very expensive “medicines”? Or will citizens with resources have to pay or co-pay for them? In that case, is it necessary to keep prioritising public spending on this research, the results of which will be available to just a few? Do we need to set down prior “rules of the game” in order to prevent social discrimination and to prevent the fact that, with the money of everyone, especially that of those who pay taxes (and who know that precisely the richest are who are best at avoiding doing so), it is being made possible to extend life and improve the quality of it by slowing the ageing of tissues for only a small social stratum of the rich?

I think these ethical aspects should be anticipated and addressed before things are taken for granted. An example is organ transplants (kidney, liver, lung, etc.), which are regulated enough to be sufficiently equitable, although not without problems, particularly recently, such as the buying of organs from poor people to be transplanted even in the formal healthcare system. A question that arises is: if a translated organ fails and it is then necessary to prioritise the patient who bought the first organ and now needs an emergency organ from the public system and therefore passes before others, won't we be violating equity and social justice?



5. Genetic manipulation of living tissue

All genetic manipulation of living tissues has significant ethical, social and environmental implications and is a potential danger for future generations.

i. The altering of plant genome, that is GM foods, is creating real battles, many of which are ideological and without scientific basis but which highlight society's fear of mankind's artificial manipulation of nature and its possible objectification and self-serving use and the loss of people's freedom and the creation of problems for the ecosystem.

ii. You would think that people would be more concerned about the genetic manipulation of animals, an important stepping stone in evolution in relation to plants. However, from what we can see, there is not too much social reluctance when it comes to the day-to-day manipulation of transgenic mice. They even sell genetically programmed pets on demand to people with the money and the whim and fancy to order them. Again, it may be that the manipulation of animals used as food for humans is of greater concern socially.

iii. To the contrary, the genetic manipulation of human tissue, starting with the human embryo itself, seems to not be of concern to people who are so sensitive to plant manipulation and they tend to think that warnings by retrograde religions go against the evolution of science. The same thing happens with the manipulation of genetic material and human cells in a laboratory. There must be special care and regulation so as not to cause true problems for future generations. There are potential dangers that must be put on the table and taken into account. As I stated earlier, not everything that can be done thanks to the constant progress of information technologies and engineering should be done.

iv. Obtaining tissues from iPS cells to treat heart disease, for skin grafts for severe burns or chronic wounds, to regenerate cartilage, to treat Parkinson's, etc. should not pose ethical problems. Other indications of less vital necessity should, on the other hand, be questioned: for aesthetics, to choose the characteristics of a child, etc.

6. Using siblings to heal the sick

This aspect of regenerative medicine creates significant bioethical challenges that can be overcome. Conceiving and bearing a child fertilised in a laboratory with cells from his/her sick sibling to later be used as a tissue donor clearly falls into the category of using human beings as a means and not an end. Regardless of whether it is only the creation of the embryo to later be destroyed or whether the embryo is implanted and a child is born to then use his or her tissues like bone marrow to try to cure or alleviate the older sibling without the risk of tissue rejection since they are fully histocompatible. It is used to treat certain types of leukaemia, bubble children, etc. With the added social and emotional pressure which makes it more difficult to take decisions.

The problem in this case is not only about the nature of the embryo, but also about the objectification and use of the newborn as a mere means. A book made into a film addresses this issue well.



7. Extending human life and the effect on future generations

Should biomedical research and specifically regenerative medicine be geared toward making humans live longer and longer? What are the advantages? Are we psychologically, spiritually and ecologically prepared for it? What will happen with the overpopulation of the earth? And with environmental and economic sustainability, pension payments, etc.? Should we have fewer children in order to live longer ourselves so that we do not use up nature's resources?

An aspect to bear in mind is the purpose of this research and of these new treatments. Extending human life for the mere fact of doing so does not automatically entail improved health as a whole, taking into account that health is "a way to live independently, supportively and joyfully" as described in 1976 at the 10th Congress of Catalan-speaking Doctors and Biologists held in Perpignan. Failure to consider the whole interdisciplinary study of the person could result in more people living longer in a dull, unhappy, meaningless and unsustainable way, while also causing problems for young people, for the new generations.

If regenerative medicine is used to extend our existence longer and longer (today it is accepted that our biological clock allows us to reach 120 years of age), maybe we are not doing things right. If we use it to "give life to the years" to be healthier until the end, then I think we are doing things well. We should not hide death or consider it our enemy; it is part of life, its final stage. Western society is very old in age and uses many more resources than cannot be replenished. The false hope for immortal life on earth is causing misery and unhappiness and increasing suicides caused by not understanding, by not being prepared for unpleasant events, for mishaps, for the inevitable suffering in our life or in that of those we know and love.

The issues raised in this workshop are very appropriate and necessary. I tried to respond to them by applying a current, promising area of research that will greatly influence ageing, research in regenerative medicine.

I think I have given sufficient arguments to show that ethics should influence decisions about what is researched, how we research and why we research. In pursuit of the common good, we should address issues in an interdisciplinary manner and not leave a single discipline or science exclusively to its particular interests, which are legitimate but partial and can severely harm humans and their dignity, society in general and the ecosystem.

Research and innovation in healthy ageing should have this primary purpose, not the mere extension of life with its briefly presented negative effects on future society and individuals themselves. Scientists and researchers have a great responsibility and cannot hide behind the argument “I research what they pay me to research”, which is similar to the “due obedience” of the military which has done so much damage to society. All research must be responsible and directed at the common good, whether it is paid by a private company or with public funds. Using democratic mechanisms, society should approve or prohibit –and then provide the means to pursue and put an end to– research it sees as harmful to most people or to future generations and that only benefits a few who become rich and benefit from its results at the expense of harming others.

Ageing itself should not be considered a disease but as something natural. The problem is unhealthy ageing. Healthy ageing is natural, and filling life, giving it meaning, enhancing the happiness of the elderly is a task of many disciplines and various approaches, not only the field of science. A rational observation of religion helps in doing so. Unhealthy ageing can easily become a social disease in the First World where increasingly more people live longer and longer. Only bad habits (such as a poor diet) can stop the continued increase in life expectancy, which would increase the disease of society.



FINAL CONSIDERATIONS

Science and medicine make us live longer but they don't give our lives meaning or resolve the problem of suffering. There are “existential” diseases. Health should not be an element of consumption. We should have a holistic view of human beings.

Regulation of regenerative medicine is needed to direct it at the common good and not at the good of just a few. The dignity and sanctity of all humans and the common good must be guaranteed. Not everything that is possible to do should be done or is good to do.

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Ética de la Medicina Regenerativa.

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Acronyms & abbreviations

| Item | Description |
|-------------|---|
| CARINNA | Carinna Agence Pour La Recherche Et L'Innovation En Champagne-Ardenne |
| COMMTORINO | Citta di Torino |
| EURAG | Eurag Bund fuer die aeltere Generation Europas |
| GMK | Gmina Miejska Kraków |
| ISCTE | Instituto Universitario De Lisboa |
| UPPA | Université de Pau et des pays de l'Adour |
| WP | Work Package |
| BCC | Basque Culinary Center |
| UFSD | University of Sheffield |
| INVESTORNET | InvestorNet Gate2Growth Aps |
| UB | Universitat de Barcelona |

