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CSG Next  
2008-2013



Harvesting Results  
Preparing for the Future

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# Foreword

It has been a privilege and a pleasure to have been associated with CSG Centre of Society and the Life Sciences since its inception in 2002/03. Under Hub Zwart's inspirational and inclusive leadership, CSG has become an internationally recognised beacon for the development of the society in science and the science in society agendas. Over the last decade, its notable achievements include the building of a network of participating universities in the Netherlands; the fostering of interdisciplinary collaborations; joint activities with other Centres of Excellence in Europe and North America; academic conferences, seminars and workshops; the provision of opportunities for PhD students and post-docs, and most significantly a variety of innovations in public outreach and public engagement. The Centre leaves a splendid and solid legacy; its activities will be sustained and further developed in the pursuit of responsible research and innovation.

George Gaskell  
*Chairman of CSG's International Scientific Advisory Board*  
*Pro-director, London School of Economics, UK*

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# Summary

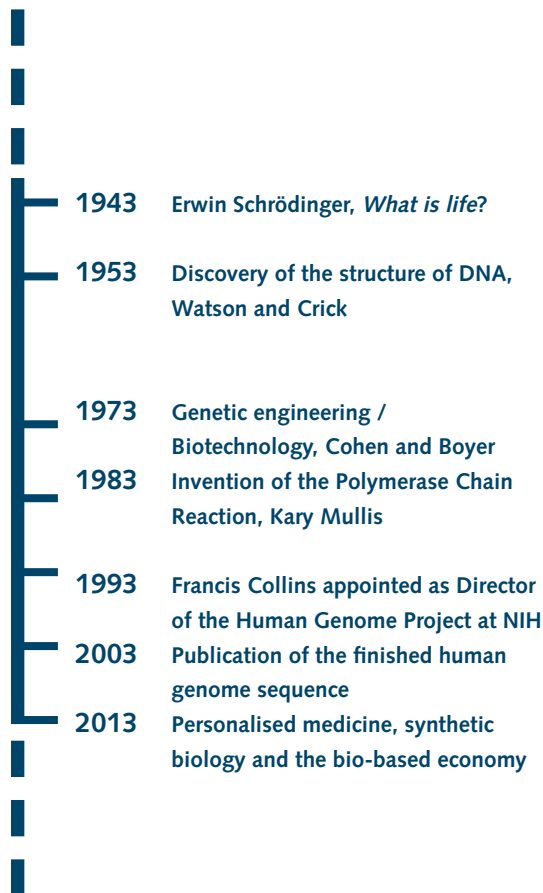
*The Centre for Society and Genomics (CSG) was established in 2004, funded by NGI (the Netherlands Genomics Initiative). Funding was continued in 2008. This report summarises the basic outcomes of almost a decade of interactive societal research, in close collaboration with the other centres of the NGI network.*

There are two reasons for presenting these results. First of all, at the end of this year, the CSG *Next* programme (2008-2013), encompassing more than 50 research projects conducted at 10 Dutch universities, will be completed. Moreover, we are currently preparing ourselves for the years to come. The network of principal investigators, together with the research communities they represent and the societal and international networks they are involved in, have agreed to continue to work together, on the basis of mutual learning, transdisciplinary collaboration and collegial support. Notably, we offer our networks, experiences and expertise to help prepare the ground for promoting *Responsible Research and Innovation (RRI)* in the context of Horizon2020, together with our European colleagues.

This report summarises what our type of research can achieve and how we want to continue our activities in the future. After a concise sketch of the life sciences landscape as it has evolved during the past seven decades or so, we explain how CSG came about and what kind of approach we have developed. Subsequently, we list our main results, notably in the form of project vignettes, so as to make the harvest of the CSG *Next* programme as tangible and concrete as possible. Finally, we explain how we see our role in the future.

As is already indicated by the title: this is not merely a retrospective summary of our results (CSG harvest), but an invitation to readers (from academia, industry, policy and civil society) to reassemble and to optimally prepare ourselves for things to come, by strengthening and broadening our collaborative efforts, building on what we have achieved so far.

# Prelude: from molecular life sciences to genomics and post-genomics - a short history of a scientific revolution



During the past 70 years, life science research has changed dramatically in terms of pace and scale, but also in terms of methods, technologies and research funding schemes. In 1943, Nobel laureate Erwin Schrödinger argued that life should be studied at the molecular level and that physicists and biologists should learn to work together. Ten years later, Watson (a biologist) and Crick (a physicist) unravelled the molecular structure of DNA, building on data produced by crystallographers Rosalind Franklin and Maurice Wilkins. The spread of the 'molecularization' of life from laboratory to society surfaced in the form of

the biotechnology revolution, unleashed by genetic engineering techniques developed by Boyer and Cohen in 1973, and amplified by subsequent innovations such as the PCR-technique developed in 1983 by Kary Mullis (working for a Bay Area biotech company called CETUS Corporation). Subsequently, the shift from single-gene to genome-oriented (genomics) approaches paved the way for the *Human Genome Project* (HGP), building on high throughput, automated sequencing technologies. In 1993, with the appointment of Francis Collins, the HGP really got off the ground and ten years later (three years after the famous press conference in 2000) the first finished sequenced of a (composite) human genome was finally published. Currently, the revolution has begun to propagate to other, 'post-genomics' arenas such as personalised medicine, synthetic biology, systems biology, proteomics, and a whole variety of other forms of -omics research. On the societal level, important new debates and developments include the personalised (\$ 1000) genome, neuro-enhancement and the macro-societal turn towards a more sustainable, bio-based (post-fossil fuel) society, also known as the 'second' (i.e. bio-based) industrial revolution. These developments offer challenging prospects for sustainability, employment and health, but also entail possible conflicts and even global collisions between potential 'winners' and 'losers'. Important issues such as naturalness vs. refurbishing nature, self-determination vs. surveillance and control, global justice vs. exploitation, and credibility vs. uncertainty and lack of trust are involved. In other words, the techno-scientific and societal, ethical and socio-economic dimensions of these complex transitions are closely intertwined from the very outset. They must be addressed in an interdisciplinary, interactive way, through research, public deliberation and mutual learning.



From the 1970s onwards, sensitivity to the societal implications of the techno-scientific developments outlined above quickly increased. In 1974 for instance, a committee of prominent scientists led by Nobel laureate Paul Berg published a paper on the potential biohazards of recombinant DNA molecules in *Science* and in 1975, a sizable group of prominent life scientists convened in Asilomar (California) for a conference to address these issues. They even discussed the option of a moratorium on potentially hazardous experiments. The participants felt that anticipatory deliberations on the possible societal implications of emerging life sciences should become an intrinsic part of

“Who would nowadays dream, even for an instant, of stopping the movement, the discourse of science in the name of anything whatsoever that might result from it? Things have already happened, they show where we are going, from molecular structures to atomic fission. Who can think, for even an instant, that the revelation of this new power can be stopped? That it is still possible not to obey the command of contemporary science – Go on! Continue!

Keep producing more knowledge!”

Jacques Lacan 1991, p. 120)



responsible research. Thus, the Asilomar Conference became an important marker in the history of deliberations on life sciences and society.

In 1988, when the preparations for the Human Genome Project (HGP) were in full swing and HUGO (*the international Human Genome Organisation*) had its first meeting at Cold Spring Harbor, this issue resurfaced. At the press conference announcing his appointment as first Director of the HGP, James Watson announced that 3 % (later: 5 %) of the NIH budget for genomics should be spent on research concerning the *ethical, legal and social* implications (ELSI) of sequencing the human genome. This idea became a model worldwide (*Table 1, next page*). In various countries, genomics research was now flanked by societal programmes addressing the ethical, legal and social *implications* (ELSI) or *aspects* (ELSA) of genomics. In other words,

a close liaison evolved between HUGO and ELSA.

Like the HGP itself, the US ELSI programme was formally established in 1990. Its mission was to anticipate and address the ethical, legal, and social implications of genetic and genomic research. From 3 up to 5% of NHGRI research budget would be devoted to this type of work. Thus, NIH became the largest public funder of bioethics research in the world. Triggered by the American example, other countries began to set up similar ELSI / ELSA genomics programmes of their own. In the United Kingdom, this led to a network of ELSA centres funded by the *Economic and Social Research Council* (the ESRC Genomics Network: EGN).

In the Netherlands, during that same period, the *Netherlands Genomics Initiative* (NGI) was established in 2002. For more than a decade, this funding agency invested 560 million euros

in genomics research, conducted at 15 genomics centres. 5 % of its budget was spent on ELSA activities, on the one hand in the form of an NWO programme issuing calls for researcher-driven, stand-alone projects (entitled: “The societal component of genomics research”) and, on the other hand, in the form of a Centre for Society and Genomics (CSG), established in 2004. Subsequently, building on the results of CSG I (2004-2008), the CSG *Next* programme was launched in 2008 as an effort to combine these various strands of Dutch ELSA activities. Since 2004, CSG has conducted more than 70 research projects and a plethora of societal activities. *Proximity* (i.e. collaboration with the other centres of the genomics network) and *interaction* (i.e. the combination of ELSA research with education, communication, valorisation and societal outreach) have been key elements of our work. In this document we will outline why this type of research is important and what we have achieved.

Country	Acronym	Programme	Funding agency	Year
USA	ELSI	Ethical, Legal and Social Implications	NIH / NHGRI	1990
Canada	GE <sup>3</sup> LS	Genomics-related Ethical, Environmental, Economic, Legal and Social Aspects	Genome Canada	2000
South-Korea	ELSI	Ethical, Legal and Social Implications	Government of South-Korea	2001
United Kingdom	EGN	ESRC Genomics Network (Cesagen, Innogen, Egenis, Genomics Forum)	ESRC	2002
Netherlands	CSG, MCG	Centre for Society and Genomics (now: Life Sciences); Societal Component of Genomics Research	Netherlands Genomics Initiative	2002
Norway	ELSA	ELSA Programme	Research Council of Norway	2002
Germany, Austria, Finland	ELSAGEN	Transnational Research Programme	GEN-AU, FFG, DFG, Academy of Finland	2008

**Table 1: Overview of ELSI/ELSA Programmes**

# Centre for Society and Genomics (CSG)

In December 2002, the *Netherlands Genomics Initiative* (NGI) decided to establish a Centre for Society and Genomics (CSG) at the Faculty of Science, Radboud University Nijmegen, led by Prof. Hub Zwart, following a call that invited experts in the field of ELSA research for setting up such a centre.

To those involved in setting up CSG at the time it was clear that they were taking part in an experiment and involved in developing a novel kind of organisation, without precedent in the Netherlands. CSG became a national centre, responsible for developing and conducting a national programme of research, combining mass and focus. Until then, this type of research had been implemented through stand-alone projects and open calls. As a national network did not yet exist, it was built *through* research. All major players were assembled into one programme.


CSG adhered to the ELSA profile. Research was conducted in close interaction with education, communication and societal outreach. Rather than opting for a particular identity in terms of discipline (such as Bioethics, STS or TA), the objective was to join forces and to combine tools, insights and experiences from a broad range of relevant fields. Moreover, CSG was part of the network of the centres of excellence of NGI. Virtually all research projects of the CSG programme entailed collaborations or at least interactions with genomics research centres at various stages of the research trajectory.

CSG's mission was to *analyse, assess and improve* the conditions for societal embedding of genomics. CSG developed a portfolio of 20 research projects, which were conducted at various universities throughout the Netherlands, in combination with education

“The money dedicated to [ELSA] does more than simply finance research, dialogue and education; it also helps to erect buildings of knowledge and practice: social institutions of intermediary character that are geographically and organisationally close to the research centres with which they interact. These institutions serve as public and academic forums for converging sciences and societal actors.” (Stegmaier 2009)

and communication activities, such as the public website *All about DNA*. In 2007, when a sequel programme for genomics research in the Netherlands was launched, NGI decided, on the basis of a mid-term review in 2006 and other assessments, that CSG should continue and that all ELSA-type activities should be brought together into one comprehensive programme, combining mass, focus and visibility. CSG was to combine and coordinate all research, communication and education activities that were previously the responsibility of several organizations (NGI, the Genomics





Centres and the NWO programme MCG). CSG *Next* was launched on 1 January 2008. The new programme was a joint endeavour of all the centres of the NGI network (sixteen partners in total), under the lead of CSG, and it entailed collaborations with partners from society and industry as well. The Business Plan 2008-2012 stated basically the same mission as before: to *analyse* (through conceptual and empirical research), *assess* (in a critical manner) and *improve* (through recommendations and interventions) the prospects for societal embedding of genomics, by aligning research and policy agendas and feeding (and improving the quality of) societal and policy-debates over genomics-related issues.

This mission was translated into four main objectives:

- add to the academic body of knowledge about society-genomics relations
- improve quality of public debate on genomics
- strengthen the governance of genomics
- educate researchers, professionals and citizens to assess genomics and its value for society.

The new plan was not only supported by all NGI centres, but also positively assessed by international peers.

CSG *Next* integrated communication with societal interaction, so that communication and interaction provided input for research activities and vice versa. The proximity of ELSA research to the genomics research infrastructure allowed for the study of on-going and emergent developments in genomics. Thus, CSG's research could anticipate and affect the actual course that science and its applications were taking.

“The Review Committee was impressed with the results achieved by CSG. CSG has put societal aspects on the research agenda in an integrated manner and has pursued a transdisciplinary approach by bringing together researchers from different disciplines. This collaboration has not grown spontaneously: it took time, critical mass and engagement. An important success factor is that CSG researchers work closely together with genomics researchers, not only by regular meetings, but also by having a desk in or close to laboratories where genomics researchers work. CSG has shown to be successful. The CSG approach is a very strong concept and a best practice for other research programmes and organisations.”

(Breimer et al, Mid-Term Review Committee

NGI, 2011)



Thus, CSG *Next* developed into a large-scale centre for interactive research and communication, with approximately 50 research projects designed and conducted in collaboration with the other 15 centres of the NGI genomics network. CSG research provided challenging opportunities for other reasons as well. It has been a test-bed for a new style of doing and organizing research. As a national research centre, CSG developed an open network of trans-university collaborations for developing and conducting its interactive research programme. Proximity to (and collaboration with) prominent large-scale life sciences programmes was a key feature of the programme.

In 2011, CSG was subjected to a formal external review. The review committee judged the CSG approach as a very strong concept and a best practice for other research programmes.

Over the years, the focus of research broadened from 'genomics' to 'life sciences'. In 2011, this was reflected in CSG's new name: CSG Centre for Society and the Life Sciences.

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## *Participants of CSG's international scientific conference*

*Amsterdam, May 2010*

### Programme Committee of CSG Next (2013)

Hub Zwart	Philosophy of Science	ISIS, Radboud University Nijmegen	Scientific Director
Jacqueline Broerse	Science and Technology Studies	Athena Institute, VU University Amsterdam	Principal Investigator
Martina Cornel	Community Genetics	VU University Medical Center, Amsterdam	Principal Investigator
Michiel Korthals	Applied Philosophy	CITE, Wageningen University	Principal Investigator
Patricia Osseweijer	Science Communication	Biotechnology and Society, Delft University of Technology	Principal Investigator
Arend-Jan Waarlo	Science Education	Freudenthal Institute, Utrecht University	Principal Investigator
Guido de Wert	Bioethics	HES, Maastricht University	Principal Investigator

### Management Team of CSG Next (2013)

Hub Zwart	Scientific Director
Gijs van der Starre	Managing Director
Frans van Dam	Communication Manager
Maud Radstake	Project Manager
Maria-Lucia Cantore	Office Manager

### Scientific Advisory Board of CSG Next (2013)

The 50 projects of the CSG Next programme, developed by principal investigators and other project managers, were subjected to a quality assessment by the Scientific Advisory Board of CSG.

Prof George Gaskel	London School of Economics, UK (chair)
Dr Roger Busch	(formerly) Ethik-Institut Technik-Theologie-Naturwissenschaften, München, Germany
Prof Anne Cambon-Thomsen	INSERM Toulouse, France
Prof Ruth Chadwick	CESAGen, Cardiff, UK
Prof Herbert Gottweis	Department of Political Sciences, Universität Wien, Austria

# The CSG Approach: From ELSA to RRI

In order to realise our mission to analyse, assess and improve the societal embedding of genomics, our research not only involved a combination of empirical analyses and critical assessments, but also resulted in options for improvement or concrete recommendations and activities, in order to further societal embed and to stimulate interaction between society and genomics. Another basic characteristic of CSG research has been that interactions with genomics researchers, professionals, societal organisations and other stakeholders are not limited to the development and / or dissemination stages of our research, but rather

constitutes an integrated dimension of our methodology, our work. In a number of publications, statements and meetings, these ideas have been further developed.

One CSG project was explicitly devoted to the question “What is ELSA genomics?” In September 2008 a workshop was organised involving several ELSA researchers from the Netherlands and abroad, resulting in a special issue of EMBO reports (Science and Society series on convergence research, Stegmaier 2009). In one of these reports, a general profile of ELSA genomics research is outlined (Zwart & Nelis 2009). At least four important features are typical for ELSA genomics research, namely: *proximity* (critical participation and embedding in genomics programmes), *early anticipation* (of social issues involved in genomics research), *interactivity* (encouraging stakeholders and publics to assume an active role in ELSA research), and *interdisciplinarity* (bridging boundaries between research communities such as bioethics, philosophy and STS). In a similar document written on behalf of NGI and entitled *The Societal Aspects of the Life Sciences 2020* it is concluded that ELSA research consists of four basic activities: (a) *identification* of (ethical, legal and social) issues; (b) *interpretation* and analysis of these issues; (c) *organised interaction and dialogue* with stakeholders (including publics) and (d) *interaction* with policy, politics and professional practices (Bijker et al 2011).

Recently, both on the European and on the national level, a new concept has been launched: Responsible Research and Innovation. In the opening lines of *A vision of Responsible Research and Innovation* (2013) René von Schomberg argues that “RRI has become an increasingly important phrase within policy narratives, in particular in Europe, where it will

## Characteristics of ELSA research

- Proximity to life science research
- An anticipatory, forward-looking approach; a focus on the agenda-setting and design stages of innovation trajectories, rather than on the product stage
- Interaction with a broad range of societal stakeholders (media, policy, NGO, industry) as integral part of the research
- Interdisciplinarity: ELSA research as a converging field involving a broad range of disciplines (philosophy of science, bioethics, social science, TA, STS, innovation studies, science communication etc.)
- A focus on micro-analysis ('case studies') rather than on macro analysis (socio-economic studies)
- Drawing on a wide variety of sources: from academic philosophy via policy reports up to media coverage of public debates and genres of the imagination (genomics novels, genomics movies and the like)



be a cross-cutting issue under the prospective EU Framework Programme for Research and Innovation *Horizon 2020*. And yet, “there is no agreed definition of the concept, and approaches how it should be implemented may vary”. Indeed, the field is explicitly invited to join the debate as to what RRI exactly is. In two recent publications on RRI (Von Schomberg 2011, 2013), the following definition is proposed: *Responsible Research and Innovation is a transparent, interactive process by which societal actors and innovators become mutually responsive to each other with a view to the (ethical) acceptability, sustainability and societal desirability of the innovation process and its marketable products (in order to allow a proper embedding of scientific and technological advances in our society).*

Another recent report (Van den Hoven *et al.*) defines RRI as follows. It is:

- **Anticipatory:** Anticipation asks researchers and innovators to include new perspectives in the research and innovation process and to think through various possibilities to be able to design socially robust agendas for risk research and risk management.
- **Inclusive:** Inclusiveness asks researchers and innovators to involve diverse stakeholders (such as users and NGOs) in the process to broaden and diversify the sources of expertise and perspectives.
- **Reflexive:** Reflexivity asks researchers and innovators to think about their own ethical, political or social assumptions to enable them to consider their own roles and responsibilities in research and innovation as well as in public dialogue. Reflexivity should raise awareness for the importance of framing issues, problems and the suggested solutions.
- **Responsive:** If research and innovation claim to be responsible, it has the capacity

“There can be no viable innovation in the life sciences without a proper ‘landing’ in society, as science and technology only function when they are socially well embedded. For an adequate embedding of innovations in society, research into the societal aspects of specific scientific and technical developments will continue to be necessary, now and in the future.”

(Bijker *et al.*, *The Societal Aspects of the Life Sciences* 2020)

to change its direction or shape when it becomes apparent that the current developments do not match societal needs or are ethically contested. Hence, responsiveness refers to the flexibility and capacity to change research and innovation processes according to public values. (p. 58)

From this definition it is clear that there is continuity between the ELSA and the RRI approach and that responsible research can build on the ELSA legacy of the past two decades (1994-present). Still, there is a new emphasis in RRI in comparison with ELSA, namely the focus on socio-economic benefits and collaboration with private and industrial partners, the use of ethics as a *design principle* for technology (for example: privacy through design) as well as the ensuring of market accountability through standards, certification, accreditation and labels as a new form of governance to manage the floods of products coming to the market. Von Schomberg (2013) notably refers to “...the ambition of the European Union to ensure that research and innovative ideas can be turned into products



and services that create jobs and prosperity, as well as help preserve the environment and meet the societal needs of Europe and the world” (p. 11). The point of RRI is to help achieve this ambition: “RRI has the potential to make research and innovation investments more efficient, while at the same time focusing on global societal challenges” (p. 16). Inclusion of ethics beforehand, it seems, will lead to less contestation of innovations afterwards.

Involving societal input in science and technology innovation implies that ELSA / RRI- researchers become part of the very processes they study, immersing themselves in research consortia whose work they intend to critically assess. The tension between ‘going native’ and giving voice to critical concerns is there to stay. For the ELSA community, the new liaison (or even ‘marriage’ with) RRI and its socio-economic agenda (including the commodification of research this seems to entail) raises an issue that is not unlike the one that haunted Elsa of Brabant, the female lead in Wagner’s *Lohengrin*: will there be questions we are no longer supposed to (but will find impossible not to) ask?

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## Discussing the flu pandemic

*LUX-Nijmegen, September 2009*

# 4 Expectations and deceptions: the issue of complexity

*“Scientists aren’t generally prone to effusiveness. We are privately excited about our work, but in public we often, and rightly, emphasize skepticism and caution. But there are exceptional moments where skepticism is set aside, electricity fills the room, and a scientist with palpable passion and flashing eyes describes unabashedly a change in the landscape that will have lasting significance. Just a few months into the new millennium, I had that experience ... After much anticipation, and many tumultuous moments, the achievement of an almost impossible audacious goal that had motivated all of us for a decade was now essentially assured. (p.1)”*

This is how Francis Collins (2010) described the atmosphere shortly before the presentation of the human genome sequence in the year 2000. It was a moment of big hopes and stellar expectations. Yet, since then, the immediate implications of the human sequence for medicine and health have been ‘underwhelming’, to put it mildly. Hardly any drugs or therapies resulted from this costly, ‘big science’ investment. It soon became clear, not only that life as such is staggeringly complex from a biological point of view, but also that the translation and implementation of new forms of knowledge and information into medical practice and daily life is beset by complexities as well. In other words, not only biological life, also societal life is complex. It is only now, during the present decade, that practical options and benefits become gradually visible, but even now, in many cases, these benefits often entail mixed blessings. The implementation of genomics in health care is not a matter of technological dexterity and sizable data sets only. It is also (perhaps even more so) a question of policies, regulations, culture, world-views and a whole range of other

socio-cultural facets. In other words, in order to turn knowledge into practice, genomics experts and ELSA experts, but also policy-makers, professionals, patients and teachers will have to continue to learn to work together.

This not only goes for the health domain, but also for agricultural, industrial and environmental genomics. Not only genomics insights (and the biological systems studied by genomics) are complex, the societal fabrics and tissues in which this knowledge must become embedded are staggeringly complex as well. And indeed, to put it in mathematical terms, ‘complex’ times ‘complex’ is squared complexity. This means that the focus of our projects often is on case studies: punctuated samples allowing us to probe a bewilderingly complex global reality. But very often, these ELSA vignettes entail important lessons of much wider relevance. It is in this manner that the prospects opened up by genomics, such as personalised medicine and the bio-based society, can be realised, not by way of one big gesture, and not in a top-down fashion, but through continuous effort. Therefore, the projects results, which are listed below in the form of an anthology of project vignettes, must be seen as preliminary harvest of a common research effort that must and will continue during the years to come.



In general terms, our main results can be summarised as follows:

- Although genomics (i.e. sequencing and understanding genomes) as such is a basic and generic field, when it comes to implementation and application it is not a matter of 'one size fits all'. Rather, implementation has to be carefully tailored to specific circumstances, in close interaction with the various 'local' stakeholders involved. This involves mutual learning ('implementation work').
- In many fields of application, a basic decision has to be made: do we opt for self-determination or standardisation and surveillance, for an open-source or rather for a proprietary course, for a nature-friendly or an exploitative attitude? In other words, the real *meaning* of genomics for human life and society will be determined in the socio-cultural arena, not by the technology as such.
- In order to use new knowledge forms (such as genomics) for addressing the major global societal challenges of today, research disciplines (in science, the social sciences

## *Statue of Marjolein Kriek, the first woman whose genome has been sequenced*

and the humanities) must continue to learn to work together and opt for a collaborative rather than an introvert, self-centered approach.

- The genomics (or life sciences) revolution is a dynamic, time-consuming, cascading process, rather than a dramatic, punctuated event (such as the sequencing of the human genome).
- So far, the biggest impact of genomics has been a cultural one: rather than leading to new products or therapies, it has profoundly changed our view of life, nature and ourselves.

This general message has been implemented and brought to life in various concrete settings by CSG research projects.



# Anthology of project vignettes<sup>1</sup>

## Health

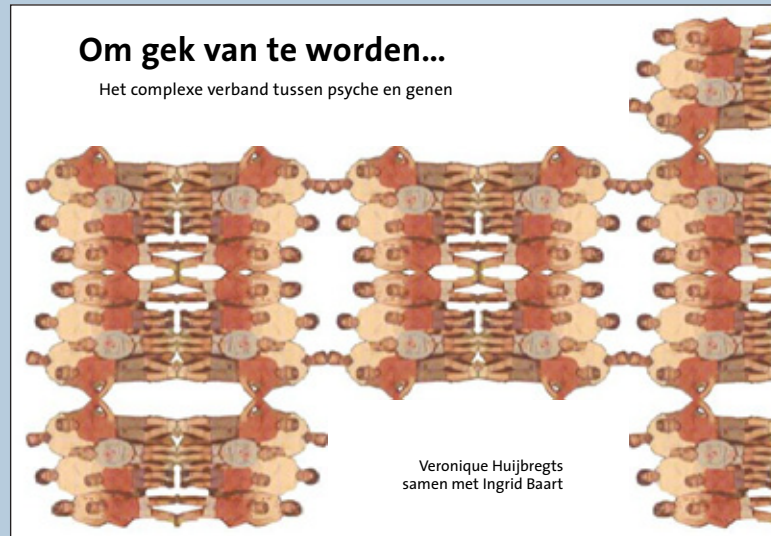
“Early identification, prevention and treatment of antisocial behavior raise concerns about labeling and stigmatization. Yet, the juvenile participants in our project did not react in this way. Rather, they emphasized the possibility of making their own choice, which allows them to take responsibility.”

Dorothee Horstkötter, Guido de Wert: *The promise and pitfalls of the genomics of antisocial behaviour*



“The newness of biobanking not only resides in the collection and storage of biomaterials and data for future and unspecified research, but also in patients and citizens acquiring new forms of agency and developing new roles in the biomedical research system.”

Conor Douglas, Carla van El:  
*A wealth of data*



“Attempts at resolving tensions pertaining to the governance of biobanks often reproduce these very same tensions in other ways. This is the main irony of ‘Biobank Governance’: problems related to a lack of governance easily evolve into problems related to an overkill of governance.”

Martin Boeckhout, Gerard de Vries: *ELSA Involvement in Biobank Governance*

“The amount and detail of information offered by new screening techniques such as whole genome sequencing does not automatically deepen our understanding of the prospects of embryos. From an ethical point of view, the increasing complexity will rather lead to challenges to reproductive autonomy and the right of the child to an open future, and may complicate the responsibility of clinicians regarding the welfare of the future child.”

Kristien Hens, Guido de Wert: *Towards the Transparent Embryo?*

“Our outcomes reflect a turning phase in genomics. After hopes and promises about the potential contribution of genomics for prediction and prevention of common disorders began to fade, attention shifted to monogenic subsets of common complex disorders. Here, there are several potential applications that might be implemented in health care. For instance, for some cardiac disorders, diabetes and cancers, tests have been developed that can detect high-risk genes, notably for index patients who are not detected in primary care.”

Eric Vermeulen, Martina Cornel: *Governance of preventive genomics*

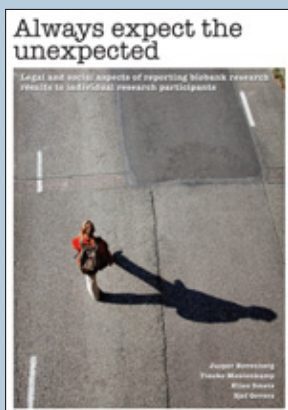
1. Names refer to principal researcher and project manager respectively, although in many projects, more researchers and/or supervisors were involved. For more info please consult: [www.society-lifesciences.nl](http://www.society-lifesciences.nl)

# Anthology of project vignettes

## Health

“New techniques for detecting foetal abnormalities find their way into prenatal screening strategies, causing the scope of testing to be far from evident. The decision what to test for is open for discussion. We conclude that replacement of one standard test by the alternative of an “individualised choice” better accords with the basic aim of prenatal screening.”

Antina de Jong, Guido de Wert: *Individualized choice in prenatal screening*



“General practitioners should directly ask patients suffering from diabetes or heart failure about similar health problems in their family histories, while gynaecologists should be able to discuss issues involved in prenatal diagnostics during consults. Therefore, our project has resulted in the website ‘GPs and Genetics’ where answers to such questions can be easily found.”

Isa Houwink, Martina Cornel: *Genomics training for primary health care workers*



“Although the development of alternatives to animal models was generally regarded as a perfect solution for addressing the issue of animal experimentation, funding strategies tended to shift the focus from value conflicts to technical solutions and depolarisation. This implied a broadening of the concept of ‘alternatives’ so that, in the end, no significant reduction of animal experiments was achieved. A real reduction presupposes that value conflicts are explicitly addressed rather than evaded.”

Meggie Pijnappel, Hub Zwart: *Developing animal testing alternatives: social values in dispute*

“Dear Minister of Health, Welfare and Sport. Searching the entire genome for genetic causes will often allow a diagnosis to be made, but the advantages of analysing an individual’s ‘personal genome’ without medical indication depend on the realisation of the ideal of personalised forms of prevention and treatment (‘personalised medicine’). This remains largely something for the future.”

Wybo Dondorp, Guido de Wert: *The 1000 dollar genome*

“The discussion in the Netherlands on neonatal screening so far has focused primarily on equality in health care and concerns over stigmatisation of certain groups in society. Our results support midwives, obstetricians and GPs in providing tailored health care for pregnant women from various ethnic backgrounds, focussing on anaemia and HbP (carrier) status in different ethnic groups.”

Suze Jans, Martina Cornel: *Neonatal Screening and beyond: Integration of hereditary hemoglobinopathy screening into primary care*

# Anthology of project vignettes

## Agro-food, industry and the environment



“ It has been argued that eco-genomics may open up new forms of interaction with nature, holistic rather than reductionist, based on biocompatibility and sustainability rather than on exploitation, and eco-centric rather than anthropocentric. We have found that, although eco-genomics certainly has this potential, this change will not occur by itself, but requires active commitment on the part of scientists and societal stakeholders who must be willing to move beyond a view of nature as a resource, waiting to be prospected and exploited.”

Sanne van der Hout, Hub Zwart: *Epistemic profile and societal prospects of eco-genomics*

“ The value of Sartre's analysis for present biofuel debates is not so much that he offers a specific framework for analysing existing situations, but rather his claim that colonisation is never only about economic dominance but comes with a cultural dimension as well. Analyses of debates and practices regarding biofuels should pay attention to this cultural dimension of economic power. This is highly relevant for biofuels, where a 'patent-rush' has taken place during the last five years in patenting of biofuel technologies.”

Menno van der Veen, Patricia Osseweijer: *Food vs. Fuel: Neo-colonial tendencies in biofuel debates*

“ We are in the midst of a rupture that will dramatically change the way our life is organized and will very probably involve a break with the epoch of sedentarization to which agriculture belongs. What is most troubling about a strongly IP-based, privatized and corporate-led agriculture is that it tends to destroy the dimension of care and responsibility that is essential to agriculture as a culture. Agriculture first of all is a system of care. From its very beginning, agriculture is a taking care of the living, cultivating life.”

Pieter Lemmens, Bart Gremmen: *Towards a participatory, commons-based innovation in the agrotech industry*

“ Pharmaceutical companies are now funding bio-prospecting expeditions in deep sea ecosystems, where DNA 'lab on a chip' technology can be used at considerable depths. This is part of a general movement towards marine habitats, looking for genes, enzymes, anti-freeze proteins and other novel bio-components. A deep sea ethic in the spirit of Leopold's land ethic must be developed to prevent a new tragedy of the commons.”

Erik Dücker, Christoph Lüthy: *Bioprospecting in the Genomics Era*



# Anthology of project vignettes

## Agro-food, industry and the environment

“Open source is an alternative innovation strategy in which knowledge resources are shared among producers, creating forms of social life and collaboration through the production of items such as seeds. A characteristic feature of knowledge commons is their abundance: their surplus of knowledge that cannot be completely integrated into commoditized relations. This social wealth invites and opens new collaborations, new social relations, thereby strengthening the common source itself.”

Pieter Lemmens, Guido Ruivenkamp:  
*Genomics and the production of the commons*



“New monitoring tools for water and soil quality based on ecogenomics are safe, healthy and profitable and can play a vital role in realizing a truly sustainable bio-based economy. Our research supports the development and implementation of these new tools by bringing together scientists, developers and end-users to co-shape a sustainable future.”

Tjerk Jan Schuitmaker,  
Jacqueline Broerse:  
*Dialogue as a tool for societal valorization of environmental and industrial biotechnology*

“In the debate on the use of genomics in agriculture, it is impossible to separate technical issues and their consequences from the wider context in which they emerge and the value issues at stake. The genomics debate is a value-driven debate. This means that, in discussing specific technological innovations, the values associated with concepts of nature cannot be left out of the picture”

Paul van Haperen, Bart Gremmen: *Ethical debates on naturalness*



# Anthology of project vignettes

## Culture and identity



“The concept of immunisation has migrated from viral genomics to public discourse to such an extent that it has become a paradigm for addressing societal issues and concerns. One of the implications is that auto-immunisation (i.e. the possibility of disruptive immune responses due to overreaction) becomes a serious risk for society at large.”

Inge Mutsaers, Hub Zwart:  
*Immunisation and its discontents*

“Rather than criticising science, or being locked into current scientific views of the future, science fiction may ‘think along’ with science, probing changing conditions of a technoscientific world in which new possibilities of life are opened up as processes of becoming, teeming with potential. Thus, sf may allow us to explore the potentials of science and technology in ways unforeseen by science itself.”

Tom Idema, Hub Zwart:  
*Genomics Novels as Test-Beds for Genomics Futures*

“Bioinformatics and its computational tools constitute the infrastructure of genomics research. A number of value decisions are involved in the development of such tools. However, once ready for use, these values tend to blend into the background. This may lead to the ‘naturalisation’ of value-laden aspects of identity on the population level such as nationality, ethnicity and descent.”

Jan van Baren, Hub Zwart:  
*Bioinformation and identity*

“Genomics has come to play a key role in how we see ourselves. In archaeological excavations in the Netherlands, DNA is now giving an identity to a place, but often, DNA is mobilized in to confirm pre-existing icons of identity.”

Masae Kato, Amade M'charek: *Dutch-ness in Genes and Genealogy*



# Anthology of project vignettes

## Valorisation



“ We identified five requirements for stimulating and facilitating the active involvement of researchers in policy making: Motivation, Task coordination, Communication competence, Recognition and Credibility. We are now developing tools for linking our results to governance at the institutional level.”

Zuzana van der Werf Kulichova, Patricia Osseweijer: *Engaging researchers actively in agricultural biotechnology policy making*

“ We see the valorisation policy of the Dutch genomics research system as a manifestation of a changing social contract between science and society, focusing on economic value creation and the stimulation of entrepreneurship. A societal debate has emerged, however, in which this one-sided focus on economic aspects is criticized. We have found that in their daily business, genomics researchers continue to search for relevance in several directions, far beyond the strictly economic one.”

Dirk Stemerding, Stefan Kuhlmann: *Genomics as a new innovation regime*

“ Building on our project results, options are now explored to launch a consultancy spin-off that aims to stimulate socially responsible innovation management within the private Dutch Industrial Life Sciences sector.”

Steven Flipse, Patricia Osseweijer: *Challenges and Hurdles in Genomics-based Innovation*

Responsible Innovation Collective ('Proeffabriek') is a CSG consultancy spin-off for responsible innovation. It supports knowledge-intensive organisations with integrating social responsibility in their work. Strengthening the relation between research organizations and the users of knowledge (companies, policy makers, the media and citizens) is central to our work.

Daan Schuurbijs:  
*Responsible Innovation Collective*



# Anthology of project vignettes

## Communication



"When experts mobilize their authority about the technological feasibility of new developments, this may discourage public deliberations concerning their moral desirability. As a moderator of public deliberations, you can empirically analyse and improve deliberative quality by combining observation with assessment and intervention. It works!"

Koen Dortmans,  
Tsjalling Swierstra:  
*Doing dialogue and DNA*



"Emotions should be embraced in the public engagement process as being crucial in how people connect to the transition towards a bio-based economy. A more affective approach, using images and artworks, provides insight into people's involvement the issue and may allow us to enhance their engagement. Moreover, it allows public audiences to create their own perspective on the issue, strengthening their own level of agency and interaction."

Susanne Sleenhoff, Patricia Osseweijer: *Values of Emotions for Public Engagement with the Bio-based Economy*

"An important aspect of science communication is: to empower scientists to reflect on their communication style in a systematic way, making it more interactive, for instance by actively inviting feedback from their audience"

Karen Mogendorff,  
Bart Gremmen: *Defining expertise and citizenship in plant genomics*



# Anthology of project vignettes

## Education



“Our study shows how animations, graphics and visual models can become powerful educational tools for developing a multi-level perspective on life, enabling students to bridge biological phenomena on molecular and cellular levels and to grasp cellular complexity in life-science education.”

Marc van Mill, Arend-Jan Waarlo: *Educating for visual literacy in a genomics world*

“Genomics can improve our understanding of how children learn. And although neurogenomics cannot be brought into the classroom directly, interaction between neuro-scientists, didactics experts and teachers is a point of departure.”

Rosanne Edelenbosch, Jacqueline Broerse: *Strategies for implementing neurogenomics in education*

“All citizens should have basic knowledge concerning genomics, so as to understand heredity issues in hospital or to make conscious decisions on the food we buy in supermarkets. Much more so than standard biology books, Mobile DNA Labs provide high school students with this type of knowledge. Biology curricula must be drastically revised to afford pupils a more adequate picture of life and health in the genomics era.”

Dirk Jan Boerwinkel, Arend Jan Waarlo: *Towards a strategy for embedding genomics literacy in science education*

“To engage young people in life science education activities, the feeling that they can actually contribute to a better world is an important success factor. It makes them put more effort in their work and keeps them motivated. Interaction with real scientists and working in real labs demonstrate the possibilities of a career in science. By enabling scientists to participate in education with secondary school students, we provide them with tools and experiences to communicate with new target audiences. These activities increase awareness among students and scientists about the social relevance and personal relevance of life sciences.”

Anne-Lotte Masson, Tanja Klop: *Assessing and understanding the effects of life science education activities*





# From interaction to mutual learning

CSG is committed to further responsible research, i.e. forms of inquiry that are credible and trustworthy, and open to social challenges, opportunities and concerns (engaged scholarship). Rather than seeing 'science' and 'society' as two separate entities, science is embedded in society as much as society is embedded in science. Genomics and other life sciences fields cannot be adequately understood nor conducted without paying due attention to these social dimensions. Our work is carried out in close collaboration with others: with life science researchers, with peers and colleagues at various universities in the Netherlands and abroad, but also with societal stakeholders (government, media, industry, professionals, intermediary organisations and media). Interactive research is not a specific method, but a basic attitude, an ethos if you like. It means seeing scientific and societal stakeholders not as 'consumers' of our knowledge, but as sources of inspiration and information and as partners in our work. Sharing preliminary analyses and critical assessments with them is bound to make our research more relevant, robust and precise. Interaction means that we see ourselves not as outsiders, but as active participants in knowledge production and innovation. Proximity to science is of key importance. We offer our expertise to life science consortia to help them strengthen the social robustness and responsiveness of their research activities.

This means that our research co-evolves with activities that are often listed under headings such as communication and valorisation. We see such activities, however, as mutual learning exercises and as a cyclical process. We share our preliminary views with scientists and stakeholders, asking them for their comments, identifying key parameters such as issues, research questions and valorisation

opportunities together, so that interaction becomes part of the research methodology. To support this process, a sizable portfolio of actions has been developed by the CSG staff with tangible results:

1. **Interactive research** - Every CSG research project has built mutual learning activities (workshops, focus groups, mutual learning exercises, science cafés, public lectures, mass media publications, etc.) into the research design. Lessons were learned, shared (during Researchers Days) and reported on 'best practices', efficiency and effectiveness. Extra funding was available to cover expenses for additional valorisation activities if necessary.
2. During our **CSG Researchers days**, concepts such as interaction, mutual learning and valorisation were discussed, statements were invited, case studies were presented and group discussions were organised which contributed to critical reflection on our work, prepared early stage researchers for the societal embedding of their research results.
3. Via six **mobile educational DNA labs**, developed in collaboration with six NGI genomics centres and operated in close interaction with our website *All about DNA* (below), we learned how to successfully embed genomics-related items in curricula and raised the level of awareness of genomics and its societal dimensions among secondary school students. Thus, we contributed to prepare the ground for the societal and professional debate of the future. More than 100.000 Dutch high school students have visited our mobile labs over the years. They were confronted with acute questions they may encounter later in life, as researcher, professional or citizen. The DNA labs,

whose prototype was developed by the Centre for BioSystems Genomics, were awarded the NGI Valorisation Award of 2011.

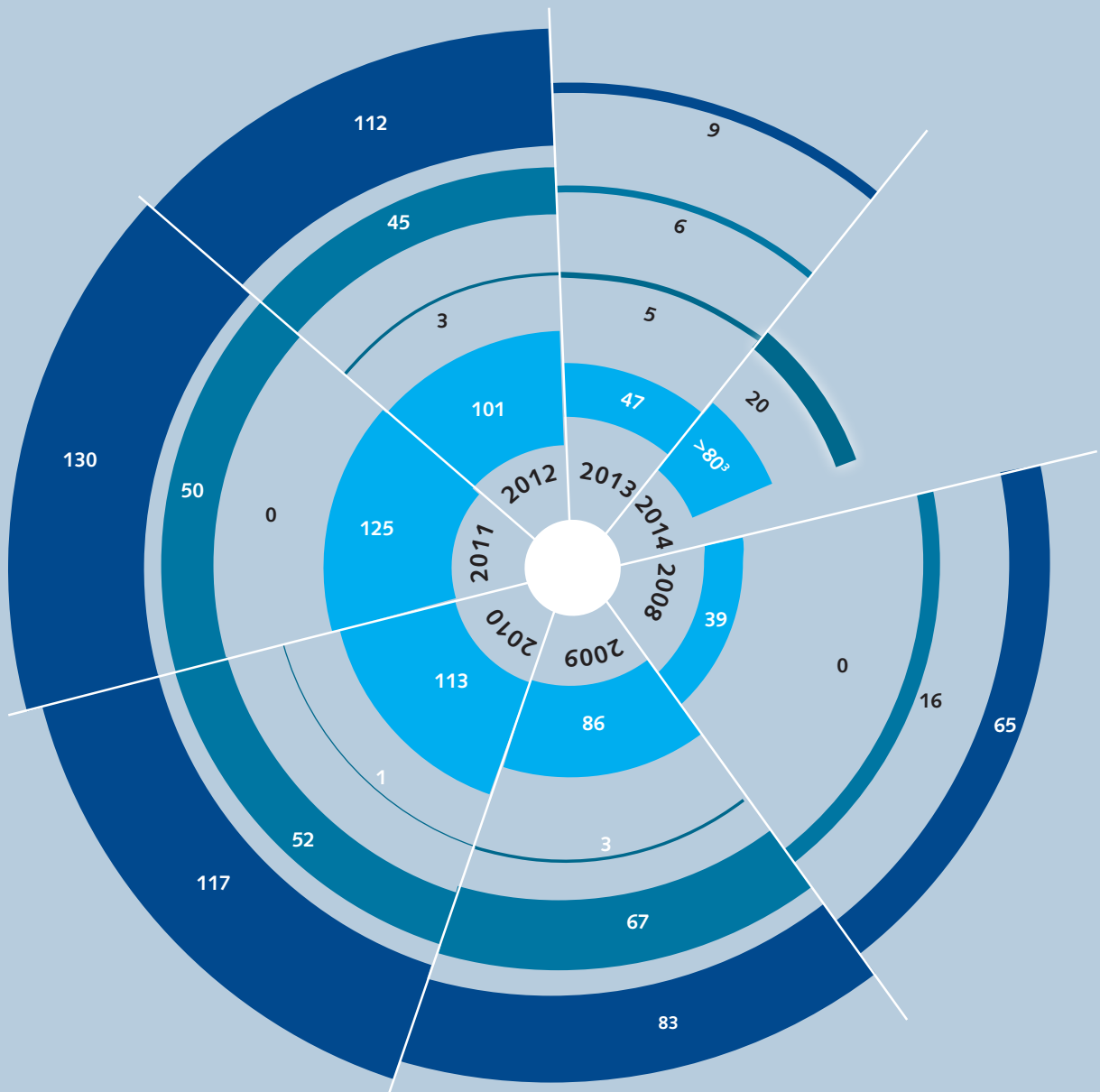
4. The website [All about DNA](#) ('Alles over DNA') developed and maintained by CSG, not only functioned as the online hub for the DNA labs, but also as an important source of information on genomics and the life sciences and their societal dimensions in its own right, notably for secondary school students and teachers. It offers a wealth of easily accessible background information on genomics technologies and concepts as well as ready-made teaching modules on specific themes. The website attracts more than 10.000 visitors monthly.
5. Since 2009 we have published the [CSG magazine LEV](#) (10 issues) covering in a lively and accessible manner the various ways in which CSG research adds to policy, professional practice and education.
6. Through [Imagine](#) (a 'spin-off' and collaboration with the Kluyver Centre) we identified key success factors in education and communication of genomics and its ethical and social dimensions. Moreover, we actively involved hundreds of secondary school students and teachers in technology development for developing countries.
7. In November 2012 we organised a full month of mutual learning activities (science cafés, lectures, demonstration, cinema debates, exhibitions) under the title [Shaking Science!](#) Representatives from virtually all CSG projects took part in this wave of events to put our lessons into practice.
8. We presented results of CSG projects at various existing podiums, not only local podiums such as debating centres, but also highly visible [national and international podiums](#) such as the Health Council of the Netherlands, the Centre for Ethics and Health and the Professional and Public Policy Committee of the European Society of Human Genetics (Dondorp & De Wert 2010) also with the aim to learn from the comments and suggestions by policy makers and professionals on national and international levels.
9. We published a series of [CSG reports](#) to share research results with broader audiences and professionals.<sup>2</sup>
10. We developed and tested a [serious game](#) on the bio-based economy with teacher instructions.
11. We organised a [conference](#) on open source alternatives to current [IPR regimes](#) covering Trademarks, Patents, Plant Breeders' Rights and Database Rights (Brussels 2011)
12. We organised two conferences in the Netherlands and one in Brussels (2013) on [responsible promise management](#) ('promisomics') in life sciences research, in collaboration with four technology centres funded by NGI.
13. We organised an [international meeting](#) with the World Intellectual Property Organisation (WIPO) and the International Centre for Trade and Sustainable Development (ICTSD) to discuss the strategies for technology transfer through (free/marginal cost) licensing to developing countries (Geneva, 2013)
14. We are currently developing [tools for RRI](#) in industrial R&D settings
15. For a more detailed account of our valorisation results, readers are invited to consult our report *Science of life: the value of societal research*, available on the CSG website.<sup>2</sup>

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2. Available on the CSG website: [www.society-lifesciences.nl](http://www.society-lifesciences.nl) - Publications

# Quantitative results

## Scientific output

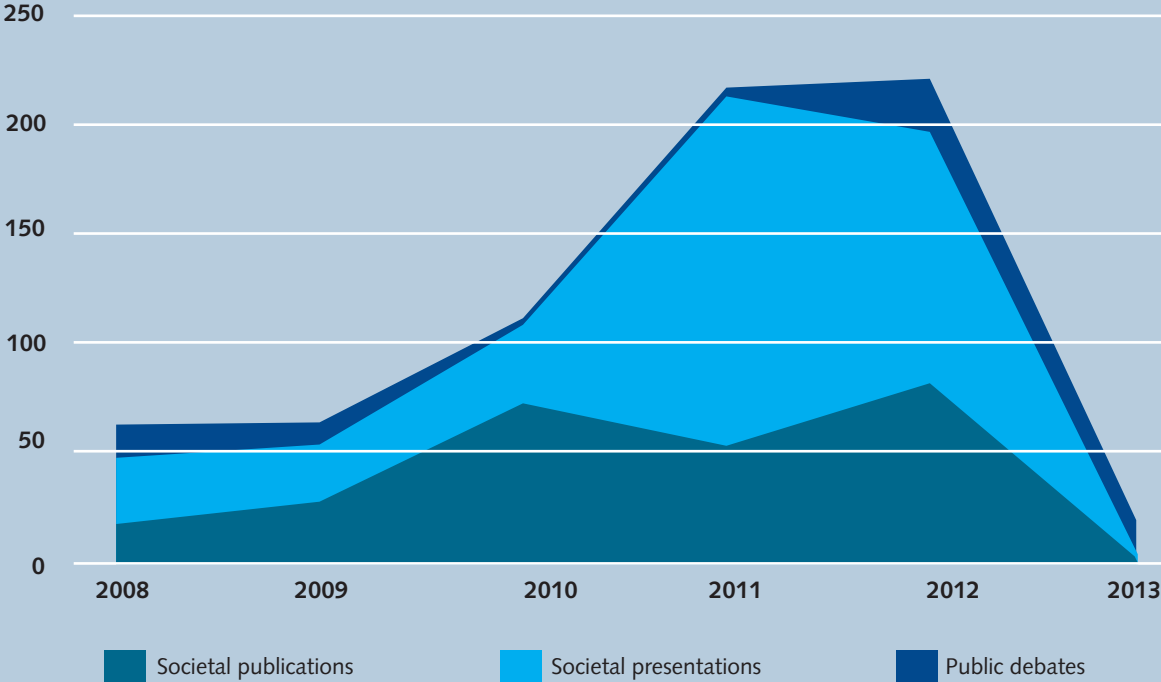


Source: CSG

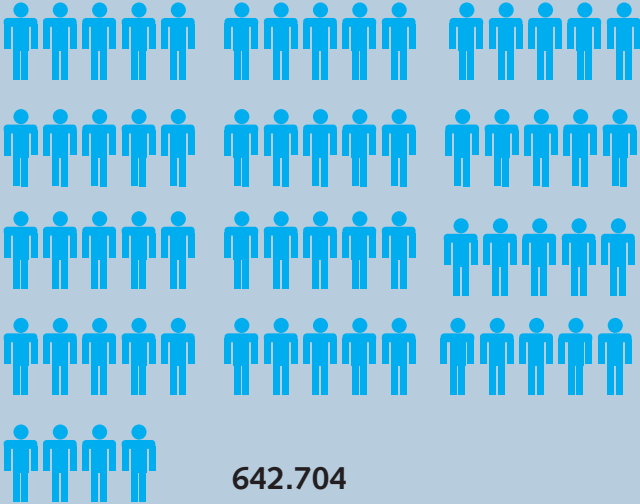
- Other academic lectures
- Invited ac. lectures
- Articles
- Theses

3. Estimate on the basis of final project reports

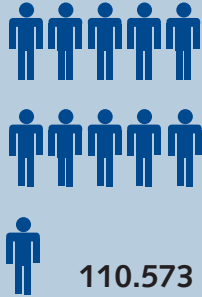
# Societal output



Visitors All About DNA  
2008 t/m 2013



Visitors DNA-labs  
2008 t/m 2013



Source: CSG

# Embedding of CSG

The CSG network / research community is becoming firmly embedded. Many researchers on CSG projects have found new positions both inside and outside academia. Six CSG researchers for instance have been appointed

as professors. Moreover, a series of new projects have been developed in collaboration for which funding has been acquired outside the NCI grant. Notably, the CSG network became involved in four new European projects:

Title	Funding	Lead	CSG
Towards a sustainable bio-based society: Aligning scientific and societal agendas for Bio-Innovation	ESF	CSG (Zwart)	Osseweijer; Korthals
Neuro-enhancement Responsible Research and Innovation (NERRI)	EU FP7 MML	LSE (Gaskell) SV (Noronha)	Zwart (WP3) Mutual learning exercises
PARRISE	EU FP7 MML	Freudenthal Institute	Knippels (FI, van Dam)
KIT	EU FP7 MML	Karlsruhe KIT	Waarlo



*Designers & Artists 4 Genomics 2012, Aqua Vita*



### Spin-offs

Three former CSG researchers have decided to valorise their expertise as private consultants.



**Daan Schuurbijs** set up *De Proeffabriek* (*Responsible Innovation Collective*), CSG's first spin-off. The Responsible Innovation Collective is a consultancy for responsible innovation. It supports knowledge-intensive organisations to integrate social responsibility in their work, strengthening the interaction between research organisations and 'users' of knowledge (companies, policy organisations, research funders, the media and citizens). The Responsible Innovation Collective provides advice, organises training sessions and other activities and supports interaction and engagement projects, also on the EU level. For instance, the Responsible Innovation Collective is involved in the EU support Action NanoDiode, fostering Europe-wide outreach and dialogue on governance of nanotechnology, combining upstream, midstream and downstream engagement, thus adding to the further development of RRI in the nano field. But the company also supports projects on responsible data management for personalised Diagnostics (ReDaPeD) and translational medicine (with CTMM). [www.proeffabriek.nl](http://www.proeffabriek.nl)



**Steven Flipse** conducted a CSG research project on how to stimulate responsible innovation practices in the Dutch Life Sciences industry and now works as a consultant. He has developed a licensable software tool that supports organisations in innovation project execution. The tool scores project quality based on technical performance indicators, but also on success factors relating to social, societal and financial-economic indicators. Combined with coaching activities, the tool helps innovators complete innovation projects more effectively and efficiently, with less financial resources. [www.stevenflipse.com](http://www.stevenflipse.com)

### }} Tertium

**Menno van der Veen** did a CSG research project on the transformation towards a bio-based society and started Tertium, which organises workshops, debates and other activities to bridge the knowledge gap between science and society, and between wealthy and less affluent regions of the globe, notably focusing on the public sector. [www.tertium.nl](http://www.tertium.nl)

# Our agenda for the years to come: National and international networks for Life Sciences ELSA/RRI

In the context of CSG, a solid **network of principal investigators** has evolved, in combination with a community of senior and early stage researchers and an international network of peers. We have decided to continue and strengthen this PI network during the years to come. By joining forces, making use of our complementary expertise and strategic positions, the CSG PI network already managed to develop and acquire funding from various sources (both NL and EU) for a significant portfolio of new (post-CSG *Next*) projects conducted at several universities. We have agreed to continue and intensify our collaboration notably in view of the recognised valuable contribution of our expertise and knowledge in the context of Horizon2020. The EU will provide substantial resources (~500.000,- euro) for research and other activities under the heading of *Responsible Research and Innovation* (RRI). We want to use the added value of our collaborative PI network to **exchange** strategic information and to **mutually support** one another in generating competitive proposals for (both stand alone and embedded) RRI research and interaction activities.

## CSG Network for Society and the Life Sciences

On the national level, CSG will continue as a research network.

The objective of the network is threefold:

- The Network as an **expert network**. We want to strengthen our position as an intellectual partner for the European Commission and the international peer community in further developing the RRI approach through (international) meetings, lectures and strategic activities, notably (but not exclusively) in the context of Horizon2020.
- The Network as a **'proposal machine'**. Building on our expertise and international peer networks, we will join forces to create

optimal conditions for developing competitive proposals in the context of Horizon2020. In response to specific calls, teams will be set up, with PIs 'taking turns' in acting as coordinator for work-packages or proposals (MML and otherwise), but building on support from others.

- The Network as a **research community**. We will organise research days for mutual learning and exchange, where early stage researchers can learn the trade of RRI (capacity building) through lectures, interactive sessions and discussions, while making the output of new projects, as well as the legacy from previous CSG projects, available through the Network website (open access repository).

Prof. Hub Zwart will continue to lead and represent CSG in the period 2014-2015. The research focuses on a number of key (post-genomics) themes such as: bio-based society, sustainable bio-innovation, personalised health and human enhancement. The new network meets for the first time in December 2013.

## LISTEN network

A similar structure has been set up at the international level, namely LISTEN (Life Sciences, Innovation and Society Network). Our goal is to strengthen and develop this international network in parallel, predominantly at a European level (in view of contributions in the context of Horizon2020), but also on a global scale. So far, this has led to four EU FP7 projects (on neuro-enhancement, synthetic biology and two on science education) and an ESF Conference Series on sustainable bio-innovation, but also in the launch of an open access journal with Springer, *the Life Sciences, Society and Policy journal*,<sup>4</sup> edited by Ruth Chadwick and Hub Zwart.

4. [www.lssjournal.com](http://www.lssjournal.com)

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# Colophon

<b>Text</b>	Prof. Dr. Hub Zwart (ISIS, Radboud University Nijmegen) Scientific Director of <i>CSG Centre for Society and the Life Sciences</i>  On behalf of the Programme Committee and Management Team of CSG: Prof. Dr. Jacqueline Broerse, Prof. Dr. Martina Cornel, Drs. Frans van Dam, Prof. Dr. Michiel Korthals, Prof. Dr. Arend-Jan Waarlo, Prof. Dr. Patricia Osseweijer, Prof. Dr. Guido de Wert
<b>Images</b>	Rob Acket, Suus van den Akker, Bert Beelen, Digidaan, Thomas Fasting, Duncan de Fey, Maartje Geels, Sascha Schalkwijk, Tammo Schuringa
<b>Lay-out &amp; graphics</b>	Studio-HB