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viewpoint

What is ELSA genomics?

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The name Elsa might arouse various literary associations, from the female lead in Richard Wagner's (1813–1883) *Lohengrin*, to the wealthy socialite, Countess Elsa Schräder, in the musical *The Sound of Music*. This article, however, discusses a rather more recent personification of the name, ELSA as an acronym, which describes a particular field, or rather, a particular style of research that has emerged during the past two decades.

Some see ELSA as an 'artefact' of contemporary research funding strategies; a neologism coined for strategic reasons, but in need of a clear definition

Research into the ethical, legal and social aspects (ELSA) or issues (ELSI) of genetics, and later genomics, was originally developed in the context of the Human Genome Project (HGP) in the USA, from where it subsequently spread to Canada and Europe—it is important to emphasize the genealogy of ELSA genomics as a 'by-product' of the HGP. It was James Watson himself who, as the first Director of the HGP, decided that some of the project's budget should be devoted to studying the societal issues related to genetics research and its applications. At the press conference to announce his appointment as director, Watson suddenly and unexpectedly declared that the ethical and social implications of genome research warranted a special effort and should be funded directly by the US National Institutes of Health (Bethesda, MD, USA), which financed the larger part of the human genome sequencing effort (Cook-Deegan, 1994/1995). Watson argued that, in the face of unprecedented challenges presented by modern biological research, the 'contract' between science and society was bound to be revisited by the large-scale application of genomics research. Thus, in addition to discovering the structure of DNA together with Francis Crick, Watson can also be credited with 'inventing' ELSA and providing the impetus for what came to be called 'Elsification': the integration of societal research in large-scale techno-science programmes.

Here, we present ELSA genomics as a recent episode in the ongoing history of reflections on the societal impact of scientific and technological change. It raises the question of what this field or style of research has to offer, both to genomics research and to society. We consider some of the criticisms and scepticisms that have been articulated about ELSA genomics, and compare these to its achievements. Our objective is not only to describe and assess, but also to indicate possibilities for improvement by pointing out some viable options for strengthening the academic quality and societal robustness of ELSA genomics. In fact, we indicate several conditions that seem to us to be of pivotal importance for a sound methodological development. In short, what are the challenges that ELSA genomics faces, and what viable strategies can be used to meet these successfully?

During the past few years, the acronym ELSA has been making its appearance in an increasing number of calls for proposals, research programmes, reports and academic papers (Nelis *et al*, 2008; Radstake & Penders, 2008). Centres for ELSA research and funding programmes have been initiated, while references to ELSA research—or what might loosely be called the 'ELSA approach'—are found in descriptions of various research programmes and in the self-presentation of several research institutions. Some see ELSA as an 'artefact' of contemporary research funding strategies; a neologism coined for strategic reasons but in need of a clear definition. Others regard it to be something of a paradigm shift that is likely to have major consequences for the ways in which research into the societal dimensions of science and technology will be carried out. The greater part of the debate is still informal and, thus, largely unpublished.

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In essence, ELSA research addresses the relationship between the new and emerging techno-sciences and society, a relationship that is understood in terms of co-production (Jasanoff, 2005) or reflexive co-evolution (Rip, 2005). Although many ELSA practitioners share the idea of co-production—the idea that technological evolution is shaped by interaction between internal (technological) and external (societal) processes and constraints—there is neither a strict consensus over what constitutes an ELSA approach or an ELSA methodology, nor a common object of study. ELSA research addresses not only innovative and convergent technologies such as nanotechnology, biotechnology, and information and computer technologies, but also other emerging fields. One might say that there is a Wittgensteinian resemblance among the various initiatives that call themselves 'ELSA research': they

have overlapping similarities, but there is no feature that is necessarily common to all.

The fact that there are several answers to the question 'what is ELSA?', implies that any 'neutral' and 'empirical' description of ELSA's evolution will inevitably become entangled with the more normative or programmatic question of what ELSA should or could become. Here, we regard ELSA genomics as an emerging research practice, the methodological and epistemological profile of which is gradually becoming more discrete, although it still needs some clarification. It is an approach that tries to overcome some of the restrictions of previous research strategies, but it is also facing new challenges of its own.

Although we occasionally refer to developments in other countries, we focus on ELSA research in the Netherlands because it is with the Dutch research community and practice that we are most familiar (Zwart & Nelis, 2005). Furthermore, although we occasionally refer to the literature on ELSA genomics in academic journals and elsewhere, in order to add some context to our deliberations, this paper is not intended as a review article on ELSA methodology. Rather, it is a critical reflection 'from within'; an assessment of our own hands-on involvement—as Director and Scientific Director of the Centre for Society & Genomics (CSG; Nijmegen) in the Netherlands—in helping to shape ELSA genomics, primarily in our own country, but also in collaboration with international partners.

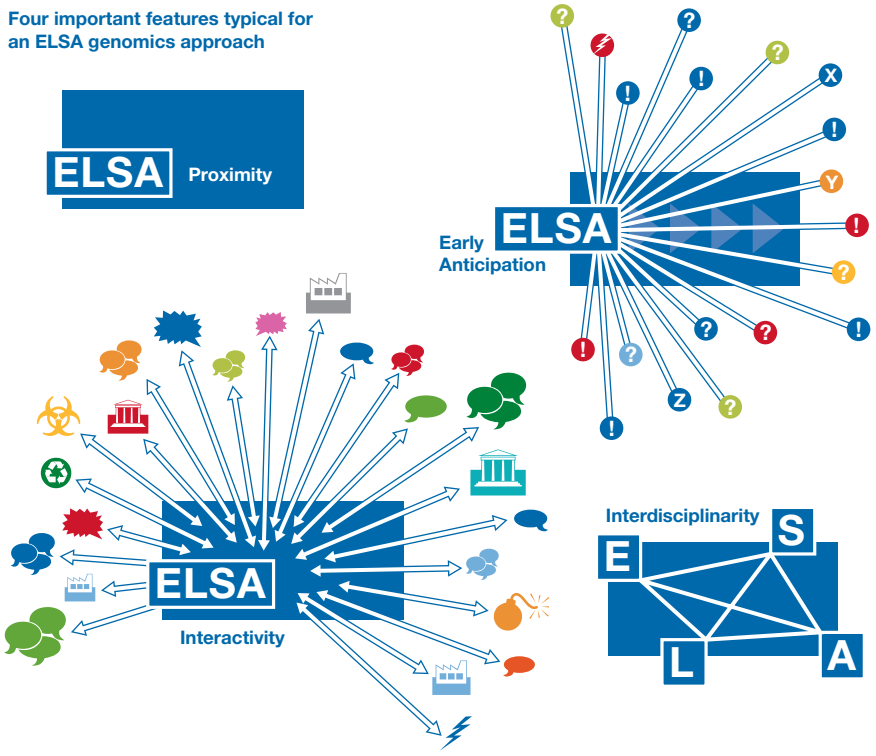

Fig 1 | ELSA genomics programmes can be diverse, but the 'family resemblances' are proximity, early anticipation, interaction and interdisciplinarity.

The aim of the ELSA programme initiated by Watson was to offer an interdisciplinary approach to the societal issues emerging as a result of genome sequencing and genetic testing. This programme was set up to help society anticipate and avoid the possible adverse consequences of advances in genetic technology (Yesley, 2008). Building on the human genome sequencing effort, several large-scale genomics research programmes have also been launched in other countries. In the contexts of such initiatives, major programmes for societal research and communication have been set up, sometimes in the form of centres and networks, such as the ESRC Genomics Network (EGN) in the UK and our own CSG in the Netherlands; sometimes as the result of programmatic calls for proposals issued by governmental funding agencies, which allowed research groups to submit proposals for such programmes. In Canada, a hybrid combination of both models—the genomics-related ethical, environmental, economic, legal and social issues (GE^{3}LS) programme—has been launched. Sometimes the research developed under these headings is an integral part of large-scale genomics efforts, so-called embedded research; on other occasions, it remains more independent. Nonetheless, one could argue that a certain level of embedding in large-scale science research programmes is a distinctive feature of a typical ELSA approach.

Several ELSA genomics programmes have also been initiated in Europe, with those of the UK and the Netherlands being the most developed (Nelis *et al*, 2008). In the UK, the EGN explicitly aims to assess the impact of genomics on society, whereas the Netherlands Genomics Initiative (NGI; The Hague, the Netherlands) defines ELSA research as an integrated part of its efforts to stimulate genomics research and the emergence of a genomics infrastructure in the Netherlands. The mission statement of NGI endorses a positive attitude towards genomics as fostering health and prosperity. This institutional positioning implies proximity to genomics research or to the life sciences in general, thus encouraging interaction with genomics researchers and research centres. It not only allows ELSA research to stay relatively well-informed and up-to-date, but also allows the development of an anticipatory orientation that can be seen as typical of ELSA projects: studying the possible societal impact of genomics in the near or distant future, and the ways in which future agendas of genomics research can or could be shaped by broader public and societal developments.

What links the various ELSA genomics programmes that we have discussed so far? What are the 'family resemblances'? Besides proximity, we argue that it is a combination of early anticipation, interaction and interdisciplinarity (Fig 1).

In 1902, the British author Herbert George Wells (1866–1946), argued in an article in *Nature* that we need reliable scholarly methods for exploring the future (Wells, 1902). Sophisticated methods have been developed for carefully analysing past events, whereas the exploration of the future has so far been left to novelists.

Owing to science, we are able to produce a fairly clear picture of what life must have been like in the swamps and forests of the Mesozoic age or in ancient Rome but, for some reason, we keep underestimating the possibilities to produce visions of the future with a similar degree of accuracy. Knowledge of the future is attainable, Wells argued, and well worth attaining, as the societal impact of the techno-sciences means that we cannot expect the future to be a continuation of the past. Rather, the past will be the raw material from which the future will be designed.

ELSA genomics aims to transcend the traditional dichotomy between 'desk' (or 'hands-off') and 'hands-on' research

In recent years, various strands of foresight research have been developed. ELSA genomics clearly has some of its roots in technology assessment (TA), which deals with the assessment of the future impact of technology on society. Often, this means that researchers investigate as-yet unknown futures and deal with what has become known as the 'Collingridge dilemma': although it is most effective to shape innovative technologies in a societally desirable direction at an early stage of their development, it is during this early stage of development that it is difficult to assess what the societal effects of a technology are or will be. In more advanced phases, however, societal effects might become clearer, but there is also less room for adaptation and change (Collingridge, 1980). Early anticipation not only helps to define both unwanted and desirable solutions for the future, but also asks for critical and reflexive anticipation.

Although early TA approaches were primarily a scientific method for expert policy analyses, over time it became clear that for TA to have an impact on policy- and decision-making, it needed more than profound scientific analyses. Rather, TA practitioners had to engage actively and interact with other groups such as scientists, professionals, publics and policy-makers (Van Est, 2010). The development of constructive technology assessment (CTA) is a direct result of this realization.

Similarly to CTA practitioners, those from science and technology studies (STS) and other scholars have criticized social science and ethical research for taking place too far downstream in the innovation process (Wilsdon & Willis, 2004). Rather than being postponed to the final implementation stages of the innovation process, critical reflection and interaction should move upstream to give rise to bench-side ethics as a counterpart to bedside ethics (Felt *et al*, 2009).

In fact, the rise of ELSA initiatives in Europe coincides with a tendency to enlarge and foster public engagement, which is particularly visible in northern European countries, but also in the EU-funded Science & Society programme that is part of Framework Programme VI. Within the emerging field of ELSA genomics, researchers intend to actively involve and engage societal stakeholders and various publics from the outset. Through interactive techniques such as focus groups or scenario workshops, the future societal risks and benefits are fleshed out in the form of collective foresight explorations.

In our own ELSA centre, we describe this interactive engagement in terms of 'agenda-building': the articulation of issues, publics and those responsible for dealing with these issues. Agenda building might include citizens, practitioners, policy-makers, non-governmental organizations or genomics researchers. The aim of agenda-building is to help shape policy-making through the early identification of social, legal and ethical issues. In addition, society *per se* might benefit from an interactive process to identify—together with experts—issues and arguments. This is valuable not only because it might lead to informed citizens, but also because such discussions, debate or dialogue might eventually help to shape the agenda of science and culture in general (Davies *et al*, 2009).

ELSA genomics aims to transcend the traditional dichotomy between 'desk' (or 'hands-off') and 'hands-on' research. Societal interaction is not something that can be set apart from societal research in a strict sense: it must be an integrated part of the research from the outset. This does not mean that the ELSA researchers are merely the organizers or mediators of debate; rather, they must regard interactive work as providing a test-bed for elaborating their emerging ideas.

Crucial to many ELSA initiatives is what Peter Stegmaier has called "doing society and genomics" (Stegmaier, 2009). In all the examples mentioned above, ELSA is more than merely an academic research effort. It strives not only to provide an academic understanding of the interaction between science and society, but also to improve it. Interaction, in other words, is often related to intervention.

A final important feature of ELSA research is that it brings together various academic research practices that, until recently, evolved more or less independently in research communities such as bioethics, philosophy of science, TA or STS. In the context of ELSA programmes, experts from these fields are encouraged to join forces to address the societal impacts that emerge from the large-scale development and use of genetics and genomics research. Each of these disciplines has developed different historical strengths with respect to studying the normative and societal issues of emerging techno-science.

Although studying research practices in great detail and from a relatively close distance is certainly a strength of STS research—or at least of particular branches of STS research, notably those devoted to laboratory ethnography—STS often refrains from raising and addressing, let alone 'solving', normative issues. The latter is more the trademark of bioethics, which emerged as a new discipline in the 1970s, whereby bioethicists treated medical professionals as their objects of study rather than their collaborators. Over the years this situation changed, as bioethicists and medical professionals came to work more closely, for example, on ethical committees and advisory boards. More recently, bioethics has been experiencing an 'empirical turn', by using both empirical data as well as broader societal issues in its analyses.

An often-heard concern is that ELSA and genomics are becoming too close, that ELSA genomics has become the 'handmaiden' of genomics

Ideally, bioethicists could profit from collaboration with STS experts, and their tools and experiences of empirical science research. However, bioethicists too often make use of social-science methods and repertoires without seeking collaboration with social scientists. Conversely, STS scholars could profit from the expertise

of bioethicists when it comes to assessing and addressing the normative dimension of new and emerging technologies. In practice, however, such a synthesis of apparently complementary fields proves to be rather problematic.

…one of the most daunting tasks of ELSA genomics research is to change the social framework in which genetics is cast

In summary, there are at least four important features typical of an ELSA genomics approach: proximity—that is, embeddedness in scientific programmes; early anticipation of issues, publics and those responsible for dealing with these issues; interactivity, to encourage stakeholders and publics to assume a more active role in co-designing research agendas; and interdisciplinarity, to bridge the boundaries between research communities such as bioethics and STS.

Although ELSA programmes have been praised for their good intentions, critical voices have questioned whether ELSA research has been or will be successful. In the case of the ELSA programme of the HGP, for example, some have asked whether the programme has had any policy relevance at all. Michael Yesley, who was responsible for the US Department of Energy's part of the ELSA programme, claims that it had little to no effect on policy-making. It was, in his view, installed purely to avoid the necessity of setting up a more critical and independent advisory board. According to Yesley, the relatively ineffective ELSA programme was used from the outset 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" (Yesley, 2008). In Europe and Canada, where ELSA was embraced at a later stage, similar discussions are now evolving. The question for ELSA practitioners to answer is how and in what way should these critiques—Yesley is not alone in his opinions—be addressed in the set-up and performance of ELSA programmes?

Funding agencies and research councils have developed their own methodologies and language to measure the impact of research and to assess large-scale scientific programmes. Concepts such as '(societal) valorization', 'dissemination' and 'impact indicators' have become a routine part of the repertoire of research funding agencies. This, no doubt, has had an effect on the institutions that perform large-scale ELSA programmes, and both the UK and the Netherlands are interesting examples. The EGN in the UK funds three centres where critical scientific research is being performed. The fourth centre—the policy forum in Edinburgh (UK)—was established to bring the results of the network into policy circles and into policy-making. The CSG also has an explicit assignment to organize and monitor the societal valorization of research results. We have translated this assignment into the ambition to incorporate interaction with one or more relevant stakeholders or publics in each project at an early stage, in order to collectively shape an agenda for future research or future uses of genomics.

The ambition to increase the policy relevance of ELSA research is not only a top-down formulated requirement. Within the field itself, the necessity to increase the policy impact of ELSA has been recognized. Interesting articles and books do not 'speak' for themselves; they need to be spoken for. 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 various worlds to have an impact. Academics will have to develop new networks with actors from various realms outside academia, exploring new and different routes of interaction and engagement (Rip, 2005). Convergence work, in other words, is what is desperately needed (Gannon, 2009; Stegmaier, 2009).

Another point of criticism concerns the proximity between ELSA researchers and their object of study. As we indicated earlier, ELSA programmes, whether for nanotechnology, biotechnology or genomics, are typically embedded in large research programmes. There are several good reasons for this proximity, but it also has several obvious risks and downsides. The expectation is that close interaction with the object of study—the scientists and their research—will allow the outcomes of ELSA genomics research to be more relevant for the genomics research community. At the same time, aspects of the research that might be troubling to other stakeholders might be identified and singled out for critical consideration more easily and at an earlier stage. This proximity also allows criticism to be more timely, consequential and precise; in other words, it can be framed as adding to the 'social robustness' of the research outcomes. 'Socially robust innovations' (Nowotny *et al*, 2001) are firmly embedded in existing socio-technical arrangements of governance and control, and there is little conflict and uncertainty.

However, proximity to science has also been criticized for fostering a pro-genomics bias (Huijer, 2006). An often-heard concern is that ELSA and genomics are becoming too close, that ELSA genomics has become the 'handmaiden' of genomics. This critique—whether of a perceived or actual problem in this regard—is relevant and should be taken seriously: there is a danger that ELSA research might fail to remain independent and critical of the promoters and developers of techno-science. Although ELSA genomics obviously strives to analyse questions that are relevant for genomics researchers, the ELSA experts can and should retain their intellectual autonomy when it comes to the manner in which these questions are framed and addressed. Countering this argument, one might also say that there is not enough proximity between the natural and social sciences or humanities. Modern technosciences such as nanotechnology or biotechnology bring together elements of the knowledge society and the risk society (Rip, 2005). This calls for a mutual exploration of issues, risks and problems by diverse fields.

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During the past ten years, the social sciences, humanities and natural sciences have changed. ELSA experts increasingly partner natural scientists and work closely together on research projects—a model that we promote in our own Centre. Often, this collaboration is part of a learning process, an experiment that aims to increase the social robustness of innovations. In the case of synthetic biology, for example, Paul Rabinow has argued that such collaboration requires more than goodwill: "At best, the scientists are willing to talk to us about [synthetic biology]; at worst, it evokes a lot of resistance. […] [T]he claim that synthetic biology needs new forms of collaboration is basically accepted […] [but] collaborations demand a change of habits, and these scientists, for whatever reasons […] resist that demand" (Lentzos *et al*, 2008).

Social and natural scientists also tend to learn mutually from one another through the respective literature. ELSA experts have become increasingly science-literate, reading *Science* and *Nature* as eagerly as the main authors from their own fields, whereas many genomics experts have learned to address societal issues explicitly. However, this does not mean that the ideal of proximity is really met. A genuine assessment of progress in this area would call for empirical research into several indicators: how often do genomics experts and ELSA experts publish together? How often and in what ways do both address similar—thus mutual—questions? To what extent do genomics journals pay attention to the ELSA of research and vice versa?

Is there a future for ELSA research? One criticism that is voiced with regard to ELSA is that it is perhaps simply "a rhetorical device used to gain support among policy-makers and funders for particular research topics and technologies" (Hedgecoe, 2003). Its dependency on this type of funding makes ELSA genomics vulnerable to instrumentalization, either in order to further the interests of genomics research, or by realizing specific strategic missions. This argument, however, builds on the false premise that research is either embedded, and therefore biased, or independent, and therefore autonomous. As we have indicated, something similar to participatory criticism is a viable option.

Robert Cook-Deegan, Director of the IGSP Center for Genome Ethics, Law & Policy at Duke University (Durham, NC, USA) has summarized the assignment of ELSA research by saying that it should reframe and recast previous debates about genetics that tended to focus on the search for single genes. The twentieth century began with the emergence of genetics as a discipline that quickly became caught up in simplistic interpretations. Subsequently, when the mass-media discuss genes, it often builds on a deterministic understanding of our genome, equating human beings with their genes (Lippman, 1992). Yet, as Cook-Deegan has argued, genetic determinism—the idea that we are our genes—is totally unable to fully explain the complexity of life. As long as deterministic interpretations of genetics dominate public discourse, efforts to identify and address the complex societal challenges implied in genomics research might be hampered (Zwart, 2007). Therefore, one of the most daunting tasks of ELSA genomics research is to change the social framework in which genetics is cast. Science has only begun to understand the extreme complexities of life. ELSA should similarly replace caricature with nuance and provide a richer vocabulary for understanding the societal impacts of genomics (Cook-Deegan, 1994/1995). This, as we have argued, calls for a research strategy that is characterized not only by proximity, early anticipation, interaction and inter-disciplinarity, but also by a willingness to reflect continuously in a critical manner on the opportunities and challenges involved in this approach.

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