Social aspects

The social aspects of the life sciences in 2020

IX Social aspects

A. Introduction

In recent decades, science and technology have had an increasing impact on society. This impact is beneficial when you think of increased health, increased mobility, increased safety (from natural disasters, for example). However, science and technology also produce new risks and vulnerabilities; examples include the toxicity of new chemicals, risks of large technical system failure or ecological damage. New scientific and technological developments therefore often cause public reactions: positive hype, negative fear or debate. Examples range from food additives to GM food and the radiation risks of mobile phones.

Scientific and technical developments are increasingly (though not always) accompanied by public reaction or debate. The virtual ban on GM foods is often cited to illustrate the damage that can be done by not taking public worries seriously enough. Current investments in public dialogue on nanotechnologies show how the Dutch government is trying to do better. The case of the radiation risks of mobile phone masts is an example of a technological development that initially seemed good to society, but which later became cause for debate and even worries among public and experts. In these cases we see a clash between our evolving *knowledge society*, marked by exploiting the benefits of science and technology, and our *risk society*, marked by coping with the risks and side-effects of science and technology.[1]

Social science research is needed to better understand the interactions between science, technology and society; to chart the shifts in depicting our society positively as a knowledge society or negatively as a risk society; and to better deal with sudden changes in public appreciation from hype into fear or *vice versa*. Such social science research also helps design better interactions between a broad range of stakeholders, experts and members of the general public.

The key message of this chapter is that there can be no viable innovation without its acceptance in society: science and technology only function when they are well entrenched in society. And for such adequate embedding of innovations in society, research into the social aspects of specific scientific and technical developments is necessary. With the insights of that research, we then can proactively design adequate forms of dialogue, public debate and interactive forms of development. All these elements should be part of the core business of PPPs that try to move the life sciences into the 2020s.

This chapter thus presents three closely related messages:

1. **Research** into the social aspects of life sciences, also in 2020, is indispensable for a strong life sciences sector;
2. **Organized interactions** – participation, engagement, dialogue and education – with and between different stakeholders and civil society are necessary for a democratic and thereby sustainable development of the life sciences and technologies;
3. **Good governance** of social issues surrounding life sciences innovation requires the facilitation of checks and balances between different types of knowledge, discourses and views.

Together, these activities – research, interactions and good governance – are indispensable for the social entrenchment of life sciences innovations. Without such, innovations cannot be sustained.

“ **We need solid information and good education**

To me, it is beyond a doubt that public acceptance of life sciences innovations is crucial to whether such innovations will actually be used and produced. What we should avoid at all times are unrealistic promises and expectations and we should use solid information to rigorously refute Frankenstein stories that in no way relate to what is really happening in the life sciences. The benefits of life sciences innovations can be high, alleviating pain and suffering, for example, in seriously ill populations. But one mouse with an ear on its back seems to have more impact than 100 serious articles.

It cannot be repeated enough that scientists need to pay due attention to their communication with society. This includes communication with media, politicians and future teachers as these actively shape the different forms of knowledge and images that we find in society. And don’t forget the young generation!

Communication thus is not an additional task for the life sciences but should be an intrinsic part of it. Scientists have a responsibility to provide good information and to reflect on the social aspects of their work, even if this is complex and if it is uncertain what future results may yield.

The social sciences and humanities, in turn, should critically assess what are the issues at stake in life sciences innovations. They should enable good communication about these issues and allow for well-informed and inclusive discussions and debates. Innovations only are viable when they become embedded in society. In that sense, there is still an entire world to win over. ”

Erica Terpstra, Chair of the Dutch Olympic Committee (NOC*NSF) and former Chair of the Standing Committee on genomics in the Dutch Parliament

Photographer: Julia de Boer

Quote from Erica Terpstra

B. Social aspects of the life sciences

What are social aspects?

Over the past decades, attention for the *social aspects* of newly emerging and converging sciences and technologies – such as genomics, nanotechnology, biotechnology, bio-nanotechnology and other innovative technologies – has become an almost natural component of science and technology development.

What do we mean when we speak of *social aspects* of the life sciences? Asking this question to a random group of (life) scientists will generate an array of answers. Where one scientist will define it as a matter of public communication *(the public does not completely understand what we do)*, another will mainly refer to ethical concerns *(how far are we allowed to go in intervening in life?)*, or rather to legal, practical and/or organizational problems *(do participants in biobanks also have the right to obtain research results, and how can this be arranged?)*. These answers are all relevant, to be sure, but they also reveal that the social aspects of the life sciences are diverse and multifaceted.

Background of ELSI/ELSA research

The introduction of the term ELSI is historically tied to the Human Genome Project (HUGO). During his installation as director of HUGO, James Watson, who in 1953 together with Francis Crick elucidated the structure of DNA, rather unexpectedly announced that the ethical and social aspects of this research required special attention and that 3-5% of the National Institutes of Health budget would be spent on social issues involved.[2] Others followed the example of Watson, and the Human Genome Project invested generously in academic research into the social aspects of genetics and into educational projects that familiarized citizens with the pervasive presence of genetics in tomorrow's world.

Interestingly, as a concept ELSI (or ELSA, as is more common in Europe) is used more and more to refer to social study of innovative technology in general, rather than being limited exclusively to genetics or genomics research.[1,3,4]

Research into the social aspects of the life sciences is often called ELSA or ELSI research, which refers, respectively, to innovative technology's Ethical, Legal and Social Aspects or its Ethical, Legal and Social Impact. ELSA research is performed by social scientists (technology scholars, sociologists, psychologists, communication experts, etc.), philosophers (ethicists, theologians), political scientists and legal experts.

In this chapter, we will systematically use "ELSA" as shorthand for scientific study into the ethical, legal *and* social issues and the interrelated activities aimed at education, public debate and dialogue, and interactions between stakeholders and life scientists. ELSA thus includes both analyses and critical reflection (what is the issue, what is at stake) and activities to discuss and interact about issues with different parties.

ELSA typically includes:

- The identification of (ethical, legal and social) issues;
- Interpretation and analyses of these issues;
- Organized interaction and dialogue with stakeholders (including publics);
- Interaction between policy, politics and professional practices;
- Development of new forms to organize the governance of ELSA issues;
- Evaluation of the design and development of the governance of ELSA issues.

While this list may suggest there is a certain order to the activities, this is not necessarily always the case. Interactions may lead to new research questions concerning a particular ethical, legal or social issue and vice versa.

In the next section we will further explore the aim, task and use of ELSA research. This section will continue with discussing what are the social issues concerning the life sciences.

The interrelationships of science, technology and society

The application of new knowledge and technology has not only made our life more enjoyable, efficient, healthy or prosperous; it has also changed our habits and lifestyle, as well as our views and normative frames for judging the world. For instance, the development of the contraceptive pill has contributed to a new sexual morality; large-scale application of prenatal diagnostics has contributed to acceptance of abortion among certain groups; and the development of alternative sources of energy has raised our collective awareness of changes in climate and the environment.

Does technology automatically steer our society in particular directions, including the individuals who are part of it? Things are slightly more complicated than that, because society has a major influence on technology development as well. Research priorities are partly triggered by questions about social issues and are realized in a process in which various parties – such as governments, social organizations and advisory bodies – act as representative of particular public interests. In the public domain, debate and dialogue take place that in part shape science and technology development. In many cases, public debate even functions as a major catalyst: it causes particular developments in research either to *accelerate* or to *decelerate*. While examples of deceleration – such as nuclear energy, GMOs and the sinking of the Brent Spar for example – are mostly well known, acceleration is also common. Developments in forensics research are a case in point, as will be shown in the next paragraph. Importantly, a catalyst itself does not change in the chemical process; it remains unaltered. The metaphor, then, does not apply fully: the nature of a public debate is altered of course as soon as its content changes.

In recent years, calls for *tough policies* against crime and delinquency have increasingly become common in public debates. In this context, DNA study is often presented as irrevocable proof (even if this is not always true). Cases that receive a lot of public attention and about which there is great public outcry and concern – such as the murder of Marianne Vaatstra in a village in the province of Groningen, in which the initial suspect, an asylum seeker from a nearby refugee center, proved to be innocent – have contributed to social support for expansion of criminal investigation methods. As a result of this case, the Netherlands became the first country where it was *legally* possible to determine the appearance of perpetrators – hair color, eye color, origin – on the basis of DNA material.[5] Although the options for applying this method are *technically* still quite limited, its legal adoption has already stimulated more study of forensic techniques. Another example of accelerated development is given by Steve Epstein in Impure Science.[6] Epstein shows how in the 1990s, AIDS activists pushed for accelerated admission of AIDS medication in clinical trials, thus bringing about a change of regulation.

The abovementioned examples show how science and society mutually influence each other, or, as social scientists call it, *co-construct* each other: developments in science coincide with developments in society. This may imply that knowledge and technologies are developed less rapidly, for instance because their social consequences are unclear or because major parties in society reject a certain development (for the time being). But the reverse is also possible: in some cases, social parties and social developments in fact call for accelerated deployment of knowledge or technology. Both the pace and direction of innovation may need to be *fine tuned* in order to be in line with the social conditions, expectations and opportunities involved.

The concept of co-construction does not only provide an angle for *understanding* the dynamic relationship between science and society; co-construction of science and society may also be actively shaped to enable a better handling of knowledge and innovation. This process of *coordination* between science and society is geared not so much towards creating a social base or public support; rather, it is aimed primarily at creating alignment between specific social institutions, conditions and expectations, on the one hand, and new technological possibilities and promises on the other.

Social issues in 2020

How will the life sciences affect us in 2020? Science and technology increasingly are complex processes, incorporating both scientific and social trends. The transition towards a bio-based economy or poultry farming organized by genetic selection – to use two examples from this volume – requires a transformation of habits and lifestyle, the chain of production, and our attitudes towards energy, mobility and meat consumption. This raises a whole series of questions and it is unclear what will emerge as the main social issues. This has become less and less easy to foresee:

- It is characteristic of recent discussions that topics are complex in a scientific-technical sense. **Example:** *the convergence between biotechnology, nanotechnology, information technology and new technology based in cognitive sciences. This brings together expertise and knowledge from different paradigms and leads to new approaches and bodies of knowledge*
- Social issues increasingly are (connected to) technical and scientific issues. **Example:** *the issue of "ownership". This is connected to questions of open-source and intellectual property rights, biobanks and the use of bodily material, indigenous species and bio-piracy, the use of DNA in court cases and scientific publishing*
- In public discussions, one increasingly is looking for methods that avoid black-and-white contradictions and possible deadlocks. Undoubtedly this also leads to the clouding of political discussion and to results and choices that are not very transparent. **Example:** *the discussions on the widening of PIGD and the freezing of egg cells. These discussions are not just geared towards either an outspoken "pro" or "con", but rather towards the (prior) conditions and circumstances under which these developments would be acceptable*
- In a normative sense, there are multiple voices. It is hard to predict in advance which positions parties will take. On top of this, it is unclear what role religion will play in future issues and debates
- Social issues do not necessarily always affect the public directly. **Example:** *the discussion on breeders' rights and patent rights. This discussion is about access to genetic material and whether it impedes innovation, and this pertains to the business sector, government and universities alike*
- Scientific expertise does not always equal authority, since social issues cannot be reduced to techno-science. For one, scientists do not always agree with each other; nor do we expect them to agree with each other at all times. **Example:** *discussions on climate change or biofuels and the question of whether these are an effective source of alternative energy*. Differences in scientific insights increasingly have become publicly visible and as such have enriched many a debate. However, this trend also shows the uncertainty and diverse character associated with science and technology development

While it is difficult – if not impossible – to predict what the social issues will be in 2020, it is possible to say something about the *nature* of these issues. They will be complex, include multiple questions, address not just the general public (but also industry, scientists and governments), resist simple solutions and mobilize ad-hoc coalitions and spokespersons. As the example of ownership illustrates, issues are not necessary life sciences topics, but are typically issues that require knowledge and understanding of the life sciences. This is exactly what ELSA has to offer.

Dealing with social issues in a sensible way is crucial for the social entrenchment of life sciences technologies. ELSA thus does not aim to avoid issues or prevent them from emerging, but rather aims to allow the *right* issues to emerge, and to use this to improve the quality of innovations and their embedding in society.

C. The contribution of ELSA

ELSA research

The task of ELSA research is twofold. First, it aims to contribute to the theoretical development and understanding of the relationship between (life) sciences and society by asking fundamental questions about this relationship. Second, ELSA research aims to shape and facilitate the relationship between (life) science and society by organizing different forms of interactions and interventions in order to anticipate (emerging) social issues connected to scientific developments. These tasks relate to one another in a productive tension (between critical analyses and interactive design). ELSA research thus can be said to uncover the different and multiple meanings, expectations, forms of knowledge, discourses, opinions and interests related to science and technology development, and, if possible, to confront them with each other. The first part of this task focuses mainly on (fundamental) research; the second requires interaction and intervention with different parties. In the following, we will first explore what we mean by different and multifaceted expectations, framings and discourses and how to anticipate future impacts or effects of science and technology. In the paragraph that follows, we will discuss the interactive design of ELSA research.

Multifaceted developments considered more closely

The starting point of ELSA research is the multifaceted character of developments in the life sciences and how they are addressed. As we will show, the issues we are faced with, as well as the solutions offered by the life sciences, are more ambiguous than commonly represented – also by the authors of this book. This is hardly surprising. The life sciences and social sciences or humanities are different disciplines that have different tasks. We will return to this point later in this chapter, when we discuss the organization and governance of ELSA.

Developments in the life sciences, as described in this volume, will influence our life more and more. In 2020, the life sciences will provide a substantial contribution to major and urgent questions, problems and opportunities in the fields of health, the climate, energy, food distribution and the environment. This book sketches the contours of a world in which energy is no longer derived from fossil fuels, our food pattern will come with fewer animal proteins and be more tailored to our body's specific needs, and the health of an ageing population is monitored at regular intervals. In other contexts – advisory reports, corporate websites, brochures, presentations, documentaries, articles newspapers and weeklies – we find the same promises and we are told that the life sciences address the most pressing and urgent social issues.

There are few people who will deny that the climate, energy, food issues and health pose important future challenges and are therefore worthy of our attention. However, the issue of how these subjects ought to be addressed and which solutions or contributions are needed is much harder to answer. In many of these cases there is no consensus. Urgent social problems are linked to quite diverse solutions. Moreover, in this discussion, different figures, facts and data tend to be used as evidence. We illustrate this point with the example of the global food problem in the box: "The global food problem as an example of shared goals & multiple evidence and solutions".

The parties that we describe in the box – the Minister of Agriculture, Monsanto, plant researchers and NGOs such as Greenpeace – agree that the development of new agricultural knowledge and technologies cannot and should not be limited to national borders. The Netherlands is co-responsible for world food distribution. How this should be arranged by government, science, industry and social organizations is less evident, however.

For example, parties are fighting over whether GMOs offer the right solution and which risks or socio-economic effects

The global food problem as an example of shared goals & multiple evidence and solutions
In discussions about the global food problem it is usually assumed that in 2050 the world population will have climbed from 6.8 to 9 billion people. This growth perspective can be heard in many discussions about the life sciences, often represented by the same figures yet from a different angle.

Recently the Dutch Minister of Agriculture argued for a new evaluative frame for GMOs during a meeting in The Hague. It should focus not so much on the safety of GMOs, but on the question of whether and how GMOs may contribute to sustainable agriculture. A major element of sustainable agriculture, the Minister claimed, is its contribution to solving the global food problem. By making use of GMOs, acreage can be used more efficiently, the certainty of harvests can be raised and it becomes possible to use land – such as with saline or dry soils – where before crops did not grow. **To be able to feed all 9 billion mouths in the future, the Minister argued, a new evaluative frame for GMOs is necessary.**

Science and technology, including possibly GMOs, play a major role in the chapter on agricultural life sciences in this book. Here too arguments around efficient use, harvest certainty and new acreage come into play. However, its authors underscore the significance of investments in research, rather than a new evaluative frame. **To feed all 9 billion mouths in the future, according to the authors of the agricultural life sciences vision of this book, research is inevitable.**

In 1997, Monsanto decided to sell its chemical division and focus exclusively on the life sciences. The then director Shapiro explained this step as follows: “We create a new kind of company that concentrates on meeting the worldwide need for food and health” (cited from de Vriend and Schenkelaar, p. 25).[7] In recent discussions on the question of whether patent law would annul breeders’ rights through a backdoor, a situation from which large companies seem to benefit for the time being, Monsanto stresses that it has to earn back returns on its investments through patents. **Only in this way, according to the spokespersons of Monsanto and other large companies, it will be possible in 2050 to feed 9 billion mouths.**

NGOs such as Greenpeace and Solidaridad are probably no less concerned about the world food problem than Verburg or the scientists at Monsanto. However, in their plea GMOs are not automatically the solution to the global food problem. “Food security will not be achieved by technical fixes, like genetic engineering (GE). People who need to eat need access to land on which to grow food or money with which to buy food. Technological ‘solutions’ like GE mask the real social, political, economic and environmental problems responsible for hunger” (www.greenpeace.nl). Poverty, the lack of acreage for poor farmers, unfair trade regimes and disproportionate attention for industrial agriculture are much more important causes. **Small-scale agriculture and attention for these problems contribute to the possibility in 2050 of feeding 9 billion mouths.**

are involved. Moreover, they use the food distribution issue to argue for other things: a new evaluative frame (the Minister), patent rights (Monsanto), research funds (scientists), biological agriculture and assistance to small farmers in developing countries (NGOs).

When we look at the applications of the life sciences, we also find profound differences in how these are framed and valued. Life sciences innovations may lead to pressing questions about their use and value. Which innovation should be applied for what purpose? It is impossible in our pluralist society to give a single answer to this question. It will be no surprise that here, too, we are dealing with a wide array of opinions, views and perspectives. These partly involve ethical questions. For instance, if one party considers the use of embryos for stem cell research a chance to cure people who suffer from serious, untreatable disorders such as Parkinson's, others will dismiss such a proposal as an outright violation of the "right to life". Next to ethical or moral differences, there are also differences of interpretation that flow from a difference in focus or perspective. For example, biological meat production is regarded by many as an important contribution to sustainable animal husbandry; others stress that biological production requires more feed and is generally less efficient. Whether or not something involves a sustainable solution depends on the comparative basis involved (sustainable as relative to what?).

What should we conclude from all of this? Although the same notions, concepts and goals are frequently used, such as environmental problems, climate change, health benefits and sustainability, it is evident that they do not always have the same meaning. These terms and concepts are *seemingly* clear and unambiguous, but they actually disguise the pluralist meanings and stakes we encounter in everyday practices. Meanings, rather than being objective or neutral, are always moral and political.

INTERMEDIATE CONCLUSION The seemingly transparent concepts and goals used in discussions about the life sciences disguise the plurality of meanings involved. ELSA research aims to uncover this plurality. **!**

Anticipating impacts or effects of the life sciences and technologies

Science and technologies are not merely used to solve or address social issues and concerns; they contribute to the emergence of new questions, issues and problems. We are living, according to Ulrich Beck, in a "risk society".[8] The risks that pose a challenge to modern societies are no longer determined by fate – such as natural disasters like storms, droughts and floods – but rather originate in the application of manmade science and technologies. The paradox of today's world is that it is faced with "mega-dangers or hazards that are on the one hand created by society itself, but on the other are neither attributable nor accountable nor even manageable within society" (cited from Strydom, p. 59).[9] It is also true for the life sciences that the knowledge and techniques we deploy in the next ten or twenty years to solve social issues and problems also result in a number of unknown and unplanned consequences.

There is much speculation as to the future social, ethical and legal effects and impact of developments in the life sciences. At an *early* stage, ELSA researchers, but also novelists and the media, try to anticipate the unknown and unplanned consequences of science and technology development: who is affected by new developments, who benefits from them, but also who or what will suffer possible adverse effects or even harm? The objective of early anticipation of social consequences of developments that have not yet crystallized is to push developments in a socially desirable direction.[10,11,12] ELSA research, we may say, functions as an early warning, indicating what social issues may become relevant or contested in the future.

One way to address future consequences of life sciences developments is through “future images”. Through scenario studies, foresight exercises, risk analyses, Delphi-methods and real-time technology assessment, scientists – often together with stakeholders – try to reflect on technological futures. This goes beyond extrapolation of current developments and is actively aimed at desirable futures. Interesting examples can be found in the field of nanoscience. Also in the life sciences, as developments will become more complex and uncertain in terms of applications and effects, such exercises will be increasingly needed.

Promises and expectations, if broadly accepted and subscribed to, push the process of science and technology development into specific directions.[13] This is true both for the promises of life scientists as for the future images created by ELSA researchers. Promises and expectations thus guide future actions and therefore need to be relevant and somewhat realistic. However, sometimes promises are not realistic at all and this too may serve a purpose. This may be a warning, an attempt to frighten people, or an intervention to make developments go into a different direction. A critical analysis of promises, projections and expectations is part of the ELSA agenda. What do promises do? Can we assess the quality of a particular promise? Which promises does ELSA research produce? How do scientists themselves relate to specific promises?

Setting the agenda

Through the anticipation of unknown social consequences, ELSA aims to identify issues and problems that need to be addressed to improve the social entrenchment of the life sciences and technologies. ELSA scholars, from time to time, put issues on the agenda before others have done so and before these have become an issue in the public domain. But, unlike what life scientists sometimes suggest, ELSA is not capable of making an issue public if this is not supported or picked up by others. ELSA can only help put issues on the agenda.

When ELSA identifies problems that should be addressed – as in the case of nanotechnology[14,15,16,17] – this is something to heed. What are the risks associated with new technologies? Which social sensitivities, concerns and worries perhaps play a role at a later stage? Who is concerned about what issue? Where may we expect resistance or support? In short, the work of ELSA researchers establishes which problems, issues and questions may come into play in the future. Naming them provides *insight* into future issues and possible problems and enables their anticipation.

ELSA activities

We have shown that promises and statements around the developments of the life sciences are hardly neutral or unambiguous; rather, they imply a large number of assumptions, choices and perspectives. We have argued that one of the tasks of ELSA researchers is to reveal these differences and to confront, contrast or bring them into line with each other through interactions and interventions. The aim of these interactions is to help shape the social entrenchment of the life sciences. This, then, is done by organizing a confrontation between the different types of knowledge and discourses that are brought to bear on the risks and uncertainties concerning the life sciences. ELSA research, we might say, aims to facilitate the right “checks and balances”.

Facilitation of checks and balances

The concept of “checks and balances” originated in 18th century political theory and practice. Applied to political governance in constitutions of all democratic regimes the world over, it is still a vital method to keep single individuals or (interest) groups from becoming too powerful.

Organizing checks and balances is based on a combination of functional separation and sharing of powers. Usually, governance *powers are formally divided* between three branches or entities of government: the executive, the legislative and the judiciary. Equally important in this doctrine of *trias politica* are *mechanisms of formal and informal power sharing*. Essentially, each branch of government has some control over the actions of the other two branches. In this way, the separate branches are empowered to prevent actions by the other branches, but induced to share power at the same time.

Thus, the *checks* attribute to each power the right and actual possibility to monitor and evaluate the decisions and actions by the other branches. We encounter this idea in modern governance often as the transparency requirement; or, in legal terms, the right to be informed. The *balances* part confers on each branch or entity the resources, authority and powers to limit the resources, authority and powers of the others. Jointly, these checks and balances define a control mechanism that guards against abuse of power. For example, the executive (government, cabinet) has the right to propose policy or bills and direct their implementation; but the legislative (parliament and other representative bodies) has the right to approve, reject or amend such proposals, the right to give or withhold funding, and to formally evaluate modes and results of policy implementation; the judiciary may declare executive (and sometimes even parliamentary) decisions as unconstitutional or as contravening administrative laws and principles of good governance.

Applied to the field of the life sciences, ELSA research *facilitates* the right checks and balances between other players. ELSA research and other scholarly activities involve not just inquiry into the ethical, legal and social aspects of distinct innovations and technologies. Moreover, and *unique to the ELSA perspective*, it envisages and conceptualizes the entire governance of an innovation system. By critically examining the relative influences on this system of science, business and government and posting early warning signs on certain phenomena, events, trends and developments, the ELSA perspective contributes to and facilitates good governance of life sciences innovation by enabling the other players to achieve a proper set of checks and balances. Of course, as a *method of "empowering"*, ELSA research and scholarship can never achieve this alone; it clearly depends on dissemination and reception of its messages through fruitful boundary arrangements with the other more powerful and resource-rich players in the field – especially business and government. Yet, good governance is not just about powering and preventing abuse of power. It is also a matter of *creative puzzling*.

INTERMEDIATE CONCLUSION The unique contribution of ELSA research and scholarship is in the uncertain part of the good governance of innovation: its (early) warning signs provide creative confrontations between valuable perspectives on life sciences innovation that will increase these innovations' sustainability.

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The role of ELSA within the life sciences is facilitation of the proper *checks and balances*. Parties are thus actively involved in various ways. They are

- **informed** of developments in the life sciences;
- **consulted** on knowledge, views, fears and expectations;
- **mobilized** to participate in discussion, dialogue and decision-making on the application of new knowledge and technology.

Facilitation of the proper checks and balances offers no guarantee for the solution of problems or an effective tackling of issues. ELSA research stimulates the creative confrontation of different perspectives, for example in debate and dialogue, but it can only do so when others join in as well. Creative confrontations may concern particular segments of the public (such as patients, consumers, parents, citizens or students), stakeholders (industry, NGOs, citizens, professionals, retail), scientists (the life sciences as well as social sciences and humanities) as well as those from policy and politics (administrators, finance experts, legislators, decision makers or members of parliament). Diverse groups contribute variously to the articulation of a multiplicity of ideas, expectations, notions and goals around the life sciences. While we often make use of simplified distinctions, such as that of experts, policymakers and citizens, these categories in fact refer to a wide diversity of groups and individuals. In the following, we focus in particular on interactions with the public and with policy/politics.

Interactions with the public

The general public, ranging from citizens to workers in laboratories, plays a major role in the development of science and technology. People are confronted with the applications, and hence the risks, unplanned effects and benefits of life sciences developments. Furthermore, the general public in democratic societies is entitled to join in decisions on public matters. In the context of the life sciences, this means that citizens have indirect decision power (through elections) or direct decision power (as consumer, patient or citizen). The public forms an important check or counterbalance: “Expertise is constituted within institutions, and powerful institutions can perpetuate unjust and unfounded ways of looking at the world unless they are continually put before the gaze of laypersons who will declare when the emperor has no clothes” (cited from Jasanoff, p. 397-98).[18]

It is often argued that, to be able to join decisions on public matters, it is essential that citizens have access to information, (various forms of) knowledge and expertise. Both ELSA researchers and life scientists have an obligation to provide such information and, related to this, education and communication. Various different examples are available to achieve this, such as:

- Education at schools (competitions, websites, workshops, internships and site-visits);
- Training (young) scientists to communicate (even better) with various public about their field;
- Public meetings and discussions with scientific experts and other stakeholders;
- Entertainment, festivals and exhibitions;
- Films, books and documentaries.

The availability of information and education is a prerequisite for the public to understand and evaluate developments in the life sciences. However, providing information and education about life sciences developments is not a goal in itself. It aims to empower citizens to assess and counterbalance different forms of expertise. Experts and the knowledge and information that they provide – life scientists and ELSA researchers alike – have their own biases. “Public engagement is needed in order to test and contest the framing of the issues that experts are asked to resolve. Without such critical supervision, experts have often found themselves offering irrelevant advice on wrong or misguided questions” (cited from Jasanoff, p. 397-98).[18]

Public engagement or public participation exercises may take different forms at various levels. The key to public engagement is that the public is actively involved in some issue. This applies to more than just an exchange of ideas and points of view. In many cases it calls for the organization of genuine dialogue. The results may vary: organized interactions may contribute to the exploration of difference and the formulation of possible directions for solutions. Interactions may be aimed at a) shared study of issues; b) exploring differences in views and/or perspectives; or c) formulation of shared frames, rules, solutions or visions. In some cases (consensus conferences, stakeholder meetings) participants are explicitly asked to develop a shared point of view. In other cases the conclusions may well reflect the various input, but a single conclusion or consensus is not pursued.

More important than the actual organization of public engagement activities is the framing or the context of engagement activities. The facilitation of the right checks and balances primarily asks for an analysis of *who* participates, who determines the *agenda* and what is the *aim* of the event.

Framing the debate

Social issues concerning the life sciences may affect the public, industry, scientific experts or government regulators, to name just a few parties. How these issues are addressed and who is allowed to join the debate cannot be derived automatically from an issue itself. Who may join a debate about some issue and – perhaps even more importantly – who decides on its topics are part of the dynamic and debate around technological innovation. A case in point is the debate on Food and Genes *(Eten en Genen)* that took place in 2002. This debate, organized by the Terlouw Commission, was criticized by a coalition of the Dutch branch of Greenpeace and 14 other Dutch NGOs. In a press release they claimed that they very much welcomed public debate, but that it should be based on an open agenda. The debate's main goal was to clarify under which conditions the application of modern gene technology in food production would be acceptable to society. According to Greenpeace and the other NGOs, this was too limited a question: "The fundamental question of **whether** gene technology is desirable and necessary at all does not seem at issue. We are only allowed to talk about **how** it is to be applied" (cited from de Wilde et al, p. 66).[19] At a recent meeting in The Hague, organized by the Dutch Minister of Agriculture, a discussion erupted on the 2002 debate's agenda. In her opening speech, the Minister indicated that as far as she was concerned the question "do we want GMOs?" was no longer relevant. In feed, cotton and other products, she argued, so many GMOs are used already that there is simply no way back anymore (NRC Handelsblad, June 10, 2009). Reactions from the audience and also in the various workshops revealed that many people disagreed. Attempts to put this on the political agenda were to no avail, however.

The question of who or what sets the agenda for public debate is not just limited to the debate's topic. Part of this question is also which arguments in the debate are considered valid. Emotions, for example, tend to be pushed aside as unfounded, not objective (hence, subjective) and therefore "invalid".[20] Thus it is ignored that precisely emotions may have a major effect. The British minister who during the BSE crisis offered his daughter a hamburger in front of the TV cameras to prove that eating beef was not a risk has become legendary. It led to major public and even media distrust. What this incidence showed is that the public, in these cases, is always right. The public uses different forms of evidence to establish whether British beef is safe or not. It is the *effect* of this process that matters (to British industry and farmers for example). Emotions have a large influence on social perception, acceptance and therefore also the uptake of new developments.

Finally, the stakes of the debate are important as well: what, exactly, is the purpose of articulating views in the context of a debate? It should be clear from the start which interests are at issue. An example is the assignment of the recently established *Public Dialogue Nanotechnology Commission*. In its assignment letter to the Commission, the Dutch Minister of Economic Affairs writes that the Commission should make clear to the participants that they ought not to expect the government to "follow up on all outcomes". The Cabinet, the Minister points out, has the responsibility to weigh the issues on its own, even if it will also "deal very carefully with the outcomes of the public dialogue".[21] That the government does not follow up on all suggestions from citizens seems obvious. Conversely, the meaning of "dealing very carefully with" leaves ample room for interpretation or implementation.

INTERMEDIATE CONCLUSION To allow for the richest possible review of the risks, benefits and implications of new technologies, the following questions are important:

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- Who has the opportunity to join the discussion?
- Who has a say about the concerns addressed?
- Which arguments are considered to be valid? Which arguments are kept outside of the discussion (or should have to be kept outside of it)?
- What is the purpose of the discussion and thus what is at stake?

Policy interactions

A major critique of the American ELSI program of the 1990s is that it mainly generated academic output, but that the program has had little influence on policies. According to Michael Yesley, who for years was responsible for part of the ELSI program, it was used from the start "to avoid establishing an independent advisory commission, selecting topics of ethics research that will facilitate rather than challenge the advance of genetic technology, and spending ELSI funds on promotion in the guise of education" (cited from Yesley, p. 4).[22] The ELSI program, Yesley argues, was *uncommissioned* and it was also unclear who specifically was awaiting its results. It served as a pretext to be able to say that attention was given to the social aspects involved.

Others agree with Yesley that the ELSI program has had little impact.[2,18] However, the question is whether Yesley is right when he points to the "uncommissioned nature" as the main cause for the lack of impact of the ELSI research. Another possible cause for this shortcoming is that ELSA researchers have poorly succeeded, if at all, in linking up with decision makers.

Scientists and decision makers, according to Lomas,[23] often have a distorted image of each other and insufficiently recognize that both are part of an intricate but shared context. Implicitly, they confirm the image they have of each other: scientists deal with facts and truth, policymakers with values and power.[24,25] Scientists expect that decision making takes place in a specific setting and at a certain point in time. Likewise, decision makers expect from scientists that their results are ready available when they need them: "it is like two people completing a jig-saw puzzle, each with half the pieces but each working in a separate room" (cited from Lomas).[23] In practice, policy as well as research are pragmatic and context-bound. Both research and decision making are heterogeneous, complex and often take up much time.

More attention for what in the Netherlands we awkwardly refer to as "knowledge valorization" might increase the impact of ELSA research. An important aspect of the valorization of knowledge is early involvement of decision makers in both the overall process and the results of the research.[23,26] Experience with technology assessment (TA) underscores that this is no simple task. This experience "show(s) that just publishing the results of these quantitative and qualitative studies within academic journals will not lead to a big impact in the real world. To achieve that, the results need to be purposefully translated and communicated towards, for example, the policy arena or a wider public. Moreover, one needs to build personal connections with these different worlds to have an impact on these worlds" (cited from van Est).[4]

INTERMEDIATE CONCLUSION The relationship between scientists and policymakers cannot be shaped in an ad-hoc fashion. It requires intensive mutual exposure and interaction between scientists and decision makers. This exposure is needed for the actual use of research results in policy.

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D. Governance of ELSA research

Attention for the social aspects of innovative knowledge and technology is hardly new. This type of research has been performed since the 1970s from various angles, including bioethics, technology assessment (TA) and science and technology studies.[27] From the start of this century, universities, aside from doing fundamental research, have paid increasingly more attention to the *governance* of new, innovative and converging technologies and the question of how the expectations of the market, government, civil society and science can be aligned. This is what, in this chapter, we have called the facilitation of the right checks and balances.

The need for ELSA research and other scholarly activities that contribute to the good governance of new, innovative and converging technologies is not restricted to PPPs. These are only one place or setting where ELSA matters. While it can be argued that there are social issues that are perhaps pecifically relevant for PPPs, such as the analysis of bold promises to solve issues that worldwide are seen as global problems, these social issues, however, are not restricted to PPPs. The questions and issues that we have identified in this chapter are related to life sciences development and innovation in a broad sense. As we have shown, technology and society co-construct one another: technology, by implication, is *socio*-technology.

For technology to become embedded in society, both technical and social expertise are necessary. These are only partly separated domains. ELSA researchers have to be very knowledgeable about the technologies they study while life scientists, either through experience or interest, are knowledgeable about social issues. However, disciplines have different tasks. Scientists consider it their task to *develop* science and technology that contribute to the solutions of concrete social problems or issues. ELSA researchers and scholars also contribute to solving or coping with concrete social problems, but do so by questioning the (anticipated) *effects* of science and technology development. There is, then, a clear distribution of tasks between the life or natural sciences and the social sciences or humanities. Both bring different competencies, but have mutual interests and together their skills are complementary.[28] It is only together that these disciplines are able to improve the embedding of technological innovation.

Today, ELSA research of the life sciences is organized and funded in different ways, via single projects of individual research groups, small programs funded by NWO or the EU or sizable programs that are part of a PPP. ELSA research around genomics is, in a number of respects, the absolute priority. ELSA genomics is well funded, well coordinated, is visible in many contexts and it has led to a consolidated program. Within NGI, the social aspects of genomics are explored by the Centre for Society and Genomics (CSG) and the Genomics Centres of CMSB, Kluyver, CGC and CBSG. In the current round of subsidies for NGI (2008-2013), EUR 25 million have been earmarked for the social aspects of genomics. While other programs, such as the Leading Technology Institutes (TTIs), also pay attention to social aspects, they do so at a much smaller level and in a less coordinated fashion.

ELSA research of the life sciences requires coordination and a substantial investment. This will enable programs that consolidate different questions and approaches, are visible to life scientists, industry, politics and society and have the ability to have a substantial impact on the social entrenchment of the life sciences.

INTERMEDIATE CONCLUSION To make a genuine contribution to the life sciences, substantial research and public communication around the social aspects of the life sciences are necessary. Internationally, 3-5% of the life sciences' total budget is considered standard for ELSA.

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The need for a coordinated effort and a substantial budget does not necessarily imply that ELSA research should be organized in one single project or location. Rather, we advocate a pluralist approach. Characteristic of the way in which present and future societies deal with science and technology development is the existence of different forms of knowledge, norms, values, ideas and expectations. This is no less true for ELSA itself. ELSA research, the scholarly activities of ELSA and the institutions involved in this work are multifaceted: ELSA brings together different disciplines, views, approaches, experiences and interests. This pluralism is enriching and should not be reduced to a single type of organization. Different forms are needed:

1. Open calls

Open calls, such as the recently completed NWO program on "societal aspects of genomics", enable research that poses a range of questions and makes use of a variety of methods, approaches and themes. More importantly, open calls allow researchers to ask both fundamental questions and to use methods or approaches that are innovative, experimental and/or – theoretically or methodologically – "daring".

2. Commissioned programs

Commissioned programs are coordinated efforts characterized by producing focus and mass and providing a context in which specific questions can be addressed or where questions can be addressed in a specific way. With respect to PPPs, commissioned and coordinated programs can be either embedded in a PPP or be realized in independent programs with a critical distance from PPPs:

2.a Embedded programs

PPPs, as defined in this book, are collaborative projects in which partners from industry, government and universities work together on equal footing. The aim of PPPs, as we have seen, is to produce innovations that realize social and economic value. PPPs themselves have a responsibility to deal with the social aspects of their work. This may concern several things, such as the anticipation of and reflection on social issues and communication with the public, but also the public legitimating of PPPs. Since PPPs are set up with a majority of public funds, they are publically accountable for what they do. ELSA research may need to be embedded within PPPs as the place where mutual learning between ELSA research and the life sciences takes place.

2.b Independent programs

It is also important to acknowledge the critical function of ELSA research. Facilitating the proper checks and balances calls for a critical attitude with respect to, for example, the vested interests, the hegemony of scientific knowledge and the parties playing a role in creating innovations. If we take serious the assignment of ELSA research to address and confront the many different types of knowledge, promises and discourses brought to bear on the risks and uncertainties surrounding the introduction of life sciences, research should also be independent of PPPs. This does not eliminate the possibility of collaboration. However, it points to the necessity to have a part of ELSA research that is independently organized and funded. For this type of research, matching with industry is problematic, as the governance of ELSA issues in these settings requires critical and independent analyses of the types of knowledge, discourses, parties and institutions of *all* stakeholders, including those partners of PPPs.

CONCLUSION ELSA research and scholarly activities demand different modes of organization, both embedded in and independent of PPPs. In case of the latter, matching is not a feasible option. !

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