The pace of scientific progress right now is breathtaking, but our 21st century regulations, institutions — even ethics — are holding us back. In the genomic era, what is the cost of doing nothing?

Op-ed by Professor Stephen Scherer (UofTMed Magazine — Winter 2017)

Years ago my old mentor, Lap-Chee Tsui, made a discovery that helped launch the genomic revolution. It took his team a decade to do it, but in 1989 they won the international race to discover the cystic fibrosis gene. Back then approvals were quick, or non-existent, and a scientist's "common-sense" ruled.

With today's technological advances in genomics, the same research could be done in a matter of months — but I believe paperwork may have tied his team up for years, which in today's world would have meant losing the race, or even worse maybe not entering it at all.

I'm increasingly concerned by the way science in Canada holds itself back today — how much tougher it is navigating legal fears, increasingly complicated rules and reporting, endless sign-offs, and sometimes ethics approval processes that come to their first annual review before the project has even started.

It's time to ask: What's the cost of conservatism?

Genomic information may offer insight into the past, present and future. For some medical conditions, we've never had a biomarker so powerful, but the science is moving faster than our ability to contemplate its implications — causing major bottlenecks and missed opportunities that could be a matter of life and death.

I believe the inherent conservatism of medicine has served us well overall — the idea of "first do no harm." But the new technologies, like whole genome

sequencing and high-resolution imaging and gene-editing, aren't conservative. They are instead disruptive, and tension has been building because of it.

In my lab, we sequence genomes every day looking for the cause of rare disorders. In our search for, say, genes linked to autism, we increasingly bump into a mutation that causes something else like cancer.

Because of the fear of these "incidental findings" some research and clinical labs intentionally use "old" technologies or approaches so they don't see all the genes in the genome, or at least only see the gene they want to see. I never feel good discarding those genome-wide results, especially if there are medical interventions available. Here, and with other breakthrough technologies, who's calculating the risk of doing nothing?

To be sure, we need to think hard about the ethics and potential social impact of this new science — we need medical ethicists more than ever before. We also need experts in knowledge translation and project management. However, the balance of funds to these areas has tipped too fast. There seems to be more administrators "helping" medical research than scientists actually doing it. So maybe it's no coincidence that we're becoming more conservative and risk averse by the year.

Sticking our heads in the sand — or burying ourselves under a mountain of red tape — is not the solution. We need science to self-perpetuate, not its regulators. The gradual ebbing of our right to take risks in the name of medical research adds up to real harm when it neutralizes progress.

We need to face our ethical and legal challenges head on, getting government to catch up with the science by legislating strong protections on genetic privacy. This should reduce the worries that stop individuals from taking advantage of genomics. And we need to start weighing the risks to people, and to those eager scientists starting their own research race, of endless regulations, some of which are frankly only meant to protect institutions.

It may still be better not to do something, or even to do nothing, than to risk causing more harm than good. However, as with incidental findings arising from the new genomic scans, sometimes not acting — or over-regulating processes of generating or conveying data — may also cause harm.

Progress is happening. Starting this year, medical students are learning about genetic counselling during their very first week at U of T. Parliament is now considering new laws to protect patients — another very good step. I've been asked increasingly to lecture on the topic of "common-sense" science.

But this is not enough and we in the medical community need to work harder to bring back the right balance of scientific progress and protection. Nobody I know wants to cause harm, or come second in a race. We all just need to be reminded to think about the consequences of inaction and risk aversion that way. ■

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