

**GE³LS capacity issues:
an environmental scan for
CIHR Institute of Genetics**

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Abstract

In Canada GELS has become a well-established interdisciplinary field of enquiry involving bioethicists, legal academics, social scientists and others. However there are a number of concerns amongst both researchers and research funders regarding capacity within the research community. This report provides an overview and preliminary analysis of the concerns expressed by research funders, policy makers, those within the GE³LS community and other academics whose work might bring them within the GE³LS frame, even if they do not currently receive GE³LS funding. Comparison is made with the US and the UK. It is based on a series of 21 interviews with senior figures in Canada, the UK and US conducted in late 2007. Its main findings are:

- Widespread concern about the lack of tenure-track appointments for junior researchers entering the field as a result of tensions between interdisciplinary research and discipline-based nature of faculty appointments
- Concern that certain disciplines are under-represented within the field in contrast to the situation in the UK and US
- A range of views on the future directions of GELS research
- Need for improved capacity in research dissemination to general public, policymakers and scientists

Options for future directions outlined include:

- Long-term funding for development for one or more interdisciplinary GELS research centres
- Increased funding for a greater range of smaller studies
- Support for joint tenure-track appointments in two or more departments

This study has identified a range of perspectives and a range of policy options. It may well be that further research is required before deciding on the future course of action. Consultation with colleagues in Genome Canada who are conducting their own appraisal of GE³LS funding also seems appropriate and given the need to broaden representation from the social sciences, consultation with SSHRC involvement may be helpful.

1 Introduction

A commitment to research on the ethical, legal and social issues (ELSI) surrounding genomic science has been integral to the research process since the launch of the Human Genome Project. This unprecedented attempt to address the wider social implications of a scientific research project as it unfolds has brought together a diverse interdisciplinary group of academics, scientists and clinicians. Funding for ELSI research (or GE³LS as it has been termed in Canada) has been provided both by funding bodies for scientific, social science and humanities research. In the United States the primary source of funding is the National Human Genome Research Institute, in the UK funding has come from the Economic and Social Research Council and the Wellcome Trust, and in Canada funding has come mainly from Genome Canada and the CIHR Institute of Genetics.

In Canada GE³LS has become a well-established interdisciplinary field of enquiry involving bioethicists, legal academics, social scientists and others. There is sufficient funding to support a number of major research initiatives. Canadian GE³LS researchers are contributing to the academic development of their field of enquiry and participating in the development of policy at a federal, national and international level. Senior figures from the Canadian GE³LS community have a high international profile, with Canada showing particular leadership in the field of bioethics.

Yet there is concern about a possible lack of capacity with the GE³LS community, which is shared both by researchers and their funders. One concern is that the interdisciplinary nature of the field may mean that junior researchers do not have clear long-term career paths. Thus it is possible that talented researchers are lost to other fields and that valuable resources are used in training up these people, only for the process to have to begin again. So there may be a problem of **depth of capacity**. Another concern is that it is not clear whether there is much capacity beyond the major

centers of research. There is a perception that competition for research grants is limited with the same people applying for most of the funding. Furthermore the field is currently dominated by legal scholars and bioethicists. So there may also be a problem with **breadth of capacity**.

1.1 Scope of research and methodology

The aim of this project has been to provide a preliminary analysis of the issues to try and clarify the concerns of research funders, policy makers, those within the GE³LS community and other academics whose work might bring them within the GE³LS frame, even if they do not currently receive GE³LS funding. The key goal was to clarify the issues, using interviews to understand stakeholder perceptions of capacity; whether there are any issues which need to be addressed and if so, what they are and how they might be addressed.

This study should help to identify future priorities for capacity development and clarify if capacity concerns are widely held. Given its limited scale, it may also identify an agenda for future research on this issue.

1.2 Methodology

The project began with an analysis of relevant academic and grey literature (including the reports produced as part of the ERA-SAGE project). Two preliminary interviews were conducted with key stakeholders for orientation purposes and to road-test the list of research questions. One-to-one and group interviews were conducted with another 14 stakeholders in Canada. The majority of these were academics active within GE³LS research, but healthcare policymakers and representatives of GE³LS funding agencies were also interviewed. For the purposes of providing a comparative perspective a further six interviews were held with stakeholders in the United States and the United Kingdom, in order to compare issues such as funding sources and levels of funding and

learn from capacity analysis activity in these countries, for instance the NHGRI's shift to funding research centers and the Wellcome Trust's recent review of its bioethics funding stream.

1.3 Note on terminology

GE³LS - genomics: environmental, economic, legal and social issues

ELSI - ethical, legal, and social issues

The term GE³LS is unique to Canada, in the United States equivalent research is generally termed ELSI, a term which is also used in the UK. For the sake of simplicity the term GE³LS has been used throughout this report to refer to GE³LS research activities in both Canada, US and UK.

Interviewees - Where the report attributes views to simply 'interviewees' these are Canadian interviewees. US and UK interviewees are identified as such.

2 Depth of capacity

There was general agreement amongst interviewees that there was a problem in relation to depth of capacity. Many interviewees felt that this was the single most important capacity issue. In particular, that it was difficult for researchers to gain tenure track positions because of the interdisciplinary nature of GE³LS research and the imbalance between relatively generous levels of soft funding for fixed-term research work and more limited hard funding for tenured posts. This problem is not unique to Canada; UK and US interviewees indicated that the same issues have arisen in their countries.

There was also general agreement that neither of these issues are in any way limited to the GE³LS field; they are structural issues endemic to higher education. Research funding councils have greater freedom to operate in a more fluid fashion and can develop new capacities faster than universities, whose structures are of necessity more static and slower to change. Canadian universities support interdisciplinary research, indeed some interviewees felt that they are more open to interdisciplinary work than their counterparts in other countries, but when it comes to teaching and tenure-track positions they are very department-oriented. Some interviewees suggested that this disconnect between research funders and universities is inevitable, since it is not possible, or even desirable, to establish new academic departments each time a new interdisciplinary research field is established. Some also suggested that the tension may be a healthy one; that research councils act as a lever for change; there is a pressure on faculties to bring in research money and ultimately they can't meet the demand without giving professional recognition to academics working in interdisciplinary fields, for instance through joint appointments where staff are recruited to two departments.

2.1 Problems for new researchers

However, even if this disconnect does lead in the long term to structural change, this does not solve the immediate problems faced by new researchers coming into an

interdisciplinary field of research. Even for established academics there can be concerns about whether their ‘home’ discipline will recognise the value of what they are doing. For new researchers, the practical difficulties of seeking a tenured position from within an interdisciplinary field include: how do you maintain the skills and knowledge honed in your home discipline and where do you publish? This latter problem was highlighted by one UK interviewee who suggested that even where funding was available to take research fellows onto a tenure-track position, it was not being taken up as too many potential candidates for this funding were publishing in journals which are considered ‘low-impact’ by their home discipline, thus making them unattractive for the purposes of the UK Research Assessment Exercise. This issue can have an impact on dissemination of findings from GE³LS projects as well as on researchers’ career prospects. Furthermore, it is not simply the interdisciplinary nature of the field that may cause problems, other issues such as a hostility to multi-authored papers can also cause problems for GE³LS researchers in their search for tenured positions. Both US and UK interviewees indicated that the problems identified in Canada were also apparent in their countries, although there were differing opinions about the significance of the problem.

2.2 Institutional renewal

The tenure issue was discussed by some interviewees in terms of a process of institutional renewal within the GE³LS community. The current lack of tenure-track positions was cited as one of the main reasons that the field continues to be dominated by a small number of senior researchers. Some interviewees discussed this issue as largely one of organising an orderly succession, a need for: “fresh blood to replace those close to retirement.” Others suggested that new leadership was required if the field was going to progress and rise to new challenges (see discussion of breadth of capacity and future directions, sections 4 and 5 below).

Another perspective was that the rules on research funding distorted the true picture of leadership in the field. Since generally only full-time faculty members can act as Principal Investigators, it appears as if the field is dominated by a very small number of senior academics. However, this masks the reality that the ‘true’ PIs on many projects are in fact well-established postdoctoral researchers.

2.3 Lack of a coherent research community

A further consequence of this top-heavy system is that the existence of a coherent GE³LS research network is overly-reliant on the relationships between a small number of senior academics. Many interviewees suggested that Canada still lacks a coherent GE³LS community – the only serious networking activity takes place at regional level through the research teams and networks funded by Genome Canada. Several interviewees bemoaned the lack of national infrastructure such as regular conferences, a GE³LS journal and GE³LS website. The absence of such an infrastructure makes it more difficult for more junior academics to network with colleagues across the country.

2.4 Perceptions of gravity of problem

Whilst there was agreement about the nature of the problem, attitudes as to how serious it is varied. It is not clear that these concerns are affecting recruitment to GE³LS but one interviewee suggested that whilst there are many people interested in entering the field, they are anxious about their long-term career prospects. Whether this in fact impacts on recruitment to the field is not clear. The experience in the UK is that the significant levels of research funding available in the field have attracted a large number of young researchers and US interviewees did not indicate there were any problems in this respect. Neither did they suggest that the problems identified were having an impact on their ability to carry out GE³LS research.

Some interviewees felt that the more pressing issues relate to breadth of capacity (see section 4 below). Clearly some degree of turnover in any academic field is inevitable; not all those who complete PhDs will go on to academic careers; not all those who pursue academic careers will continue to pursue the same research interests they had at PhD or even postdoctoral level. One interviewee suggested that some degree of churn was inevitable at postdoctoral level in order to separate the merely competent from the truly outstanding. Creating sustainable capacity may only require that a reasonable proportion of the most talented researchers are able to continue their research interests in GE³LS. A number of interviewees felt that in general things gradually work themselves out – that many people who are willing to move institutions eventually find tenure-track positions. Several interviewees suggested that it is a good thing that some people leave the field and move into other related areas such as policy work for the government. Others pointed out that some leading Canadian research institutes are based primarily on soft money and that many researchers can maintain successful long-term careers on such funding. One interviewee suggested that career prospects for GE³LS researchers were better than for other areas of bioethics.

However, another perspective on the tenure-track issue came from one interviewee who suggested that tenure was important as a means to give academics the time to develop a more reflective approach to GE³LS. Thus a lack of permanent posts might have an impact on the quality of work produced and the range of questions explored, as individuals who might have the capacity to develop a more mature approach to their work as their career progresses instead find their work constrained by the limitations of short-term research contracts.

2.5 Solutions

Notwithstanding these caveats, interviewees felt that the tenure-track issue needs to be addressed and a variety of solutions were put forward. Some suggestions were

focused on working within the limitations of the current system and stressed the importance of mentoring new researchers on the need to be realistic about their prospects, to be careful where they publish, to keep a foot in their 'home' discipline, and be ready to move institutions and to consider work outside academia. Institutions also have a responsibility to help new people broaden their skills set, and to give them new responsibilities and challenges as their careers progress. Implicit in this individualised approach is the recognition that solutions will be person-specific, not one-size-fits-all.

Other solutions to the tenure-track issue were more structural. Whilst it is not possible to create a new university department every time you develop a new interdisciplinary venture, there are other options. It is possible to use temporary structures to bring new groupings together e.g. grants for seminars and for interdisciplinary training programmes. Research funders should also be willing to fund joint appointments – people with tenure-track appointments where individuals are based in at least two faculties. Another structural solution relates to the rules on eligibility for research grants: it was suggested that researchers with say five years experience should be able to apply for research money.

Another issue relating to depth of capacity is the way in which funding has been structured. Creating enduring capacity, it was suggested, requires sustained, large-scale funding and might best be used to create the type of dedicated GE³LS research centers which have been set up in the UK, the US and the Netherlands. The only large-scale funding which has been available hitherto has been from Genome Canada, and whilst this has allowed the development of some large research teams it has not established long-term centers. One interviewee suggested that the two different funding models each had their own advantages: that large-scale projects of the type funded in Canada are good for developing collaborations across institutions, but that centers are more suited to creating longevity. Some interviewees who highlighted this contrast suggested

that Canada's GE³LS capacity did not compare favourably with the UK's. However, one UK interviewee was sceptical about the level of funding provided by the ESRC, suggesting that in choosing to establish three centers across five universities the ESRC had spread its money too thinly and there was insufficient funding to develop a critical mass of capacity in any one of these institutions. US interviewees indicated that in their case the centre model of funding was too recently established to be able to gauge its success but it remains a central part of NHGRI's strategy for enhancing capacity in the field.

In the UK the Wellcome Trust has conducted a review of its bioethics funding programme and now intends to improve capacity by funding a series of centers and collaborations. In doing so, it has drawn on its long experience of funding work in the history of medicine, where research centers and units have been highly successful in developing capacity. Like the NHGRI it will provide funding for those who aspire to build the capacity to have a centre in the future. However, the Wellcome does not restrict itself to a centre model, it will continue to fund postdoctoral fellowships and provide bridge funding for tenure-track positions through its university awards scheme (under which the Trust provides a gradually diminishing proportion of the funding for a permanent post for a number of years until the university takes up the whole responsibility for the salary). Again this scheme has been highly successful in the history of medicine.

There was widespread concern that there is no current Genome Canada funding for new big projects – only small ones embedded in science projects. It was felt that if this continues Canada will lose capacity and in particular may lose out to the US where NHGRI are funding new ELSI centers. Whilst there was some disagreement about what the scope and focus of any new centers should be (see Future directions, section 6 below), there was support amongst a number of interviewees for the development of a number of GE³LS research centers in Canada. The example of both the Wellcome Trust

and the NHGRI would suggest that it may be best to enhance capacity by providing multiple forms of funding, supporting both individuals through PhD and postdoctoral funding, and institutions by developing centers.

It may also be helpful to strengthen the GE³LS community by creating infrastructure such as an annual national conference, a journal and website. Such initiatives can be seen in the UK where the Economic and Social Research Council (ESRC) has supported the development of Genomics, Society and Policy, an online journal and where national conferences are run by the ESRC genetics centers on a regular basis.

3 Breadth of capacity

Whilst concerns about depth of capacity were broadly shared amongst interviewees, there were significant differences of opinion on questions relating to breadth of capacity. Whilst it was generally agreed that the GE³LS field in Canada has been, and continues to be, dominated by lawyers and bioethicists, there was some disagreement about whether this poses problems. Some senior members of the GE³LS community felt in practice this presented no difficulties since they were able to bring in people from other disciplines as needed. Others felt that the problem was more fundamental and less easily surmounted.

Those who had greatest concerns about missing or underrepresented disciplines varied in which specialisms they cited, but the list included: economists, environmentalists, historians, political scientists, health policy experts, philosophers of biology, social scientists – sociologists (in particular people from Science and Technology Studies (STS)) and anthropologists (in particular medical anthropologists), and people with expertise in research ethics. Some interviewees pointed to the need for people with multiple skills sets, for instance in social science and ethics. One interviewee noted that whilst there are a growing number of scholars emerging in the field of STS, they do not seem to be going into the field of genomics. Another suggestion was that there was a lack of people with a bioscience background who understand the cutting edge of genomics science.

This was one area where there was a clear difference between Canada and the UK and US. Broadly speaking US and UK interviewees were satisfied that researchers from a wide range of disciplines were engaged in GE³LS research.

3.1 Cultural differences

This lack of breadth of capacity identified by many interviewees was attributed to a variety of problems. Sociology, it was suggested, is dominated by quantitative work – most GE³LS work is qualitative and is thus undervalued in the discipline, an issue which would compound concerns about the downsides of interdisciplinary work explored in the previous section. One interviewee suggested that medical anthropologists may be put off by a fear that they may not be competent to master the complexity of the science they would be studying. However, US and UK interviewees did not indicate comparable concerns and in the UK in particular, social scientists have been at the heart of GE³LS research using both qualitative and quantitative methods.

3.2 Grant-writing

A practical problem for those contemplating entering the field is the need to develop an awareness of what is required for grant applications. Writing successful grants, it was suggested, is now such a highly refined art form that if you are new to a field the only way to be successful is to hook up with someone who has a successful track record. One US interviewee also referred to the grant-writing issue, suggesting that in the US social scientists have been more successful than their colleagues in law and philosophy in gaining ELSI grants because they are able to write grants that are more like NIH grants. Some interviewees in UK and US indicated that there were particular challenges associated with writing grants for panels which might include an interdisciplinary range of scholars from the social sciences / humanities as well as academics from the hard sciences.

3.3 Scope and funding

Some interviewees pointed to a different set of issues to help explain the lack of disciplinary breadth. Some felt that the most important factor was the current conceptualisation of the purpose and scope of GE³LS research by research funders, in

particular what was characterised as an “overarching instrumentalism”, in which GE³LS research was seen as a mechanism for smoothing the steady progress of science, by ‘sorting out’ any ethical and legal issues and by breaking down public mistrust. Interestingly whilst this viewpoint was expressed by academics whose own work would place them a critical distance from the science they study, it was also expressed by some policymakers who felt that the GE³LS research community was too close to scientists, clinicians and industry to engage critically with crucial issues such as patents and regulation.

The view that an ‘overarching instrumentalism’ in the approach to GE³LS research can explain a lack of disciplinary breadth would appear to be contradicted by the fact that the ‘instrumentalism’ criticism has been levelled at the field in the UK and US, yet in those countries it attracts a broader range of disciplines. Furthermore, the current GE³LS model was defended by some interviewees who felt that GE³LS researchers have managed to strike a balance between maintaining a critical distance and engaging with practical issues arising from genomic science. It was suggested by one interviewee that ethics has to be embedded within science and policy-making and they questioned whether in practice funding would have been available for alternative research programmes. Furthermore, a number of interviewees raised concerns that, far from being too close to scientists and clinicians, GE³LS researchers struggle to engage with them and are often viewed with distrust (see below, section 5).

Related to this is the issue of co-funding. Whilst this is not an issue with CIHR Institute of Genetics research funding it was a concern with funding from Genome Canada. There was a view from some interviewees that the need for co-funding shuts out a large number of researchers who do not like this model and builds bias towards those who are pro-industry and influences research towards a supporting commercialisation. Critics of this model proposed that there needs to be more independent funding opportunities which do not require co-funding. However, it

should be noted that most co-funding for GE³LS research comes not from industry but from government. This does not mean that there is no potential for conflict of interest but it does indicate that there are viable alternatives to industry funding for those who are uncomfortable with this model.

3.4 Solutions

Is building breadth of capacity best achieved by the centre model of funding which was discussed in the previous section? Centers might be an equally useful way of developing a more interdisciplinary approach but the suspicion might be that the obvious places to develop centers would be some of the existing research teams which are currently dominated by lawyers and bioethicists. However, there is no reason why the establishment of centers in these institutions could not be done on the basis that they must involve at senior level a broader range of disciplines than are currently represented.

However, the centre approach is unlikely to be sufficient to address the issues regarding breadth of capacity, particularly if the concern is not simply that there is insufficient breadth of disciplines, but that is also a question of the breadth of institutions. A number of interviewees were concerned that GE³LS research funding has been focussed mainly on a small number of research teams. There was some support for the view that involving a broader range of institutions, as well as a broader range of disciplines, might best be done by funding a greater number of small projects. Even senior figures from some of the large research teams emphasised the importance of maintaining funding for single-researcher curiosity-driven research. Improving the funding for such research is not simply a responsibility for the funding agencies; a

bottom-up approach driven by an increasing number of researchers applying for grant funding may also have a significant input.

4 Dissemination and relations with scientists

It is an important characteristic of GE³LS work that its research findings may have broad social implications and be of interest not just to a narrow academic community but to scientists, clinicians, policy makers, regulators and the general public. The importance attached to building capacity for dissemination is indicated by recent developments in the UK where both the ESRC and Wellcome Trust have made commitments to enhance capacity in dissemination (the ESRC has established the Genomics Policy and Research Forum as part of its Genomics Network and the Wellcome Trust has announced increased funding for dissemination activities and funds an annual three-month fellowship to work at the House of Parliament). This section will consider both the issue of dissemination to these multiple audiences and more specifically the relationship between GE³LS researchers and scientists.

The tensions inherent in trying to address multiple audiences were discussed by many interviewees. Whilst traditional academic outputs in peer-reviewed journals are still important, not least for career progression, there is clear pressure to deliver policy outcomes. It was felt by several interviewees that some senior figures are delivering to policymakers and that their performance sets expectations for their colleagues. Some researchers also appear to have a better track record than others of reaching out to a wider audience by publishing shorter articles in the scientific and medical press. No research is disseminated well enough, it was suggested, GE³LS included, but there is a need for GE³LS research to be better – to reach out to diverse audiences. A number of GE³LS researchers suggested that it is hard to reach policymakers in Canada, in part because of the federal / provincial split, in part because of the dissolution of CBAC. Researchers suggested they lack a forum within which they can engage with policymakers. Some interviewees also highlighted the importance of regular national or regional GE³LS meetings as an opportunity to present their findings to diverse audiences.

US interviewees indicated the pressures on researchers who are still judged by their high-impact publications and whose policy work is not recognised by their academic colleagues. US interviewees agreed that in general ELSI researchers are poor at disseminating to a wider audience and making their work useful to policymakers. UK interviewees felt there was a mixed picture with some excellent dissemination to scientists and policymakers in certain areas which had made a real difference to policy. UK interviewees noted that GE³LS researchers in UK had good links with the Human Genetics Commission. However, UK interviewees also noted a lack of success in dissemination to clinicians and in broader public engagement.

4.1 Two cultures?

There was considerable discussion about the need to improve dialogue between ELSI researchers and scientists. One US interviewee suggested that genome scientists only engage when they want help dealing with a controversy; another suggested that scientists have a “speed-bump” view of GE³LS research, viewing it as an obstacle to doing good science rather than a means to help make science better. A similar view was expressed by a UK interviewee who stated that in the UK ethics is seen as a barrier to research. The Genome Canada model of ‘embedded’ research was seen by US and UK interviewees as one possible approach to bridging this gap. One interviewee cited a variation on CP Snow’s “two cultures” problem to describe the difficulties of doing ‘embedded’ research – researchers in social sciences and humanities are used to working independently and in a contemplative/reflective mode but people working in genetics work in large teams and are mostly engaged in generating data; they are not used to a more reflective model of research. Overcoming this cultural gap takes time and a willingness to engage with new modes of working.

Another approach to bridging the gap through links with specific research teams or institutions can be seen in the US, where there is an expectation that the Centers for Excellence in Ethical, Legal and Social Implications Research will engage with the scientists in their home universities.

5 Future directions

Whilst this study does not aim to flesh out a new research agenda for GE³LS research, discussion of concerns about the breadth of research capacity and dissemination capacity leads naturally to consideration of the future directions of GE³LS research and was the subject of some discussion in the interviews.

Those who expressed greatest concern about breadth of capacity and under-representation of many disciplines from the humanities and social sciences were unsurprisingly also advocates of new directions in GE³LS research. One strand of thinking focused on the desire for work which engages with genomics at a critical distance. For instance, one interviewee suggested that what is needed are one or two genuinely interdisciplinary research centers for social implications of genomics which bring together sociologists, anthropologists, philosophers, population geneticists trained in biological anthropology to create a very broad interdisciplinary conversation on where molecular biology has taken us and where it will go next.

A recurrent theme was how much broader the scope of GE³LS research should become. A number of academics and policymakers suggested that whilst many of the traditional themes such as privacy and patents may not have been exhausted, it is now time to visit fresher pastures. Some advocated focusing on some of the more cutting-edge technologies such as metabolomics, proteomics and nanotechnology. Some suggested that what is needed is more small studies focused on particular technologies. One response was to suggest that whilst there was a need to sustain and build capacity in GE³LS research, it should be seen as a way to address broader issues of ethics, technology innovation and technology assessment in biomedicine.

Several interviewees suggested that it would be more useful to focus research on more immediate pressing priorities, i.e. things which are in, or very near to, clinical practice such as dissemination of HPV vaccination and new highly invasive interventions in

neurobiology. One interviewee proposed pursuing this broader research agenda through a programme with a 5-10 year horizon funded jointly by the CIHR and SSHRC. Policymakers highlighted the government's new agenda on regulation – its desire for Canada to be a world leader in regulation and the possible consequence of lowering of regulatory hurdles – as a topic which raises important issues worthy of research

The view that it was time to expand the GE³LS remit was linked to changing perceptions of the scale and pace of change in genomic medicine. Several interviewees subscribed to the view that GE³LS had been fuelled by an apocalyptic vision of imminent medical revolution and that now that the hype has diminished, there is a more realistic long-term vision of gradual progress in genomic medicine. This was linked to the view that issues which ten years ago seemed highly novel and unique to genetics, now seem neither novel nor exceptional.

However, some senior GE³LS figures stressed the importance of carrying on in their established sphere of activity where they feel there is still much to be done. Policymakers also pointed to particular issues which had yet to be resolved and suggested, for instance, that GE³LS has had little impact on the regulatory framework except in case of assisted human reproduction and that even the field of AHR is a big topic where much remains to be done.

This view of much work still to be completed was also expressed by US interviewees who suggested that GE³LS funding had thus far produced insufficient work which addresses practical issues faced in scientific research and its clinical application. It was suggested that whilst it may have been appropriate in the early years of GE³LS for work to be focused on building a conceptual base, more applied research activity was now urgently required. It may well be that the more rapid pace of commercialisation in the United States (for instance the rise of consumer genetics companies such as 23andme) makes applied research on unresolved issues such as the regulation of genetic

testing seem more urgent there. NHGRI are currently undertaking a review of their GE³LS funding which is seeking to identify future directions for the field and it is likely that this issue will be addressed in that review.

6 Conclusion

This relatively modest study can only indicate stakeholder perceptions and cannot aspire to provide a conclusive analysis of the scale or gravity of the problems. The problems we have identified in breadth and depth of capacity may have an impact on GE³LS research without always being easy to identify or measure. The absence of whole disciplines from GE³LS research is easy to spot and its likely impact on the quality of research can be guessed, but it is harder to spot (and more difficult to assess) the lost opportunity costs incurred when a lack of tenure-track appointments forces people to leave the field who may have had novel, interesting questions to ask, or expertise which will be difficult to replace. Assessing the impact of capacity issues in a research field may be easier when clear research goals have been established and the sole purpose of funding the field is to meet these goals. To the extent that GE³LS research does not meet those criteria then evaluating the problem becomes more difficult. As one US interviewee noted in relation to the NHGRI, GE³LS researchers are rarely given highly specific goals with measurable outcomes.

Nevertheless, in deciding future directions in capacity-building, the pragmatic question which must be addressed is: to what extent are the issues we have identified actually affecting the ability of the research community to carry out high-quality GE³LS work? It is also necessary to answer the question: capacity to do what? Although identifying a future research agenda for GE³LS was not the primary purpose of this study, it was impossible to discuss the issue of capacity without exploring the future direction of GE³LS research.

This study has identified a range of perspectives and a range of policy options. It may well be that further research is required before deciding on the future course of action. Consultation with colleagues in Genome Canada who are conducting their own appraisal of GE³LS funding also seems appropriate and given the need to broaden

representation from the social sciences, consultation with SSHRC involvement may be helpful.

UK / US background

1 UK

Funding for ELSI research in the United Kingdom has come from two main sources: the Economic and Social Research Council and the Wellcome Trust. Additional funding has come from the Leverhulme Trust, the Medical Research Council and the European Commission.

ESRC

The most significant ESRC funding has come from its establishment of the ESRC Genomics Network (EGN) in 2002. This comprises three research centers

- Cesagen (Universities of Cardiff and Lancaster),
- Egenis (University of Exeter)
- Innogen (University of Edinburgh and the Open University)

Which are linked through the:

- ESRC Genomics Policy and Research Forum

Funding for these centers was renewed in 2006 for a further period of five years.

A related project is the ESRC Attitudes to Genomics Survey. ELSI research has received further support from two broader ESRC research programmes:

- Science in Society and
- Innovative Health Technologies.

Wellcome Trust

The Wellcome Trust is the UK's largest non-governmental funder of biomedical research and funded the UK's contribution to the Human Genome Project. It has also funded work in the history of medicine for decades and established a biomedical ethics programme in 1997. This programme began with a focus on two areas: genetics and

neuroscience and has funded a mixture of projects, PhDs and postdoctoral fellowships (although far more PhDs than fellowships). University awards are also available which provide bridge funding for five years to help create permanent s for early/mid-stage researchers.

The Trust has conducted a review of its bioethics funding programme which has resulted in a new funding policy. The Centre now intends to improve capacity by funding a series of centers and collaborations. The ratio of fellowships to studentships will also be improved and there will be enhanced funding for dissemination activities.

Other research centers

Other research centers in the UK which are engaged in work related to genomics and society include:

- the Centre for Family Research, at the University of Cambridge
- the Institute for Science and Society at the University of Nottingham
- the Science and Technology Studies Unit at the University of York;
- the Policy, Ethics and Life Sciences Research Centre, a partnership between the Universities of Durham and Newcastle and the Centre for Life;
- BIOS, at the London School of Economics;
- the Science & Technology Research Unit (SPRU) at the University of Sussex
- the Oxford Centre for Ethics and Communication in Health Care Practice (Ethox), at the University of Oxford.

In addition, the Department of Health funded a network of five Genetics Knowledge Parks between 2001 and 2006. Although funding for these has ceased, several continue to operate in some form, for instance the Cambridge Genetics Knowledge Park has become the Public Health Genetics Foundation.

2 US

ELSI research in the United States has been funded primarily by the National Human Genome Research Institute (NHGRI), although additional funding has been available from the Department of Energy (DOE) and the National Institute of Child Health and Human Development (NICHD). Other sources of funding have included non-governmental bodies, such as the Pew Charitable Trust, who have provided substantial funding to establish the Genetics and Public Policy Center at Johns Hopkins University.

Until 2004 NHGRI funding was available primarily for PhD's, postdoctoral fellowships and projects. However, in 2004 the NHGRI established four Centers for Excellence in Ethical, Legal and Social Implications Research.

- Case Western Reserve University's Center for Genetic Research Ethics and Law - works on the ethical issues in the design and conduct of human genetic research, including issues regarding the protection of human subjects in research.
- The Duke Center for the Study of Public Genomics - works on the role of publication, data and materials sharing, patenting, database protection and other practices that may affect the flow of information in genomics research.
- Stanford University School of Medicine's Center for Integration of Research on Genetics and Ethics - focuses on the ethical, legal and social consequences of uncovering the genomic contributions that may contribute to behavioral and neurological conditions, addressing how such research has the potential to stigmatize both individuals and groups.
- University of Washington's Center for Genomic Health Care and the Medically Underserved - addresses two overarching themes resulting from the clinical integration of genomics: the need to define criteria for clinical integration that lead to clinically and socially appropriate applications of genomic health care,

and the need for a translational pathway that incorporates the goal of reducing health and health care disparities among the medically underserved.

In addition to funding these four centers, three exploratory grants were awarded to institutions to help them plan and develop into new centers. NHGRI grant funding for projects, PhDs and Fellowships continues to be available.

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Interviewees

Canada

- 1 **Margaret Lock**, Emeritus Professor in Social Studies in Medicine, McGill University
- 2 **Bartha Knoppers**, Canada Research Chair in Law and Medicine and Director HumGen International, University of Montreal
- 3 **Trudo Lemmens**, Associate Professor at the Faculties of Law and Medicine of the University of Toronto
- 4 **Michael McDonald**, Maurice Young Chair of Applied Ethics, University of British Columbia
- 5 **Michael Burgess**, Chair in Biomedical Ethics, University of British Columbia
- 6 **Bryn Williams Jones**, Assistant Professor, Department of Social and Preventive Medicine, University of Montreal
- 7 **Ross Upshur**, Director, Sunnybrook Health Sciences Centre, University of Toronto
- 8 **Abe Fuks**, Former Dean of Medicine, McGill
- 9 **Cindy Bell**, Vice President, Genomics Program, Genome Canada
- 10 **Karl Tibelius**, Director, Research Capacity Development, Canadian Institutes of Health Research
- 11 **Burleigh Trevor Deutsch** - Director, Ethics Office, Canadian Institutes of Health Research
- 12 **Lynn Mainland**, Human Genetics and Innovation Policy, Health Canada
- 13 **Edward Gertler**, Human Genetics and Innovation Policy, Health Canada
- 14 **Brian Colton**, Office of Biotechnology and Science, Health Canada
- 15 **Jodi Brown**, Human Genetics and Innovation Policy, Health Canada

USA

- 16 **Kathy Hudson**, Director, Genetics and Public Policy Center, Johns Hopkins University
- 17 **Wylie Burke**, Professor and Chair of the Department of Medical History and Ethics at the University of Washington and Principal Investigator, Center for Genomics and Healthcare Equality, University of Washington
- 18 **Allan Guttmacher**, Deputy Director, National Human Genome Research Institute

UK

- 19 **Tony Woods**, Head of Medical Humanities, Wellcome Trust
- 20 **Paul Martin**, Deputy Director, Institute for Science and Society, University of Nottingham
- 21 **Martin Richards**, Emeritus Professor of Family Research, Centre for Family Research, University of Cambridge

Interview questions

- 1) Is there a capacity problem?
- 2) Are you satisfied with current performance, if not why not?
- 3) Do you think there is the capacity to address the key research questions you believe need to be answered? If not, where are the gaps: capacity, ability or will?
- 4) Where do institutions recruit from?
- 5) How easy is it for GELS researchers to get permanent faculty positions? Which departments do they tend to get permanent appointments in?
- 6) Where do people go when they leave?
- 7) Are turnover rates too low or too high?
- 8) Is there adequate training available for GELS researchers?
- 9) Are GELS research findings adequately disseminated? If not, how could this be improved?
- 10) For research outside GELS community – why do you not apply for GELS funding? What would make you more likely to apply for GELS funding?