RESEARCH IN HUMAN GENETICS: PROMISE, PITFALLS AND POLICY CHALLENGES

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Health Policy Research Unit

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Research in Human Genetics: Promise, Pitfalls and Policy Challenges

In this paper, I address three important questions regarding genetic research. They are:

1. What are the key responsibilities regarding genetic research of the scientific community, the media, voluntary health agencies, and individuals who are affected?

2. Who should determine the allocation of resources to genetic research, including the proportion to go to basic versus clinical, and to incorporation of findings into clinical practice?

3. What are the major ethical and social issues raised by application of increased genetic knowledge, and who should be responsible for addressing them?

Clearly, any one of these topics entails far more complexity than can be dealt with properly in a brief discussion paper, and I will only touch on a few of many important aspects in answer to each of the questions.

1. Key responsibilities regarding genetic research

Here I will mention key responsibilities regarding genetic research of researchers, media, voluntary health agencies, and affected individuals. Aside from the groups mentioned below, there is also, of course, the public at large, and this is a perspective that should not be neglected. What is in the public interest clearly needs to be addressed; this aspect is considered in the later parts of this paper.

a. Researchers

Researchers have a responsibility to ensure that the research projects they conduct are ethical in that persons, genetic information pertaining to individuals, and tissues, are treated with respect. Ethical research involves fully informed choice to participate by subjects, which of course has a cascade of both prerequisites and consequences. These are such aspects as full disclosure of risks, confidentiality, full disclosure of any conflict of interest, voluntary participation etc. and have been well described in an extensive literature by now. It must also be noted that a research project is not an ethical use of resources unless there is the possibility of generating useful information - the methodology must be scientifically valid.

In general, researchers have an ethical responsibility to report promptly and openly the results of their research. There are some particular situations which are exceptions, and which should, of course, have been fully disclosed to subjects, where commercial funding has underwritten the research and the market needs of the company mean if the results are promptly disclosed, the market advantage will be lost. Researchers have a responsibility to report in peer reviewed journals where a knowledgeable assessment by those in the field can be given. Research results should not be reported directly to the media, where appropriate evaluation and assessment cannot occur.

b. Media

What are the media's responsibilities? Reporters have a responsibility to check their facts and the story for accuracy, and to present it clearly, without sensationalism. Yet quite often statements are reported as if true, without the reporter verifying if it is the case. Many people are concerned about how news is defined in today's world. If a topic can be presented in a confrontational way, it is defined as news. A very common approach to a story is to get "an opposing view", and the issue is framed by the media as dichotomous - there are two opposing views. Granted, this simplistic treatment arises in part from the nature of media coverage, and the time and space limitations that mean reporters must portray simple messages. Unfortunately, many issues are not simple and this approach almost guarantees that complexity and accuracy will be lost. For example, a simple dichotomous presentation disregards the fact that all the weight of well documented opinion may be on one side of a question - such as the harmfulness of general screening for prostate cancer - and it has the consequence that an individual with a belief in the opposite, a belief that is not supported by evidence, is presented as equal in weight by the media because it is the "opposing point of view".

Journalists have a responsibility to consider that opposing points of view should not automatically qualify for equal treatment and equally wide dissemination. Lack of judgement in this regard does the public a disservice. Of course there are many issues on which it makes sense to report several different views because the evidence is not in. But quite consistently, in an effort to achieve spurious "balanced" reporting, the journalistic approach to issues is to frame them in terms of two opposing views, and reporters neglect the responsibility to use any personal judgement. As a result the public are confused and do not know what to believe.

c. Voluntary Health Agencies

What is the responsibility and special role of voluntary health agencies concerned with genetic disorders? They are able to bring heightened awareness and focus to particular disorders or clinical problems. They have shown they can certainly make a difference, and have generated substantial funding to enable research targetted to particular disorders. Not only generation of funding is important, but in concert with researchers, voluntary agencies may enable answers to be found much sooner by disseminating information about opportunities to participate in research projects. They are important in communicating both to researchers and to the general public what it is like to deal day to day with a genetic disorder, and what the social and practical implications are for families coping with these situations. Drawing attention to the social and health realities of affected individuals can help identify research priorities, and have a positive effect on technological development. The participation and perspectives of affected people are valuable in helping the research and development process lead to therapies that are beneficial and acceptable. Voluntary agencies have also played a pivotal role in advocating and generating support for services and information resources for families.

d. Affected Individuals

What do I see as the key responsibilities of individuals who are affected or at risk? First of all, I think respect for human beings means we must respect their autonomy unless they choose to act in a way that harms others, so I find it a bit intrusive to say how affected or at risk people should conduct themselves. If I were affected or at risk, I would choose to find out as much as possible about the disorder. What my choice would be regarding being tested for genotype, or participating in research, would depend on a complex weighing of risks and benefits in the context of my values and life situation, but would include my moral obligation to take into consideration, as well as my own interests, the interests of other family members, and others in my community.

An important point I'd like to make is that these four sectors should not be viewed in isolation - because if all four work cooperatively and as partners, the effects are synergistic. A dialectic operating between these groups is an essential part of getting research opportunities and priorities identified, the output of which can be translated into the choice of a better life for people. Mutual respect and good communication is the ideal way to make progress.

2. Determining the Allocation of Resources

I'd like to move now to the second question, namely - "Who should determine the allocation of resources to genetic research including the proportion to go to basic compared to clinical, compared to incorporation of findings into clinical practice?"

The total amount of funding available for research is finite, so resources allocated to one of these three activities leave less to be allocated to the others. The money is not available to do all the research that could be of benefit, and so options need to be priorized, and trade-offs made. It is not possible to say allocation to basic research as a category is a better decision than allocation to clinical research as a category, or to pilot studies for incorporating research findings into practice. So much depends on which basic research project is compared to which clinical research project. The problem to be solved is how to determine an optimal balance of expenditures on the various categories of research activities. Finding a good balance overall depends on whether research tools and insights in a field are at the right stage to be likely to lead to "payoff" in basic research, or whether knowledge in the field has evolved to a stage where the application of a technology into clinical practice is likely to lead to more benefit. Different fields of knowledge will differ in this.

The public is a principal stakeholder in decisions about allocation because they provide the tax dollars or other contributions to underwrite the research. It must be kept in mind that at heart, research funding agencies do not exist to support scientists, but to use the skills and creativity of scientists in the interest of the public. There must be public accountability, and public trust, that the funds are being well used. This means the processes and criteria by which decisions about research funding priority are made should be as explicit as possible and publically accountable.

I am not going to answer directly the question of who should make resource allocation decisions for research. Instead I am going to describe what I see as the situation currently, because I think it will lead to clearer thinking about what might be done to change things.

Some kind of delegation of decision making is essential once a society has passed a certain size - all citizens cannot participate directly. The mechanisms for delegated decision making in a democracy are federal, provincial and local governments and their agents. Just as different levels of delegated decision making about health care resource allocation have been identified[1], so too can different levels of decision making with regard to research funding. There is a macro-allocation level, where governments must decide how much to allocate to research, compared say to education or to transportation. This will determine in an overall way, funding to federal or provincial research bodies. Moving down to a meso level, there may then be policies adopted by federal or provincial funding agencies (such as MRC) about how much goes to basic as opposed to clinical or service program oriented research. Then at the micro-allocation level, (often fairly specific grant application review committees) there are decisions as to whether this applicant or that applicant should receive grant funding or not.

These three levels, of course, are not neat and tidy. Research funding and funding bodies have "grown like Topsy" in Canada to fill different needs at different times and places, so there is not a neat, well organized structure across the country. Nevertheless, I think the concept of these three levels may be useful. They are not, of course, isolated and independent - the amount available on macro-allocation will affect how much is available in certain programs of MRC, for basic research, for example. Clearly also, at the micro level of individual grant application prioritization, the decisions in the meso and macro levels will have an effect.

It is important to recognize that the people making the decisions at these three levels - macro, meso and micro - are different. Probably the skills required to make the decisions and the vesting of authority to do so, also are different. At the micro level - whether this grant rather than that should be funded - researchers expert in that field have control and input into the decision making. At the meso level (for example MRC, or to take my own province as an example, BCHCRF), policies and decisions regarding what proportion of funding will be spent on different program areas (basic/clinical/service implementation) are made by trustees, board or council members, though with input from researchers. At the macro level, decisions are made by political authorities, with differing degrees of input from researchers, the public, and lobby groups, although it is in the interests of politicians to take decisions in line with public values because they may otherwise not be re-elected.

Thinking about resource allocation in terms of these different loci or levels leads to some useful questions. Decision making at each of these levels of allocation involves setting priorities. What criteria or what process at each level would lead to the most effective and beneficial distribution of finite resources? Are they the same or should they differ?

Another issue is public participation. There has been a loss of confidence in delegated decision making and in authorities of all kinds in many Western societies, including Canada, which is very evident on polls. There is a worrying trend to viewing the usual mechanisms for delegated decision making as inadequate or unsatisfactory. This has led to a call for greater public participation on many public policy issues. There has been much talk about greater public involvement in resource allocation decision making, particularly in the health care sector, but also with regard to research resource allocation. However, there are many questions about such public participation to be answered and thought through.[2] Is public participation advocated because it is valued for its own sake? Or because it is thought that such involvement will result in better allocations? In fact, is the public more likely than experts to make better decisions? Does this differ at the macro, meso and micro levels? There is little research evidence on whether increased public participation leads to "better" decisions. How could such participation be structured or work? Who would choose such individuals and how? What would the costs and benefits be? Would forms of public participation (such as public representatives on committees; town hall meetings; focus groups; surveys; citizens' forums) differ at each of the macro, meso and micro levels I have outlined?

An additional complexity is that individuals may bring different role perspectives to decision making - one perspective is as a potential user of the research findings, and the other is a public policy perspective[2]. In other words, an affected individual perspective, and a broader public "community good" perspective. For example, someone who has had cancer is likely to put a higher priority on funding for cancer research than others. A related concept is that the public in general have diffuse rather than concentrated interests with regard to research resource allocation policy. Researchers and some volunteer agencies tend to be better organized, have a large stake in the decisions - their interest is concentrated - and they have therefore had more of a steering effect. Yet the preferences and priorities of individuals with concentrated interests (for example, with a particular disorder) may be quite different than those expressed by members of the general public. Well organized groups with clearly identified interests are more likely to influence resource decisions than those holding diffuse public interests even though the latter are far more numerous.[3]

At the macro level of decision making, government is representative of and elected by the public, and is accountable to the public for decisions it makes. As well as voting in protest at the next election, the mechanisms for involving citizens in the public policy decision making process have been Royal Commissions, surveys of preferences and values, town hall meetings, citizen forums and focus groups. The Oregon experience was one attempt to involve citizens with regard to health care resource allocation.

At the meso level, lay representatives have been appointed to the Boards of most research funding agencies.

I think it is important to acknowledge that the call for increased public participation in allocating research resources reflects a common feeling in the public that at core, the priorities to be set are community and public preferences, and that provided the public

representatives have understandable information, technical experts are no better equipped than lay people in weighing the values leading to resource allocation decisions. It does mean a process for providing lay individuals with balanced and relevant information is needed if they are to participate appropriately. They need to be informed sufficiently to work through the scientific, ethical and economic issues on which many allocation decisions depend. Advocacy that is scientifically ill informed has dangers.

The idea of increased public participation in resource allocation decisions for research is endorsed by many as "a good thing" without further specification. However, how such participation might be actualized in an effective and useful way is not yet clear, and it can be seen that the question of who should make resource allocation decisions regarding research is a very complicated one, and may have different answers depending on the level of decision making. Public participation in research funding allocation is an area that we need more discussion and elucidation of concepts and proposals. If greater lay participation is to be advocated, we need to ask explicitly, at what level? How chosen? From what perspective? With what goals? Participation may be appropriate to decision making at some levels but not others; or the form it takes may need to differ. For example, consultation is different from participation in decision making, but may be more appropriate at the macro level. Perhaps at the macro level, individuals representing or accountable to a particular interest group are not appropriate in developing a public policy perspective? They may have a greater role at the meso level?

With regard to how pertinent research findings and new technologies should be incorporated into clinical practice - decisions about providing new technologies must be part of the broader process of deciding what the health care system should be called upon to do. It makes sense that provincial ministries of health should fund clinical trials of new technologies, because it is the responsibility of these ministries to manage the health care system on behalf of taxpayers. It is from their budgets that such treatments, if demonstrated effective in clinical practice, will eventually be paid for. Data from such trials will provide evidence on which to base rational use of health care funding, and allow better management of the system. Provinces may well be able to share the cost of such trials and to avoid duplication by coordinating their efforts - for example, through the conference of Deputy Ministers of Health.

3. Ethical and Social Issues

I come now to the third and final question "What are the major ethical and social issues raised by application of increased genetic knowledge, and who should be responsible for addressing them?" Clearly this is a very large and complex area. I've listed below some of the issues raised, and I would recommend Chapters 24 to 29 of the Final Report of the Royal Commission on New Reproductive Technologies to those who are interested in more detail on these topics.[4]

- Restriction of autonomy (coercion)
- Invasion of privacy
- Commodification of genetic patrimony (patenting)
- Attitudes to "avoidable" disability
- Diversion of resources, opportunity costs
- Workplace discrimination
- Stigmatization, labelling
- Unwanted knowledge regarding risk
- Commodification of children
- Sex selection
- Genetic alteration for "improvement"
- Inequity in access
- Skewed view of illness as "genetic"

Rather than address specific issues such as those listed above, I will give an overall framing of what I think is important, and then how I think the problem should be dealt with - who should be responsible.

We are in the midst of a worldwide knowledge revolution with regard to genetics. How scientific knowledge about human genetics is applied has the potential to change and affect how our society views individuals and their relationship to each other. Applying this knowledge to the human situation clearly raises much more than health issues - it raises societal, ethical, legal and economic issues. Our responses to the choices about how we use genetic technologies and genetic information will say much about what we value, what our priorities are, what kind of society we want to live in. Any deliberate identification of genotypes, and actions as a consequence of that identification, should be approached with both compassion and caution, and with an awareness of the harms as well as benefits that may result from use of genetic knowledge.

Capitalism and the market are major forces in today's societies. This must be taken into account with regard to setting public policies related to how we use genetic testing and knowledge; interests that are vulnerable must be protected against commercial activity. Commercial organizations are designed, both in objectives and their management to promote a single interest - to make money. They are not expected or designed to balance conflicting interests. If market forces were allowed to drive how genetic technologies are used, it would undermine important social values and harm people by leading to inappropriate, unethical or unsafe use of technology. Rather than market forces, principled social policy arrived at after wide input, should ensure that developments and use of genetic technology and knowledge is used to people's benefit. It is government's responsibility to ensure that appropriate regulation and policy is in place to guard citizens interests. Commercial activity in the field of applied human genetics should occur only in the context of a regulatory framework that ensures the market is not the deciding factor behind the provision of genetic testing or genetic technologies.

Clearly the interests of commercial firms and the interests of consumers are not identical. Throughout our economies, and in an open market, it is assumed that buyers can protect their own interests. In the market place, the basic protections for consumer interests are information and choice. But the situation is different when medical procedures such as genetic testing are involved - individuals do not have sufficient knowledge or information to protect themselves, and their interests are vulnerable while the commercial firms' interests are not. In the medical field, protection of vulnerable interests is therefore required through societies' rules and regulations, as well as professional ethics. Recognition of the need to protect interests that are not able to protect themselves is at the heart of all professional and health care regulation - the question is not whether there should be regulation of commercial activity in the medical field and in genetic testing, but rather what form it should take.

Not only individuals but the wider community too has vulnerable interests that need protection from commercial activity in the field of human genetics. We all have a stake in the nature of the society in which we live - that it not be one in which people are discriminated against or viewed as not equal to others because of their genetic makeup.

All of us take a risk of a few percent that a child will have a serious congenital anomaly or genetic disease. Some people are at greater risk, and the Royal Commission on New Reproductive Technologies found a large majority of citizens think that prenatal diagnosis should be available to those people. However, more and more conditions are becoming amenable to genetic diagnosis, and decisions will be needed about what it is appropriate to offer publicly supported services for. For example, prenatal diagnosis is widely used in some countries for sex selection. Wide-based public input into that process is essential if policies are to respect the values of citizens. We found that the public are fearful that genetics will be misused. They want to know what is being done in genetics. It is an area of concerns and one they want to be open, accountable and transparent in policy making.

It is clear that as well as benefits there are potential harms both to individuals, and to the society, from misuse of genetic identification or alteration. This means some uses of genetic technologies should not be permitted; some are beneficial and should be supported; some should be within particular limits. The Royal Commission recommended that the Canadian government, as the guardian of the public interest, should make sure the application of genetic technology to people is regulated and within boundaries. No other social institution is sufficiently broad based or has the mandate to set a system in place. Because the knowledge base in genetics is changing rapidly, and social attitudes also may change, the regulatory system must be ongoing, and be able to respond to changes.

We recommended two things. First, we recommended legislation to prohibit certain uses of technologies (such as using embryos in research related to cloning, and making animal/human hybrids), and certain commercial activities (selling of eggs, sperm, embryos, fetal tissue).

Second, we strongly recommended that the federal government establish a national regulatory body with licensing required for the provision of certain reproductive and genetic technologies to people. We recommended that a National Commission be set up to regulate and license provision of services in five areas, that it be arm's length from government - composed of 12 members, with women normally making up at least half, and including people with a broad range of experiences, perspectives, and expertise. To ensure openness and transparency, we recommended that licence hearings should be public and that the Commission should report annually to Canadians through Parliament on what is occurring in uses of technology.

We recommended the National Regulatory Commission have sub-committees to regulate five areas where it will be compulsory to have a licence to provide services to people. A licence to provide services would be conditional on complying with certain clearly specified conditions. Two of these sub-committees are relevant to genetics; they are the committees for prenatal diagnosis for genetic disorders and congenital anomalies, and for research involving human zygotes. An advantage of this system is that it can respond to change in knowledge with a change in the rules that must be complied with to have a licence. What needs to be done is common to all the technologies. We need to set policies after wide input, to have compliance with those standards and policies, and to collect information and monitor what is going on. It may be in future that another sub-committee may be helpful to deal with genetic testing and alteration in general.

These sub-committees should build on previous efforts by geneticists and physicians, as they have already done a lot of work on developing guidelines and standards of practice. Many of the technical, quality control and specialized training assessment aspects can only be done by practitioners in this field. In fact, we envisage accreditation by the Canadian College of Medical Geneticists as a pre-requisite for licensing by the National Commission. Nevertheless, primary responsibility for setting policies regarding use of scientific knowledge of human genetics cannot be left entirely to self-regulating professional bodies. Self regulation is necessary but is not sufficient in this field. Many of the policy decisions are social, economic and ethical, and a body reflecting other than medical perspectives is needed to set such policies, and to ensure they are in the public interest. The national body and clear process recommended would enable the public to have confidence that policies were being set in the interests of Canadians, and make it clear they were not being subject to manipulation from commercial, scientific or other specific interests.

Prenatal testing and in the future, other genetic testing, need to be offered within a framework of regulation and program guidelines. Those tests that have been offered at centres (amniocentesis, CVS, detailed diagnostic ultrasound) have been introduced in this way, with rigorous assessment, associated counselling, and follow-up. Canada has a history of cooperation between genetic centres with multi-centre trials early in the history of those technologies used for genetic diagnosis at centres. In contrast, those tests that can be offered outside centres, for example MSAFP, and routine ultrasound, have shown a very patchy quality control; they have simply proliferated before being assessed. They are easy to do and

many thousands of physicians can carry them out - practitioners are very dispersed. There are also financial incentives for doctors to perform them. This kind of ad hoc proliferation of testing outside program guidelines is of concern because the pace of development of genetic knowledge that could be applied is not going to lessen. If testing is not effective or beneficial, it subjects people to unnecessary procedures, may lead to harm, furthers inappropriate medicalization and uses resources poorly with substantial opportunity costs. For example over $100 million is spent annually on routine prenatal ultrasound in Canada without evidence that it leads to measurably better outcomes.[5]

The desire of parents for information about the fetus (and in future about themselves), together with continuing scientific discovery, is likely to produce a steady stream of new developments. For example, because maternal blood during pregnancy contains some fetal cells, tests for sex (or indeed for a wide variety of other gene associated traits) will likely become possible. The rapidly increasing abililty to identify genotypes in healthy people that may be associated with increased risk for disease may have harmful consequences to their self concept and happiness, to their employment and other opportunities. There is a danger that the market will intrude with direct marketing of such testing by companies to the public and to individual doctors and lead to misuse and poor quality control. It is essential to put a regulatory framework in place so that testing does not cause social and ethical harm.

The emphasis on genes and DNA has had the consequence of promoting the view that genes are the major determinants of most illnesses. This is not the case. Social and environmental factors have a major impact and need to be addressed. Framing illness as due to "a gene" leads to individual solutions addressing physiological parameters, neglecting social solutions that may not only be equally effective, but may help to build a more just society.

Between the extremes of unquestioning acceptance and outright rejection of application of genetic knowledge to the human situation is an approach based on an examination of evidence. This evaluation must be done in the context of the broader implications for individuals and for societies. If we ignore their ethical and social implications, or allow them to proceed without discussion of their positive and negative aspects, use of genetic technologies could bring about changes that contradict or clash with our society's values and beliefs, and we will become less tolerant and caring as a result.

Individuals have a responsibility to inform themselves as fully as possible before making decisions about the use of genetic testing, but governments on behalf of citizens have a responsibility to ensure that inappropriate and unethical use of technology is not occurring. How we apply genetics is not at heart a medical matter, but a matter of social policy. Many nations are grappling with these issues. Only if public policy, not the market, determines what is available in genetic testing and technology will the vulnerable interests of individuals and societies be protected. At the same time humane public policy would still allow scientific knowledge about genetics to be used to better the lives of many individuals. The field is evolving rapidly. We cannot turn back the clock, we cannot close our borders and we are all going to have to respond to how to deal with this knowledge revolution in genetics. We need

to set limits based on what society considers to be acceptable activities in the field of genetic research and treatment; to establish systems for managing the application of genetic technologies within these limits; and to provide mechanisms for continuing review and evaluation, with public and open participation, as ethical and scientific issues in this field emerge and evolve. How we choose to use, or not to use, our technological capacities in genetics will help to shape society for our children and for their children. It is essential that we deal with them wisely.

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