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Demos was responsible for the writing of the pamphlet on “Citizen scientists - reconnecting science with society”.

This pamphlet “argues that we need to find, learn from and support our Citizen Scientists, presenting five examples from around Europe – Veronique Chable from France, Angelika Hillbeck from Switzerland, Carolyn Stephens and John Sulston from the UK and Gianni Tamino from Italy. They join a long line of scientists who have, throughout history, helped science build its social conscience. By doing science differently, these scientists and others like them are challenging assumptions about the why, the how and the what of twenty-first century science.”

Demos printed 1000 copies of the pamphlet, spread a large part of the copies to the different project partners and to their own contacts. Copies were also distributed to the participants of the policy meeting of WP5 in Brussels. The pamphlet can be freely downloaded from the project website, the website of Demos and also from other project partners websites.

attached : **hard copie of the booklet**

Citizen scientists

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Jack Stilgoe

Preface: Fieldwork

Consider the cauliflower. The cauliflowers we eat now tend to be big, white and fluffy. They have been bred this way over the last 30 years, taking the place of the various Italian varieties that were once bred on farms. Europe has largely forgotten the other possible shapes, colours - green, yellow, pink and purple - and flavours of cauliflowers. In the fields and village markets of Brittany, a group of farmers, activists and scientists are trying to help us remember.

Veronique Chable is a scientist who wants to resurrect the biodiversity of cauliflowers before it is too late. She is well aware that, with the excitement of technological progress, we can ignore what is getting lost or forgotten. As scientific knowledge expands, the local knowledge of people like farmers is often downgraded. In agriculture, vast increases in productivity have meant that we get more food than ever. But, for some, the homogenisation of knowledge is reflected in the homogenisation of the food we eat.

Chable is a Citizen Scientist. She can't draw a line between her professional activities as a scientist and her responsibilities towards society as a citizen. She not only engages vigorously with the social and ethical context of her work, but has changed the way she conducts her research. She is part of a recent but rapidly-growing movement towards "participatory plant breeding" – involving small farmers and scientists. As a geneticist, she is interested in what she can offer to those small farmers who want to breed crops for their flavour rather their yield or their longevity. She helps cauliflower farmers work back through their crops' genetic heritage to rediscover varieties that were forgotten with the move to industrial agriculture in the second half of the 20th century. But as her interest in organic agriculture and biodiversity has grown, her colleagues have changed. Now, she says, "the best colleague for me is the farmer." Based at INRA (the national institute for agronomic research) in Rennes, she does the genetics while her colleagues do the breeding, the sowing, the harvesting and the eating.

The way Veronique Chable does science has evolved. She explains how most of her colleagues think “from the DNA to the plant.” She now works in the opposite direction, starting with the plants. Her lab extends way beyond the university, into the fields and her own village market. She finds it impossible to work alone. She works with NGOs like Reseau Semences Paysannes. Reseau Semences Paysannes – (the Peasants’ Seeds Network) represent those French farmers who are interested in the science of farming. The NGO connects Chable to the farmers breeding new (and often old) varieties of wheat, cauliflowers and other crops. But it has not been easy. For her to do a new sort of science, she has had to break free of other people’s expectations about how scientists should behave and the sorts of research they should do. This pamphlet is an analysis of, and an argument in support of, scientists like Veronique Chable – Citizen Scientists.

Towards Collective Experimentation

All scientists are citizens, but not all scientists are Citizen Scientists. Citizen Scientists are the people who intertwine their work and their citizenship, doing science differently, working with different people, drawing new connections and helping to redefine what it means to be a scientist.

Science is more and more important to the everyday lives of people, but it seems more and more distant. In the last decade or so, people interested in the connections between science and society have diagnosed a 'crisis of trust'. It seems that science is losing, if indeed it ever had it, its unquestioning public support.[1] At the same time, Governments who rely on the benefits of scientific progress worry that much science remains irrelevant to the economy. Across the developed world, countless initiatives try to squeeze the economic juice from scientific research. Scientists are increasingly asked to be businessmen. But the vital, if elusive, promise of science to society goes way beyond profits. If we want to reconnect science with society, we need to ask also how scientists can act as citizens.

BOX: "All scientists are citizens, but not all scientists are citizen scientists. Citizen Scientists are the people who intertwine their work and their citizenship, doing science differently, working with different people, drawing new connections and helping to redefine what it means to be a scientist."

History is full of Citizen Scientists. Their role and their interests have changed as the issues that animate civil society have changed. The two world wars and the cold war that followed revealed to society the power of science to do harm in the wrong hands. Scientists joined and in many cases led the debate about the use of technology, particularly Chemical, Biological and Nuclear weapons, in war and the use of science to legitimise such weapons. And these scientists redefined the idea of responsibility. As science grew in power, scientists accepted responsibilities far beyond their own laboratory walls.

Nobels and nobility

One of Albert Einstein's last acts as a scientist and citizen was to collaborate with philosopher Bertram Russell on a manifesto highlighting the new dangers of nuclear weapons and advocating peaceful conflict resolution. Einstein signed the manifesto two days before his death in April 1955 and it was published two months later. The manifesto's launch in London was chaired by the nuclear physicist Joseph Rotblat,

who had ten years previously worked on the Manhattan project to develop the first nuclear bomb.

Rotblat went on to establish the Pugwash conferences ("On Science and World Affairs"), which, over the next decades, would bring together scientists and others to discuss disarmament and global security. Pugwash served two vital roles, both of which depended on its status as a scientific forum. First, it encouraged scientists to discuss the consequences – intended and unintended – of nuclear war. Second, it was at times the only bilateral link between the USA and the USSR. Scientists came from either country to talk while their governments maintained frosty silences.

Certification of Rotblat's role as Citizen Scientist came in 1995 when he won a Nobel Prize: not for Physics, although he was an eminent physicist, but for his work on nuclear disarmament. Rotblat's Nobel peace prize was shared with Pugwash. In 2007, the Nobel Peace prize again went to a group of Citizen Scientists. This time, reflecting the changing prominence of big global and scientific issues, the prize went to the Intergovernmental Panel on Climate Change, who have over the last two decades analysed the scale of global warming and persuaded the world about its effects.

Rotblat, Einstein and the scientists on the IPCC have all been members of the scientific nobility. These eminent professors spoke out and the world listened. There have been and will continue to be others. Later in this pamphlet, we will meet John Sulston, a Nobel Laureate who has devoted his career to the exploration of the broader implications of his work.

But the argument of this pamphlet is that scientific citizenship is about far more than this. Scientists should not have to earn the right to engage in public life. Nor should they have to engage with geopolitics to have an impact. Citizen scientists exist at all levels and in different places within science. The challenge is to find them, learn from them, encourage them and support them.

"We have to learn to think in a new way"

Another nuclear physicist-turned-disarmament-campaigner, Frank Von Hippel, has written about the challenges of being a Citizen Scientist. He links his own activities to what he calls 'public interest science.' And part of the problem with being a Citizen Scientist is that it can be lonely:

> "Public-interest science has continued to be an activity indulged in by a relatively small number of university scientists and the small but growing number of scientists who were being employed by public-interest groups such as the Natural Resources Defence Council and the Union of Concerned Scientists."[2]

In this small world, people like Joseph Rotblat stand out because they are rare and their activities are so different from what we would normally understand as science. Bertram Russell, in his autobiography, described the sacrifices Rotblat had made in his quest for nuclear disarmament:

> "He can have few rivals in the courage and integrity and complete self-abnegation with which he has given up his own career (in which, however, he still remains eminent) to devote himself to combating the nuclear peril as well as other, allied evils."[3]

Citizen Scientists should not have to give up their careers. Indeed, one of the arguments of this pamphlet is that there are countless alternative ways to run scientific careers, many of which embrace citizenship. Rotblat, for his own part, tried not to separate his science from his other activities. Accepting his Nobel Prize, aged 87, Rotblat told the audience that, "I want to speak as a scientist, but also as a human being."He was echoing the sentiments of the Russell-Einstein manifesto forty years earlier: "We appeal, as human beings to human beings. Remember your humanity and forget the rest."

BOX: "Citizen scientists exist at all levels and in different places within science. The challenge is to find them, learn from them, encourage and support them."

For Citizen Scientists, extra-curricular activities are hard to separate from their science. As we will see in this pamphlet, engaging with civil society is rarely just a hobby. It changes the way that a scientist thinks. One of the most famous of Einstein and Russell's lines is that, if we are to tackle problems that involve science but are from simply scientific, "we have to learn to think in a new way."

Nothing personal

Looking back, we can highlight the personalities that have reshaped scientific knowledge and the scientific endeavour. But in the here and now the biographies of scientists are largely hidden. It is hard to observe scientists acting as citizens because science is resolutely impersonal. "Art is I, Science is we," as physicist Claude Bernard put it.

In a recent book, historian of science Steven Shapin looks at what it means to be a scientist and the relationship between science and the people who do it. If we take science as a systematic way of finding out the truth about the world, then scientific knowledge becomes inevitable, given enough time. This has led some to conclude that, as Shapin puts it, "scientists are interchangeable in a way that creative artists are not... it is the social nature of science that cancels out personal identity and renders it uninteresting and irrelevant."[4] Science is authoritative because it is nothing personal.

But this mutes the voices of individual scientists who, as we know from the history of science, have been involved in raising important questions about science, society and politics. We need to think about scientists as individuals because science is nothing without them. Editing out the individual aspects of science means that, first, we miss the creativity and insight that makes great scientists great and, second, we strip scientists of any responsibility. As will become clear in this pamphlet, asking new

questions and inviting new responsibilities changes the science that Citizen Scientists do.

Most scientists work for large institutions, but, more than any other profession, they are free agents, following their individual interests, building new projects, new networks and new processes.[5] Their ability to shape their own research and the world around them is often greater than they appreciate. The possibility for scientists to act as citizens in various ways is therefore enormous.

That said, they are influenced by external pressures too, and these pressures act to inhibit scientific citizenship. Public science funding has strings attached and scientific cultures reinforce particular expectations. Scientists are increasingly asked to meet the innovation needs of advanced economies and they are increasingly monitored as part of a move towards greater scrutiny of public funding. So while scientists are free to a degree, they are also constrained by an implicit set of assumptions about what counts as a good scientist.

Science is for many of its practitioners more than a career. It requires more than just an investment of time and brainpower and the rewards for scientists go beyond the financial. They do it because they think it matters. But some feel that this broader commitment to the collective values of the profession is fading. Science is changing "from a calling to a job."[6]

Learning from difference

Despite the top-down pressures of policymakers, science is still mainly built from the bottom up. In the public sphere at least, the collective edifice of scientific knowledge and the innovations to which it contributes disguise the input of thousands of individuals, all operating with a high degree of autonomy. Science is emergent and unpredictable. But as science become more socially important and asks bigger questions of policy, politics and society, we must find ways to connect it with civil society. As part of building what some have called a "new social contract for science,"[7] we need to ask how scientists can be empowered to act as citizens.

Science thrives on diversity and disagreement. We do not know where breakthroughs and innovations will come from, so it makes sense for research to point in different directions at once and to be constantly challenges by alternatives that might offer better answers. Over the last decade, we have seen groups of scientists leading the debate on the challenges facing the world, including climate change, poverty, food security and health. The IPCC are just one example. The Millennium Ecosystem Assessment and the International Assessment of Agricultural knowledge, science and technology for development are two others, and all of them have involved years of work by hundreds of scientists. Meeting these challenges will require the input of different disciplines and a huge variety of expertise.

A call to arms for Citizen Scientists is based on this need for diversity. For science to succeed in its own terms, and to meet the challenges faced around the world, we need diverse knowledge, diverse models of innovation and diverse people. But science currently risks being homogenised. Expectations of what counts as good science and

what good scientists look like are narrowing as the overlap between science, governments and industry grows. Science and civil society are pulling apart, and it is down to Citizen Scientists to bring them back together.

This pamphlet focuses on a few Citizen Scientists who are, in their own ways, doing things differently. It is a product of a larger two-year project on Science, Technology and Civil Society (STACS) funded by the European Commission. This project brought together scientists and NGOs to explore the possibilities for shaping new agendas for European research.[8] The argument here draws on in-depth interviews with five Citizen Scientists from around Europe – Veronique Chable (France), Angelika Hillbeck (Switzerland), Carolyn Stephens (UK), John Sulston (UK) and Gianni Tamino (Italy). These scientists are all asking new questions, doing things in new ways and challenging assumptions about science. Some are more famous than others – John Sulston has a Nobel Prize for his groundbreaking genetics work and Gianni Tamino is a well-known Italian politician. Much of the most valuable work done by Veronique Chable and Carolyn Stephens, on the other hand, takes place far away from the gaze of mainstream science, politics or media. Angelika Hillbeck found herself thrust into the spotlight because the topic she was working on – plant genetics – happened to erupt into public debate.

BOX: A call to arms for citizen scientists is based on this need for diversity and alternatives. For science to succeed in its own terms, and to meet the challenges faced around the world, we need diverse knowledge, diverse models of innovation and diverse people.

By looking at these Citizen Scientists and asking about their achievements, challenges, motivations, hopes and fears, we can learn some lessons about the future of science in society. The chapters deal with themes that emerge from talking to Citizen Scientists. Chapter three looks at how scientists can engage with, rather than try to disguise, the values of science. Chapter four considers the importance of scientists who do science in new ways. Chapter five tackles questions of politics, formal and informal. The final chapter concludes that we need to find ways to rediscover the diversity of science. Citizen Scientists provide alternative ways of seeing the world and engaging with it. If we want to foster innovative and publicly-beneficial science, we need to nurture and empower Citizen Scientists. But before we get deeper into the argument, we must ask what civil society is, how it overlaps with science and how links between the two might be strengthened.

Science and civil society

There has been plenty of thinking about with relationships between science and society in general. This has prompted a series of experimental conversations between science, the institutions of science and various members of the public. Citizens' juries and Consensus Conferences have blossomed, providing opportunities for citizens to have their say about science. But much of the work that takes place under the banner of "Science and Society" has failed to connect with the cultures, practices and systems of science itself.[9]

Systems of science find themselves increasingly under pressure from Governments and Industry to justify their funding in economic terms. If we are serious about engaging with the social context of scientific activity and the myriad social, ethical and political questions it raises, we need civil society to play its role as counterbalance to the private and public sectors.

Civil Society is a way to describe the mass of organisations and activities that are not captured by governments, companies or the private, family lives of people. It encompasses NGOs, interest groups and voluntary organisations whose motives are driven by some sense of values. It presents new opportunities and new challenges for science. As an idea, or a way of encapsulating a set of trends and challenging institutional and scientific dogma, civil society is increasingly important. As national governments find that power is dispersed up, down and sideways, the interactions that organise our lives can seem pretty chaotic. Civil society organises these interactions in a place that isn't the market and isn't the state. It's everything else. Those within civil society argue that it needs sufficient weight to balance the forces of privatisation, globalisation, commodification, militarization, environmental degradation and injustice that are ignored by states and markets.

Michael Edwards, a leading thinker on issues of civil society, identifies three ways of thinking about civil society, all of which provide points of engagement for science. First, civil society can be seen as a collective vision of *the good society*. This might be a society that is just, sustainable and open. But it is not just an extrapolation of particular points of view held by single interest groups. We need a way to work out differences. So, secondly, civil society is also the *public sphere,* where issues can be openly discussed and decided upon. Thirdly, civil society is the set of connections that groups and individuals draw to each other. It is what Edwards calls *associational life*.[10]

Simply put, civil society has a *why*, a *how* and a *what*. It is a goal to aim for, a way to achieve it and set of people and places that are involved. If we think about civil society in these terms, what does that mean for science and the role of scientists? Let's start with the *why*.

The *why* of science

Science, according to the standards story, is driven by curiosity. Scientists work on the problems that they consider interesting which, if we're lucky, will produce not only

good science but also benefits for society. This is the ideal of basic research, underpinned by what has been called the linear model of innovation. The linear model has been demolished time and again, but it stubbornly "outlives all falsification"[11] and is still used to justify science policies around the world.

In addition to science-for-science's-sake, science is increasingly seen as an instrument for economic growth. As European economies profess their desire to transform into 'knowledge economies,' they invest their hopes and their money in scientific research. In 2000 the European Union adopted the Lisbon strategy for growth. The aim was for Europe to become "the most competitive and dynamic knowledge-based economy in the world" by the end of the decade. The target set for R and D to hit an EU-wide average of 3% of GDP, from a mix of public and private funding.[12] Other countries and regions have been similarly enthusiastic, but what has been notably absent has been any debate of the ends of innovation – why are we so keen on investing in science? What do we want to get from science? What sort of world do we want to live in and how can science help us?

Demos has argued that there is a real need for science to rediscover a sense of 'public value' to run alongside the economic and the intrinsic value of science.[13] A closer engagement between science and civil society means that scientists can ask these questions. Civil society is rich with discussion of ends and intentions. It imagines a good society and considers what is required to get there. It focuses on needs – health, sustainability, poverty alleviation, clean water, new sources of energy and countless others – that might otherwise be overlooked. Science has a long history of talking about the public good, but its relatively weak connections with some of the neediest parts of global society mean that this is often out of step with social demands. The idea of public value means that, rather than making assumptions the public good, we find ways to talk about and explore what different groups will value.

The *how, where* and *who* of science

The last decade has seen some important innovations in how science is governed and how it is seen to relate to members of the public. Interest has grown in ideas of deliberation and democracy and how they might apply to science. We have seen attempts at public dialogue – upstream and downstream in scientific processes. And we have seen institutions start to respond, becoming more transparent and listening to a more diverse range of views.

According to one recent European report, dialogue activity that takes place around science risks being ineffectual if we don't see it as part of something bigger. The argument goes that we need to draw the connections between such activities and science itself, as part of a process of "collective experimentation."[14] The solution to the suggested gap between science and the rest of society is to acknowledge that, to an extent, we're all in this together. This means that barriers need to be broken down from all sides.

Science is driven by uncertainty. It is an unending quest to explore and explain what was previously unknown. But science is not very good at sharing its uncertainties. Scientists justifiably regard uncertainty as a technical matter, to be rationalised and

tackled. Scientists are wary of washing their dirty laundry in public, so the public image of science is often far more certain. From the outside, science is seen to deal in facts. The public acknowledgement of uncertainty is the first step towards collective experimentation. More and more institutions that use science now know that, if they want to make good decisions and keep the public onside, they must look for what they don't know. Collective experimentation invites wider discussion of bits of science that are often kept behind closed doors, which makes it messy. Society becomes the laboratory.[15]

The idea of collective experimentation is just as challenging to civil society organisations and politicians as it is to scientists. Politicians, decision-makers and NGOs often lean on science to provide them with answers. With collective experimentation, all sides have to become more open-minded. We are already starting to see changes in the way that science is organised and communicated. Much of this, as with the open source software community and Veronique Chable's participatory plant breeding, is about opening science up to public involvement while exploring new ways of doing research. It blurs the boundary between science and other social activities.

In the past, talk of citizen science has tended to focus on citizens. Galaxy Zoo, a web site that asks members of the public to help scan images of galaxies, is the latest in a line of citizen science activities that promise to get people involved in research.[16] But these activities tend to be a public relations exercise for science-as-usual. The science stays the same, while bits of the legwork are outsourced to ordinary people. In other fields, we see citizens genuinely contributing their own expertise. As concern has grown about biodiversity, amateur naturalists are increasingly recognised as experts in particular places and species, working with scientists to study the biological and ecological changes. Understanding the environment on our doorsteps demands the involvement of amateurs.[17] They extend scientific networks and become science's equivalent of what Jane Jacobs called "eyes on the street."[18] These interactions change the way that science is done and they create new sorts of knowledge.

BOX: Much of this is about opening science up to public involvement while exploring new ways of doing research. It blurs the boundary between science and other social activities.

In computing, the engagement of amateurs in innovation has taken the form of 'hacking' – a word which nicely reflects the spirit of playing and breaking with convention that has led to, among other innovations, Google and the Apple Mac. Linux began life when a computer student from Finland posted the code of for his new operating system on the Internet and asked others to comment on it and to improve it. Today, more than 20 million around the world use Linux, with more 100,000 users contributing to its code. As we will see later, patient groups are increasingly 'hacking' standard scientific research to find out more about the illnesses that affect them.

As citizens become more expert and scientists start to draw on their expertise, science changes. Veronique Chable is a scientist who knows that the farmers she works with have far more expertise about farming than she ever will. The more closely she works with them, the more her role changes. This is where citizen science gets really interesting. If we are serious about collective experimentation, we must ask what it means for science and scientists. For philosopher Bruno Latour, writing in Nature, scientists need to be actively involved in reshaping science:

> "Scientists now have the choice of maintaining a 19th-century ideal of science or elaborating – with all of us, the hoi polloi – an ideal of research better adjusted to the collective experiment on which we are all embarked."[19]

At the same time, we need to consider how organisations within civil society can play their part. Here, we can look to the US for examples. Ellen Silbergeld was senior scientist at the Environmental Defense Fund (EDF), an American NGO. Because of the opportunities enshrined in law for public participation in environmental regulation, US environmental NGOs like EDF have employed highly trained scientists on their staffs since the 1970s. According to Silbergeld:

> "Science is a respected voice in the US NGO community, and EDF for one has relied upon its scientists to develop policy positions. When I first joined EDF, after a career in research science at NIH, I found myself in disagreement with the existing NGO position on regulating all PCBs as equally toxic. When I expressed my concern, my colleagues were immediately responsive, and our position was modified... Our proposal was adopted by the EPA and eventually by most other countries."

For most European NGOs, however, they simply don't have the resources to get too involved with science. Greenpeace has a science laboratory at the University of Exeter. Other NGOs – patient groups in particular – have found ways to work with scientists. But on the whole, John Ziman (physicist, sociologist and Citizen Scientist himself) is correct to say that civil society organisations...

> "...have puny research resources by comparison with their state and corporate opponents. They seriously lack, and desperately need, the means to aquire reasonably reliable, scientifically validated information on a great variety of highly technical matters. They ought not to have to rely on whatever happens to emerge out of the research system. They need to be able to initiate research projects relevant to their political missions, and have full access to their findings."[20]

Science, Ziman argues, is increasingly important for debates within civil society, but research agendas have drifted away from the issues that matter to NGOs:

> "Because these bodies have no direct influence over the agenda of research, they are seriously limited in the use to which its results can be put... "It is not enough to talk vaguely about greater popular 'partitipcation' in science, or making scientists more 'ethically sensitive' or 'socially responsible.' Civil society badly needs its own research capacity."[21]

Ideally, NGOs would be ask and answer their own scientific questions by funding research. But as an alternative, it seems sensible to suggest that a share of public research funding should be allocated to issues that are of interest to civil society. In order for this to happen, however, we need to rethink how science is supported and who is involved.

The *what* of science

Reflecting on the *why* and the *how* of science begs the question *So what*? How will new relationships between science and civil society change science? The first response is that new types of science, involving new people, will necessarily look at different things, ask different questions and so come up with new answers. The *what* of science is in fact the product of all of the individuals who contribute to the scientific endeavour.

Science is increasingly bound up with a wider discussion of innovation. So if we take seriously the possibilities of Citizen Scientists working with civil society, we should also expect new sorts of innovations. Science and innovation are often seen as inevitable. Policies tend to focus on speeding up innovation and removing the barriers to its progress. Little thought is given to the *direction* of innovation.[22] Closer engagement between science and civil society opens up new directions for science and innovation, leading to new possibilities.

A third sector of knowledge production

Claudia Neubauer from Fondation Sciences Citoyennes argues that strong science-civil society links can create a "third sector of knowledge production." This has been observed as a powerful force in past controversies involving science (e.g. Chernobyl, AIDS, BSE, asbestos, climate change and the debate over Gentically Modified foods). Third sector knowledge can provide a powerful counterbalance to state and corporate interests by...

- ...originating outside standard academic institutions and companies
- ...being built by and for interest groups (patients, farmers, local communities, users of technology or others).
- ...exploring alternative futures and new directions for research.
- ...mobilising the reserves of creativity, curiosity and intelligence within civil society, resisting the logic of markets or professional interests. [23]

Third sector knowledge production is one way of thinking about the distinct contribution that can be made by Citizen Scientists. It suggests new possibilities for scientific knowledge and scientific practice. But it also asks difficult questions about scientific motivations. If we want Citizen Scientists to make a real difference, we need to explore ideas of scientific *value* and *values* that science is often reluctant to discuss.

The Value of Science and scientific values

In 1994, Sharon and Patrick Terry's two children were both diagnosed with a rare genetic condition.. A dermatologist finally identified Elizabeth and Ian's persistent rash as pseudoxanthoma elasticum, or PXE. The disease affects about 1 in 25,000 children. It starts on the skin, but often spreads to affect the intestines and eyes, causing blindness or countless other problems. Like other 21st century parents, they tried to gain some control by finding out anything they could about the disease. The diagnosis came two days before Christmas. Sharon describes her experience:

> "I came home numb and terrified. I called Pat, my husband, desperately wishing he had come to the appointment with us... we delved into a morass of medical literature, trying to sort truth from fiction. Popular medical resources such as the *Merck Manual* described the condition in dire terms, including the possibility that our kids would die at age thirty... And so on Christmas Eve we learned about genes, recessive inheritance, pedigrees, and mutations. The doctor was frank about the limited understanding of the condition."[24]

Realising that most of the science behind the disease was in subscription-only journals, they had to travel to libraries to read the online articles. And the more they found out, the more they realised what was still unknown:

> "We learned that helping loved ones through a health crisis was not like taking a number at the deli counter. If research on PXE wasn't being done, we couldn't just wait until they called our number—they might never get to it. So we spent the weeks following our children's diagnoses in medical school libraries... We copied every article we could find and brought them home to read, quickly learning that we also would have to invest in medical dictionaries; encyclopedias; and biology, genetics, and epidemiology textbooks. Pat poured all of his energy into understanding the science behind the research—his way of coping as a distraught dad. And every glance at the lesions on our kids' necks renewed our fear."[25]

They got in touch with university researchers who were looking at the disease. For these scientists, patients were a vital source of information, helping point the way to the disease's culprit genes. But the Terrys wanted to contribute more than just their genetic idiosyncracies. They talked to scientists around the world and asked them why the research wasn't being done. The responses suggested that scientists didn't regard it as sufficiently interesting. So they started a combined research and support group that would nudge research onwards while bringing together families with the condition. Within a year, the couple had started a tissue bank, set up an epidemiological study and built an international research consortium. At all stages, they have encouraged the free flow of ideas and open access to knowledge. Driven by their own highly personal commitment to the issue, they have reinvented the science of PXE.

Sharon Terry has continued to crusade for the illness and for issues of open access to scientific research. She became president of the USA's Genetic Alliance, a body bringing together the small organisations with interests in genetic diseases. But she

also became in 2004 the first non-scientist to be named on a patent for a gene, the gene that causes her children's disease.

Sharon and Patrick Terry are Citizen Scientists from the other side of the tracks. They join a small but fascinating group of people who have, through circumstance or passion, become experts in an area of science and helped to redefine it. The story of Lorenzo's Oil is perhaps the most famous example,[26] and in the 1980s, groups of AIDS patients also became experts as they worked with scientists.[27] PXE international is one of hundreds of patient groups who are increasingly interested in the *why*, the *how* and the *what* of scientific research. Taken together, these groups have enough influence and funding to change the shape of medical science. In the UK, the Alzheimers' Society supports research into the condition and has created a new model for funding science, using patients and carers to judge scientific proposals.[28] A US social software platform, patientslikeme (www.patientslikeme.com), which began as a way for patients share experiences of their illness is now generating some disruptive science of its own. In 2008 a group of more than a hundred Amyotrophic Lateral Sclerosis patients decided to run their own clinical trial, testing lithium as a treatment and comparing notes on the web site. This has caused alarm among some clinicians, but patients argue that normal science is too slow to help them.[29]

The involvement of non-scientists makes for a great story, but it complicates the way that we think about science. Science is normally seen as driven by rationality, not by emotions and passions. But the interaction of science and civil society is about far more than what we know. It is also asks questions about what we value.

Truth and passion

Discussions of citizenship and civil society revolve around values – interests, preferences, priorities and visions of the world in which we would like to live. Linked to this is a broader debate about the value of activities such as science, art, security and other aspects of social life. Science has trouble with values, which means it gets into difficulty when we come to discussions of its value.

Despite evidence to the contrary, institutions and cultures of science prop up the myth that science is neutral in terms of values. Science, the argument goes, gets its authority from its separation of facts from fancies. Science is impersonal and it must not be clouded by bias. Scientists need to take themselves out of the equation, suppressing values in the quest for objectivity. Galileo's vision was of “the facts of nature, which remains deaf and inexorable to our wishes.” Mathematician Henri Poincare said that science and ethics “can never conflict since they never meet. There can no more be immoral science than there can be scientific morals.”[30]

Philosophers agonise about the extent to which science is value-free or value-laden. Do values leak into the content of science or just its application?[31] At the simplest level, we know that science is a process practised by human beings, who make judgements, so we know that values matter. We need to be more open about values if we want science to play an active role in society.

A healthy civil society, according to Michael Edwards, combines and balances reason with love.[32] Science traditionally emphasises reason and is coy, at least in public, about passions, loves and values. But its practice and its people are often deeply passionate and value-driven. Behind much science, explicitly or implicitly, sits a vision of a better world. Science has always in fact been a key part of civil society.

According to one thinker, "a better knowledge and appreciation of the values embedded in scientific inquiry are essential for a liberal civil society."[33] And a better appreciation of science's explicit and implicit values gives scientists a more constructive role: "Doubts about value-free science call for similar changes in how we conceive the obligations of scientists and the public. If science makes value commitments, then scientists are responsible for those commitments – for making them explicit and considering their consequences."[34] The philosopher Helen Longino argues that "values are good for science – the values of truth, objectivity, accuracy and honesty in results are integral to most notions of good science... we should stop asking whether social values play a role in science and instead ask which values and whose values play a role and how."[35] Robert Merton famously described "the normative structure of science" – the codes and cultures that maintain science and scientific integrity.[36] Another philosopher, Karl Popper, drew direct lessons from science for the rest of society. He used science as an epitome of what he called "the open society."[37]

BOX: The increasing privatisation, commodification and constriction of science, often in the service of corporate motives, has met with a value-driven movement from within science in favour of universal access to research.

The value of openness defines science at its best but is under growing pressure within and around science. When Sharon Terry tried to find out more about her children's disease, she came up against a familiar barrier. The research she was trying to access, much of it funded by taxpayers, was inaccessible. In a sea of free online information, the newest and most authoritative knowledge was only available to those scientists with subscriptions to journals. As she took forward her research plans, she also found that scientists were unpleasantly competitive, often unwilling to share tissue samples or data with their colleagues.

The increasing privatisation, commodification and constriction of science, often in the service of corporate motives, has met with a value-driven movement from within science. The argument in favour of universal access to research, via online open access journals, has been led by scientists such as Nobel prizewinner Harold Varmus. Inspired by Arxiv.org, which is used by physicists to share early data and speed up research, Varmus asked whether a similar approach would work for biology. Hi idea, which would later become PubMedCentral, provoked a massive reaction from science publishers, who saw it threatening their own business models. And, in a turn that is familiar from our stories of other Citizen Scientists, this reaction only hardened Varmus's resolve:

> "I believe that science is one of those activities that improves the state of the world, and once you realise how important publication is in the series of acts

> that constitutes the doing of science, and once you understand the incredible transformation of that publication process that the Internet, and software, and the whole digital world, now promises it is hard not to be pretty passionate about trying to make that part of the scientific universe work more effectively."[38]

The DNA of science

The passion of people like Harold Varmus helped ensure that, when the Human Genome Project (HGP) brought together publicly-funded scientists from around the world, data was shared and published as freely as possible, in sharp contrast to Craig Venter's private efforts to concurrently do the same thing. In the UK, the leader of the human genome project was John Sulston, a scientist who has, through his involvement, become a Citizen Scientist.

Sulston spent the first decades of his career working at a lab bench, looking through a microscope at *C Elegans*, a worm whose genome would eventually earn him a Nobel prize:

> "I was a loner. I was perfectly happy. I've spent large parts of my life doing science and absolutely avoiding politics, even internal lab politics because I was much too busy and I found it a distraction... it wrecked my day in terms of doing research. The Human Genome project hugely raised the society side."

As worms have been superseded by humans, Sulston's work has taken him to the top of one of the most important scientific projects of our age and made politics unavoidable. The Human Genome Project threw him into a discussions of values, ethics and what it means to be a scientist in the 21st century. Nearing his retirement, he was surprised by the turn his career took. "I left the scene as intended, only to find myself not backstage but in another theatre and invited to keep performing."[39]

The way he tells it, his transformation began at a conference in Bermuda. The project was still in its early stages. Scientists around the world were starting to work on sequencing bits of the genome and came together for an International Strategy Meeting on intellectual property. The conference discussed the trend towards patenting newly-discovered genes in the hopes that they may one day lead to new and lucrative medical treatments.

What Sulston refers to as the "genome gold rush" had taken many of the HGP scientists by surprise.[40] Sulston and his colleagues saw that it raised ethical questions, but more immediately they saw that it threatened to scupper the interational collaborative effort to map the genome. They decided at the conference that if the project was to succeed, information would have to be shared quickly and freely between the various researchers around the world. (Sulston, incidentally, would be critical of the patenting of Sharon Terry's PXE gene).

Speed was becoming increasingly important. Less than two years after the conference, Craig Venter would start his own privately-funded project to compete with the public scientists. Sulston had seen labs around the world all trying to sequence the same

section of DNA. He was keen to avoid duplication and get all the scientists collaborating. The decision was a practical one, designed to speed up the science. But the implications were wider. What Sulston had originally jotted on a whiteboard at the conference became "The Bermuda Principles." These discussions introduced John Sulston to some new questions about how to do global, collaborative science and the ethics of openness:

> "It started with this business of data handling. It goes back to 1996, the meeting in Bermuda, where we had the Bermuda agreement that applied to all public genome labs in the world. Rather to my amazement, we got agreement that we would release all the data instantly. We had about two dozen labs around the world all trying to sequence a tiny bit of the X chromosome because it was supposed to be important in cancer. There was a combination of professional and commercial motivations that was ugly, and was going to get in the way of sequencing the human genome."

From these practical beginnings, Sulston's interest in the social and ethical context of science blossomed:

> "Once you start paying attention to one intellectual issue, you start to think about intellectual property, you start to think about this and that and the other. The NGOs got a hold of me and asked me what I thought about access to medicines and so on. It all developed out of that. But the impulse was that collision over the handling of human genome data."

Sulston went on to work with Oxfam, Médecins Sans Frontières and other NGOs. He wrote a book about his Human Genome Project experience in which he reflected at length on the changing ethics of science. Most recently, he has created a new academic institute for the study of science, ethics and innovation. In less than ten years, his career has changed dramatically. As he puts it, "I have found at the end of this process that I am a full-time *something*, but not a bench scientist."

BOX: Science has always had multiple motivations, but as biotechnology attracts more industrial interest, the private motivations and justifications for science have grown louder and those that are public, curiosity-driven, value-driven and needs-driven have been muted.

Sulston's involvement with issues of ethics reflects how the world has changed around him. One of his first jobs was at the Salk institute in California. In the 1950s, Jonas Salk invented the polio vaccine that would lead to the almost complete eradication of the disease. In 1952, Salk was asked "Who owns the patent on this vaccine?" to which he replied: "The people, I would say. There is no patent. Could you patent the sun?"

From Sulston's perspective, the clamour around biotechnology has drowned out the ideals of people like Salk. Science has always had multiple motivations, but as biotechnology attracts more industrial interest, the private motivations and

justifications for science have grown louder and those that are public, curiosity-driven, value-driven and needs-driven have been muted. As Sulston describes, “The tendency over the last twenty five years has been to thicken up the private to the detriment of the public, uncommitted funding.” His aim is to make science “more public, more transparent, so the scientists are thinking about what they’re doing.” Part of this is about individual scientists acting as citizens, but the lessons are systemic. Sulston refers to the case of Nancy Olivieri, a haemotologist who, while running a drug trial, detected adverse effects.

Oliveri was a whistleblower who broke a confidentiality agreement and was subsequently sacked from her university post, sparking a debate about research freedom and corporate control. For Sulston, the first lesson is that science needs whistleblowers. But the second, which we will see when we meet Angelika Hillbeck in the next chapter, is that we need to think beyond individuals. In Sulston’s words, “When it comes to things like the Oliveri case, it’s really an institutional issue.” Recent moves towards ‘soft governance’ in science tend to emphasise individual ethics and responsibilities.[41] We need to be constantly bear in mind the institutional and systemic dimensions. As Sulston puts it, scientists need to consider their “collective integrity” and their “institutional integrity” in addition to their integrity as individuals.[42]

Sulston is acutely aware of the trends that are taking contemporary science further away from civil society. And he sees huge value in closer engagement:

> "Will anything offset the power of companies, and provide some democratic limitation to their ambitions? A likely source of balance is to be found in the NGOs, such as Oxfam... Should scientists see themselves as part of a worldwide NGO? I think that's exactly the way they used to be... and actually this international fellowship is by no means gone - but it's threatened when people try to walk both sides of the line, mingling scientific contribution with profit-making activity. The two do not mix well."[43]

As a scientist, John Sulston has conducted groundbreaking research. As a Citizen Scientist, his impact stands to be even greater. He is interested in the protection of what he calls "the ethic of science, which recognises the commonality of the ever growing body of knowledge and the need for it to be freely available to all, for any purpose."[44] This means asserting and continually rethinking why science is valuable and what its values should be.

Doing things differently

John Sulston is clear. He was a scientist before he became a Citizen Scientist. He conducted pure research for most of his professional life, turning to ethics in semi-retirement. Others are born Citizen Scientists. Their engagement with the wider world infuses everything they do. These are the Citizen Scientists that you are less likely to have heard about, and their style of science is much more radical.

In her scientific quest to increase the biodiversity of crops, Veronique Chable finds herself working very differently from her colleagues at INRA in Rennes. Her approach of starting with plants rather than genes has turned her science upside down. She connects with Citizen Scientists across France, but her immediate collaborators are more likely to be farmers and NGOs than her colleagues along the corridor.

She now finds that, as the shared aims of her work with NGOs become clearer, the type of work she does become more varied. Much of it is scientific, and much of it involves other forms of experimentation – with local communities and with politics at various levels. Her work with local farmers' organisations has taken her into discussions of ownership and intellectual property. Organic farmers who are interested in breeding for diversity are hamstrung because they are not legally allowed to own their own seeds; they must choose from an approved list. As the movement has grown, Chable has helped create associations that can own seeds on behalf of farmers to get around this problem. The very existence of such partnerships challenges the existing models of agriculture and intellectual property.[45]

As she becomes more involved with science and politics, she has become more aware of the contradictions of scientists:

> "Even scientists who work with seed companies. They've told me that in their gardens they prefer my seeds. They know that modern seeds don't produce good food… I had to talk to someone who was writing a report about seed regulation. My first question to her was 'where do you buy your food?' and she told me that she went to the farm next to her house, because she preferred to eat good food… They have two minds: their scientific mind and their way of life, and they keep them separate. When they're in the lab, they think genetically, and at home they think completely differently about food."

For Chable, being a Citizen Scientist means being more honest about the connections between her life, the lives of others and her work. Her colleagues, however, have taken some convincing. Like other Citizen Scientists, she felt institutionally uncomfortable, so she moved. At INRA's department of Science for Action and Development, she has been able to build her work:

> "This department originally brought together all of the researchers who were thinking differently. Others at the institute thought that the department was rubbish, full of researchers who weren't able to work normally. It depends on your point of view. I have found a home."

At her new interdisciplinary home, she has not just been able to conduct participatory research. She has also opened up new avenues of science. Her work with cauliflowers

has led her, in common with geneticist colleagues around the world, to question a reductionist genetic view of nature. As she links genetics with local environmental contexts, more of her work falls into the emerging field of epigenetics, which explores the possibility that there is more to breeding and inheritance than just the alphabet of DNA.

For Veronique Chable, the way she does science is a world away from much of the science she sees taking place around her. It is, she says "a new way of thinking." Her way of thinking – what Thomas Kuhn calls a paradigm – does not just shape her science, it determines her approach to the world. She finds that some of her older colleagues are taken by her passion for a new sort of science, and some of them have changed their work because of it. But for younger scientists, who are just starting to assert themselves through PhDs or postdoctoral projects, Chable's work seems risky. One of her worries is that the pressures on younger scientists make them "afraid to say what they think." Even though science thrives on diversity and innovation, Chable is doing things differently despite, rather than because of, the system around her.

The Popular Epidemiologist

Before she came to the London School of Hygiene and Tropical Medicine, Carolyn Stephens worked for, among others, the UK Department for International development, the WorldWide Fund for Nature and a Buddhist monastery in India. Her approach to science reflects her background. She starts with the immediate needs of people, asking what makes them unwell and whether their surroundings might play a part. The area of science in which she works – environmental epidemiology – should in theory address exactly this question. But like any profession, it sometimes loses sight of its purpose. Stephens wants to help her colleagues get out of the lab and remember why they do what they do.

BOX: Popular epidemiology appreciates the limits of scientific expertise and allows for the possibility that local people might know what they are talking about.

Stephens's approach to epidemiology has more in common with Erin Brockovich – the American legal clerk who in 1993 investigated the toxic water of Hinckley, California. Brockovich is the most high profile example of what Sociologist Phil Brown calls "popular epidemiology," a groundbreaking, if messy, form of citizen science. In the 1970s, in Love Canal, upstate New York, a spate of miscarriages and birth defects led residents to discover that they were living on a toxic waste dump, described by the US Environmental Protection Agency as "one of the most appalling environmental tragedies in American history."[46] It took the combined efforts of scientists, citizens and politicians to analyse and address the problem.

Phil Brown has been involved with and documented such grassroots research. He described the collaborations between residents and scientists as both scientific and political. When they worked well, scientists listened to residents, took advantage of

their local knowledge and trained them to conduct further research. The citizens became scientists and the scientists conducted important research that directly targeted citizens' concerns.

Carolyn Stephens is a proud popular epidemiologist. She begins research projects by asking local people for their own hypotheses. She says, "I have a reputation as being a scientist who is sympathetic to listening to what communities say." She sees herself working on behalf of the public, conducting research that is relevant to them and takes account of their own experiences. This has taken her to South America and more recently to East London, where she has worked with community groups on the relationship between ground and air pollution and health problems.

Popular epidemiology appreciates the limits of scientific expertise and allows for the possibility that local people might know what they are talking about. Stephens illustrates this with an example of a colleague who was doing some work for the nuclear industry. The scientist in question was trying to explain why a group of workers with the least exposure to radiation seemed to be the least healthy. The answer, only reached by asking the people themselves, lay in the fact that this group were putting their Geiger counters in the fridge. This would reduce their readings so that their employers would allow them to continue working overtime.

When scientists start with citizens' concerns rather than their own expertise, there is no reason why one area of science alone should be able to answer people's questions. Popular epidemiology is necessarily multidisciplinary, which makes it very messy. It is as much about society, culture and politics as it is about the aetiology of disease. Stephens finds herself engaging in activities that would not normally be considered science. And, like Chable, she often finds herself working with non-scientists.

She has come into contact with people that she would never have met had she taken a more conventional approach – people like Raul Montenegro, an evolutionary biologist and head of FUNAM, a grassroots organisation in Argentina. Montenegro's work with communities on environmental issues earned him a Right Livelihood Award in 2004, often referred to by the NGO community as the Alternative Nobel Prize.

The London School of Hygiene and Tropical Medicine is unusual in focussing largely on global challenges, so researchers there are used to having their eyes opened to new cultures. But like Veronique Chable, Stephens is aware that she fits oddly into her institution. At the same time, she sees value in getting her colleagues to think differently. Since she began working with communities in East London she has invited more than three hundred schoolchildren into her university for work experience. They have conducted research projects, made films, helped in labs and started discussions among researchers about the ethics of research.

> "Two of them did fieldwork about mosquitoes in Barking and Dagenham and whether they were malarial, while another student filmed them doing it. He went onto win a couple of awards for his films. Another one wanted to look at natural resistance as an alternative to traditional cures and vaccines… One of the projects, on ethical challenges faced by researchers, really blew away the students at the school. They were a bit surprised to be asked over lunch about their own ethical crises by these very serious 16-year old girls."[47]

Working with these young people got Stephens's colleagues thinking differently. The views of one scientist after the encounter reflect pretty well the advantages of doing things differently:

> "I guess one of the things that's quite important is putting it all in context, because I suppose one of the things with research science is you can get very specific, and what can get lost is the reason why you're actually doing it and what it contributes towards."[48]

Opening up the *why*, the *how* and the *what* of science

Citizen scientists do things differently. This challenges preconceptions about what scientists can and should do. According to Stephens, the culture of science is getting more narrow-minded, as reflected in communication breakdowns among scientists. There is a possibly apocryphal statistic that the average number of readers of a scientific paper is 0.6.[49] Researchers may claim that in their particular area of science, colleagues are more attentive, but it would be hard to find a scientist who would argue that in general the world needs to publish more scientific papers. Stephens is damming about the effect of publishing on science. According to her, "the culture of science is getting worse and worse in terms of quantity of publication and citation." Pressure to 'publish or perish' is creating a system she calls "incredibly myopic," in which most science is judged, or possibly ignored, only by the tiny subculture who also practice it.

> "You publish as much as you can for a very specific audience... So science becomes narrower and narrower, not just because science is about specialisation but because science is politically dominated by a particular model."

The risk is that, while the global problems demanding scientific input continue to grow, many areas of science become increasingly irrelevant. Scientists like Veronique Chable and Carolyn Stephens exist despite a system that otherwise narrows the *how* and the *what* of science.

> "Publishing in the Lancet over and over cannot constitute my meaning of life. I find [what I do] more interesting."
>
> Q: "Does it put you at a disadvantage?"
>
> "Of course it does, I'm not playing the game that most scientists engage in. My career went very fast for a few years while I thought 'this is a fun game' but then I thought 'actually, it's doing my head in. And that was when I stopped playing. And the more you do the sort of science I do, the less time you have for publishing and the more ethical dilemmas you have."

Much of Stephens's determination to do things differently comes down to politics. Carolyn Stephens is explicitly political. She puts herself "on the left wing of epidemiology, erring on the side of uncertainty that is with communities rather than

big oil companies or with landowners." Her science forms part of a broader political drive that is common in Citizen Scientists. But science and politics are often not happy companions.

Political Scientists

Science, as with any other human activity, is political. Many scientists try to ignore or resist the politics of funding, publishing, regulation or giving advice to government. They would rather be left alone to do their research. Citizen scientists typically find themselves engaging intimately with the politics of science. Some are born political, some acquire an interest in politics and many have politics thrust upon them.

Gianni Tamino is a rare hybrid – a scientist-turned-politician. He is part of a generation of scientists turned onto politics through the growing social importance of environmental science. Many within the environmental movement trace their origins back to the publication of a scientific book – Silent Spring – in 1962. Rachel Carson, a former marine biologist, provided a compelling case against many of the chemicals, in particular the pesticide DDT, that had started to see widespread use. She prompted both scientists and activists to start asking new sorts of questions about the impact of technologies on society. In the years since Silent Spring a new breed of scientists began looking in detail at the risks posed by various chemicals in the environment.

On graduating from his biology degree in 1970, Gianni Tamino was keen to look at and raise awareness of the environmental causes of disease. Following a stint as a geneticist as the Italian National Research Council, he turned his attention to the leather industry in his native Veneto. The tanneries around his University in Padua used Chromium to treat the leather, much of which found its way into polluted waste water. Chromium is a heavy metal which, in some forms, can be highly toxic. Chromium VI was the chemical at the centre of the Erin Brockovich story. A similar situation thrust Gianni Tamino into the light of public science for the first time:

> "Very close to where I lived and worked there was a leakage into the sewer system which resulted in the population not being able to use water from the tap. Citizens could not use water to wash or drink, because it was completely contaminated by the chromium. It was toxic water…This led me to go around the country and speak at public assemblies and public platforms to address this specific issue as well as the general issue of environmental pollution and its health implications. At this stage I knew that I was a scientist who wanted to focus on the population and the health issues facing them—but which they didn't know about."

Tamino realised that the work that interested him would be as much political as scientific. In the 70s and 80s, high-profile chemical disasters reminded the world of the dangers of chemicals and the need for regulation. In 1976 a toxic cloud burst from a chemical plant in Seveso, just north of Milan, contaminating an area of six square kilometres. After more than 3000 animals were found dead and children were hospitalised, the authorities admitted that the cloud contained TCDD, a highly-toxic dioxin. By 1982, the disaster had given its name to a new set of regulations – the Seveso directive - in European law. In 1984, a far more serious chemical explosion in Bhopal, India, killed up to 20,000 people, kickstarting a long battle for full disclosure and justice for the victims.

Much of the public scepticism surrounding chemicals in the 70s was transferred to nuclear energy in the 80s. Nuclear power had seen its own accidents at Three-mile Island and Chernobyl. As Gianni Tamino's new concern with the environmental impacts of energy generation grew, he was put forward as a candidate for the Italian parliament. So began a decade and a half in which the politics behind his work were brought out into the open:

> "I have never considered parliamentary activity to be a profession as such, rather a particular phase in my life. In fact, I had no real desire to keep the position but when a dear friend and colleague who was an MEP died, I was asked to take up his role."

In both Italian and European parliaments, Tamino campaigned across the spectrum of scientific and environmental issues. He began debates on the safety of chemicals, nuclear energy and electromagnetic fields and the role of genetically-modified foods in Europe and the developing world. He has argued against animal research and patenting living organisms on both scientific and political grounds. He maintains a scientist's open-mindedness. He knows that in many such situations, the facts are uncertain and positions are up for grabs. The important thing is that they are discussed in the open:

> "I did not want citizens to have my same opinions, rather to have an opinion and to possess the tools to come up with their own options. Without this critical essence, there will be no change—there will be no new thinking and no new solutions…They must judge for themselves whether to believe or distrust an argument by being equipped with appropriate tools for critique. Everyone, in other words, must think for themselves."

This desire for open debate about science presents a challenge to civil society too. Having worked with countless NGOs, he is well aware that they are often not so open-minded, particularly when it comes to science and the developing world: "Some NGOs and international organizations do not question themselves and their policies towards the global south due to their own arrogance."

Tamino returned to science full time in 1999, following what he calls his "accidental role as an MEP." Like many academics, he finds that there is just as much politics within a university as outside it:

> "Well, I suppose I still "do" politics in a non-traditional sense, or maybe in the most traditional sense...My role is different from other university scientists, thanks to my experience within parliament… I'm not doing science just for the sake of science."

Science remains his primary passion, but he recognises the constant need to engage with society as a citizen. His life in politics was merely an extension of this desire to connect with social concerns. From an initial aim to spread awareness of environmental issues, his argument now is that science itself needs to change to respond to society's needs:

> "The old scientific paradigm ignores the collective interest and the common good. It's only aim is science for the sake of science and, as such, it is a very elite undertaking… The risk is that science is becoming ever more specific and ever more niche, in the hands of a smaller and smaller number of people. This needs to be changed, and I think that the public has more of a sense of the big picture. The risk is that science will be the property of a select few and, aside from excluding large chunks of the populations, this actually harms science too… Scientists do not always talk to each other, nor do they necessarily communicate their findings very well amongst themselves. So a change in how we distribute knowledge is overdue."

The challenge he describes is one in which both science and civil society need to change. Scientists need to open up and members of the public and NGOs need to get better at asking the right questions, challenging the received wisdom and using science for social ends:

> "Science goes hand in hand with society so we must constantly ask ourselves why study one thing or another—and this depends on the direction society is going in."

Many people have argued that, as politics becomes more and more dependent on science, we need more people like Gianni Tamino to join these worlds together. We need people who can draw connections between the possibilities presented by science and the desirability of different social and political choices. Scientists are often brought into politics as expert advisers. Their role is seen as being, as Winston Churchill put it, "on tap, not on top."[50] The career of Gianni Tamino suggests that there are other, equally important, roles that a scientist can play.

Thrust into the spotlight

Politics happens outside parliaments as much as inside them. Scientific and technological developments can raise political questions that may take scientists by surprise. From time to time, scientists find that their values and responsibilities are tested when the path of their work crosses into a particularly contentious area of politics.

This was how Angelika Hillbeck found herself at the centre of the controversy over the risks of GM foods. Hillbeck was, she says,

> "...a straightforward, typical, conventional, scientist going along the normal path of a career, getting published, going to conferences, presenting papers...Usually you're glad if anybody takes notice of what you're doing... I wasn't prepared at all for what happened."

In the late 1990s, her work on horizontal gene transfer attracted the attention of biotechnology companies who were developing new genetically modified crops. She was ready to earn her scientific reputation by publishing the first paper demonstrating that genetically-engineered Bt corn might have unintended effects on other species, when one of the biotech companies funding her university tried to silence her. Though

it was just an early study, Hillbeck's research questioned how much these companies really knew about what happened to GM crops in the environment.

In Hillbeck's words, her research suddenly became "a second rate Hollywood movie." She insisted on publishing the research, threatening to reveal instead that she had been gagged, and she found herself sandwiched between the biotech industry and campaigning NGOs.

> "I had a secrecy agreement with them and they didn't want us to publish a paper. I said 'there's no way you're going to stop me publishing this because my career is at stake. And this is as good as anything I've ever done, if not better.' So I insisted on publishing... that was when people started to explode and get really angry... Then they accused me of lying about my work."

Hillbeck was dragged into the public spotlight. She was faced with a choice – to opt for a quiet life or stand up for her science. She chose to stand and fight:

> "It's a very personal thing. You have to ask, 'Can I stand this, do I want to fight this, can I live through this? There's going to be tough times and am I up for that?' If you think you can't, don't do it... The ones that decide to fight are a certain type of people."

Hillbeck had a strong sense of her responsibility as a scientist and citizen. She felt that the interests of industry were constraining and misrepresenting her area of science, which would in turn lead to bad policy decisions. And she knew she was the only one who could represent the research she thought was important Her university tried to persuade her to back down but she has remained a powerful voice in the GM debate, working with NGOs, governments, regulators and politicians. The irony is that, as she describes, "If they (the biotech industry) had just accepted what I did, I would have gone away a long time ago... They created their own demons."

Groups that had already come out against GM foods inevitably seized on her work, and she found herself under huge pressure from both companies and NGOs. Interestingly, Hillbeck's experience has made her deeply critical of the way that NGOs instrumentally use science and scientists.

> "They would knock on your door, ask you to come and give a talk or whatever when they need it, but then you're on your own. They will offer you a shoulder to cry on, but you're still by yourself as a scientist... There's a game that everybody plays, and you only learn it the hard way."

This game is the politics of science that takes place in the overlap between science and industry. Hillbeck insists that she has just done what scientists should do – conduct research, communicate research and argue its merits in an open forum. But her activities have taken her far outside the boundaries of ordinary science. Her work became political and she stood up for her work, turning her into an accidental Citizen Scientist.

Hillbeck's gaze has widened to look at the wider relationship between scientists and society. She thinks it is vital for scientific ideas to be discussed in the open, and she

thinks society needs to be able to cope with diverse and critical scientific viewpoints if it wants to answer big questions. This is about more than just civil society; it's also about the future of science and innovation. Hillbeck has a clear sense that, if we are to meet the big challenges of climate change, food and energy security and global poverty, we need people who can ask difficult scientific questions. But she is not optimistic about current cultures of science:

> "It's critical for Europe to maintain a base of critical science; it's the source of innovation. Look at the situation we're in now. We've deprived ourselves of the people who could even conceive of the solutions to these problems, because we've only been selecting people who follow a kind of dogma. So it's a question of future survival."

Angelika Hillbeck has seen firsthand how disputes can be buried within science, and she knows how hard it can be to bring them back to the surface. She calls it 'critical science,' a term sometimes heard at the margins of science. But science should be by definition 'critical'. It should nurture discussion, debate and constant challenge. This requires a healthy diversity and a broad spectrum of alternatives. Just as biodiversity makes ecosystems more resilient, so diversity of scientific activity makes science better able to address the current and future challenges faced by society.

Rediscovering scientific diversity

50 years ago, CP Snow delivered a famous lecture in which he argued that the culture of science was drifting apart from that of 'literary intellectuals.' Science, he argued, was losing touch with the rest of society. His dichotomy is questionable, but he grasped the need to better connect science and scientists with other cultures and groups.

In the preceding chapters, we have met some scientists who are working with and within civil society to conduct research in new ways and ask new questions. They are building bridges between cultures. In doing so, they discover that such things are not easy. Being a Citizen Scientist means leaving the lab and entering the messy outside world, with all of its politics, its values and its myriad ways of seeing and doing things.

The aim of the pamphlet has been to scale up their experiences to be able to speak to science in general. These Citizen Scientists are notable because they are rare; the work they do is often an uphill struggle. Scientists and NGOs do not find it easy to mix. But both groups need to keep trying, or they too risk becoming entirely separate cultures. Both sides must learn to open up. We have recognised in this pamphlet that civil society groups are often unwilling to engage with the complexities of science, and that they rarely have the capacity to do so. But our focus here is on what science do, given that it has a greater command of resources.

BOX: Just as biodiversity makes ecosystems more resilient, so diversity of scientific activity makes science better able to address the current and future challenges faced by society.

The first step towards building links between the cultures of science and civil society is to recognise that both are in fact full of diverse cultures and practices. Science, even though it is populated by specialists, is diverse and wide-ranging when it is all put together. But there are pressures that act against the diversity of science. These are the pressures that we discover by talking to Citizen Scientists. Nurturing Citizen Scientists therefore means nurturing the diversity of science, and vice versa.

Diversity, alternatives and dissent

Much of the thinking that takes place under the 'Science and Society' banner works from the simplistic assumption that 'science' is one thing, 'society' another and their relationship is straightforward. The last book written by scientist, Citizen Scientist and sociologist John Ziman reminds us that people can perfectly reasonably have countless different attitudes to science because science can be so many different things at once.[51]

Pluralism is good for science. Like a biological system, scientific research thrives on diversity. It gets its collective strength from scepticism and the constant possibility of alternatives. If a line of reasoning or a set of technologies are found wanting, there are others that might be ready to take their place. Science is unpredictable and serendipitous. We do not know where the next breakthrough, insight or engineering marvel will occur, so governments support a breadth of research and innovation.

According to Ernest Gallner, "Civil Society is the idea of institutional and ideological pluralism, which prevents the establishment of monopoly of power and truth."[52] If science is to address the global social challenges that civil society identifies, it needs to reflect this diversity. As Ziman puts it, "our pluralistic society is itself stabilised by this plurality of the whole scientific enterprise."[53] Looking through the eyes of our Citizen Scientists, however, we see that there is a dangerous homogenisation of science taking place. In many areas, particular models of the *why*, *how* and *what* of science are crowding out alternatives.

Ever since Newton, scientists have been seduced by the possibility of a "Theory of Everything." In physics and astronomy, mechanical understandings of matter once looked able to explain everything from atoms to galaxies. In biology, the unravelling of DNA's four letters once seemed able to explain all of life from the bottom up. From such a perspective, sometimes called 'monism,' pluralism, diversity, dissent and the presence of powerful alternatives seem wasteful.

Homogenisation doesn't just take place within scientific theories. As science has become strategically important, and increasingly expensive, we have seen countries invest in 'Big Science,' to serve their national goals. This science demands confidence and it leads to consolidation of research projects – most visibly in scientific *Grands Projets* from The Manhattan Project to CERN. Science is instinctively global, but is often constrained by narrow national or regional goals.[54] As science is invested with more and more strategic importance, we need to consider what gets lost, to society, to civil society and to science itself.

People like Veronique Chable suggest alternative versions of the *why*, *how* and *what* of scientific research. The work that she and other Citizen Scientists do reminds us that there are countless ways to go about research, countless fascinating questions and countless possible directions in which innovation might travel. Many Citizen Scientists engage with civil society organisations because civil society provides such a rich source of alternatives. Civil society counterbalances the prevailing wisdom by suggesting new ways of engaging with the world and imagining the future. Closer engagement with civil society should therefore make for more innovative science while also imbuing science with a renewed sense of public value. So why aren't more scientists doing it? How can we nurture a new generation of Citizen Scientists?

Nurturing Citizen Scientists

The case studies of Citizen Scientists in this pamphlet demonstrate that challenges and opportunities exist at many levels, from the individual to the global. A coherent approach to building links between science and civil society needs to take into account the whole range of activities that make science what it is. It would be wrong

to be too prescriptive, given that the thrust of this pamphlet is towards nurturing diversity. But there are four broad ways in which we can encourage the next generation of Citizen Scientists:

1. **Opportunities to engage**

In a lecture to the American Association for the Advancement of Sciences, Neal Lane, erstwhile science advisor to Bill Clinton, spoke of the need for what he called 'civic scientists' – scientists who see it as their responsibility to address pressing social questions. He identified a gap in understanding that often inhibits civic scientists. But rather than just seeing public ignorance as the problem, he argued that science too needs to learn new things:

> "While there is great need for the public to have a better understanding of science, and we should promote this in every way possible, there is as great a need for scientists to have a better understanding of the public."[55]

Engagement between science and civil society is complicated. The gulf between scientists and NGOs often becomes more visible as both sides start to build bridges. Governments and other bodies therefore need to encourage these processes of 'collective experimentation.'

European funding programmes are moving in the right direction, opening up a 'third sector for knowledge production'. Strands such as the 'Research for the benefit of civil society organisations' within the Seventh Framework Programme are to be welcomed, and should be used as an opportunity to explore some of the ideas in this pamphlet in more depth. Around Europe and the rest of the world, various schemes have at different times tried to encourage researchers and civil society groups to collaborate. European 'Science Shops' have invited citizens into universities and invited academics out into their communities to create new research projects. In the UK, the recently-launched 'Beacons for Public Engagement' are trying to do the same. The Canadian Social Sciences and Humanities Research Council supports a network of 'Community-University Research Alliances'. And in Ile de France the PICRI initiative has since 2005 brought together citizens and researchers to fund research across areas of common interest.

Scaling up such efforts means thinking about collaborative research with the third sector in much the same way as with the private sector. Innovation systems around the world have tried to force universities and companies together. Science parks, public-private partnerships and research networks have tried to get industry and academia thinking alike, with some success. If our intention is broad public benefit and our targets are global challenges, we should start building imaginative new partnerships between university researchers and civil society.

Such initiatives can help reassert the place of academic research at the heart of civil society. They may open new avenues for research and chip away at the 'ivory tower' culture of universities. The European Commission should be applauded for their efforts to boost the role of civil society within research. Citizen scientists should now in principle have new opportunities for engaging with NGOs. But these new funding

schemes are a tiny fraction of total science spending and they could further marginalise Citizen Scientists if they are seen as a fringe activity. If they are to really succeed, we need to consider the culture and practice of science itself.

2. Building from the bottom

Science is an emergent activity. It resists top-down control. If we are interested in the governance of science towards social goals, we therefore need to consider how scientists themselves can be empowered to ask new research questions and build new research agendas.[56] The Citizen Scientists we have met in this pamphlet have done so despite rather than because of current cultures of science, and they have met with opposition from colleagues who have a more conventional model of science. Not all scientists should be Citizen Scientists, but it should not be regarded as an aberration. If we want to make life easier for Citizen Scientists, we need to think about how the rest of the scientific community views them.

As science has asked bigger and bigger social questions and public trust has remained elusive, senior scientists have expressed a need for new codes of conduct and a sense of social responsibility among scientific researchers. In the UK, former chief scientific adviser Sir David King recently published a 'universal ethical code for scientists.' Talking about the need for 'Rigour, Respect and Responsibility,' he argued that the code would "demonstrate to the public that scientists take ethical issues seriously."[57]

As a European Commission expert group report concludes, public unease about science is as much about its *ends* (the *why* of science) as its *means* (the *how*). Such codes therefore need to go beyond eradicating 'bad science' to rethink what 'good science' means.[58] Scientists themselves need to be actively involved in the debates about what science is for and what responsible science looks like in a rapidly-changing context.

Sociologist Robert Merton did more than anyone to explain how cultural expectations ('norms') shape science. Scientists, he argued, are driven by recognition and reward.[59] Current systems of recognition are almost universally dependent on scientific publications. Carolyn Stephens is certainly not the first scientist to identify the toxic effects on science of such a narrow-minded approach. For Citizen Scientists to get the recognition they deserve, and be able to build alternative but vital careers in science, we need to find ways to broaden this system. Open Access publication provides new opportunities – different sorts of science are likely to be published, in different formats and for different audiences.[60] And if enough scientists support the cause of open access, these journals will come to be recognised as equals alongside traditional publications.

Other systems of reward and recognition are connected more explicitly to government policies. University scientists across Europe are judged according to how much they publish and, increasingly, how much they engage in research with likely industrial benefits. This system of 'papers and patents' moulds scientists in its own image. Would-be Citizen Scientists are encouraged into more conventional careers. Universities need to consider alternative, but equally valid, career paths. One option is

to create the sorts of interdisciplinary research departments in which Angelika Hillbeck and Veronique Chable have found new homes. As both Chable and Hillbeck argue, such departments may be regarded by the outside world as scientific off-cuts, but they can be a vital source of innovation.

Cultures of science are largely built from the bottom up, but they are often constrained by policy. We should therefore look at the signals that are being sent by national and European policymakers.

3. Sending the right signals

With the adoption in 2000 of the Lisbon Agenda, Europe has seen a burst of enthusiasm for science and innovation, followed by a sense of frustration at a lack of progress. The aim was to create 'the most competitive and dynamic knowledge-based economy in the world' by 2010. The plan was long on vision but short on specifics. More recently it has been derailed by economic events. But its failure reminds us that innovation-for-innovation's-sake is not a sufficient policy agenda. European science now needs to rediscover the importance of governance. We need to ask again what science and innovation are for and what role they should play in Europe's future.

Current European science policies and funding distributed through European channels risk homogenising the diverse research possibilities across Europe. European science policies should try to bring out this diversity rather than flatten it. The creation of the European Research Council (ERC) is one opportunity to support a new sort of science, built on bottom-up scientific excellence. But the people involved know that scientific excellence is not fixed and not self-evident. Helga Nowotny, the Council's vice president, has spoken of the importance of threading a sense of public value through this research.[61]

European policymakers now need to consider how the institutions and messages that make up their science policies can be infused with a sense of public value. They need to send a clear signal to scientists that they don't think science is just about economic progress; it should also address global challenges. European policymakers should consider funding participatory research institutions through the ERC, addressing European challenges, with excellent European scientific research, in close collaboration with European civil society bodies.

4. Citizens and corporations

Finally, arguments in support of Citizen Scientists become all the more challenging when we consider private sector science. It is too easy to focus on universities – key institutions of civil society in themselves – and forget about the huge quantity of science that takes place within companies. Questions of citizenship are harder to ask when profits take precedence, but we should consider how scientists within companies can take responsibility for their research. We have seen with people such as Nancy Olivieri and Angelika Hillbeck that corporate interests can bleed into university research. As well as supporting those who speak out in such circumstances, we need to ensure that whistleblowers within companies are given due protection.

Scientists, whether they are in companies or universities, know that innovation needs diversity – the ability to think differently. In the 21st century, science and civil society are both faced with the need to address large global challenges, many of which have been identified through collaboration between scientists and NGOs. For too long Citizen Scientists have been seen as a fringe element of science. We should instead regard them as a model for how science can better tackle the problems that we all face.

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