Australian Government

Chief Scientist

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Frank and Bobbie Fenner Conference:

Genome Engineering for Cancer Treatment

Excellence with equity and empathy: progress the Australian way

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John Curtin School of Medical Research, Australian National University

CANBERRA

It is a great honour to open the Frank and Bobbie Fenner Conference, here in the city they loved.

There are many stories about the Fenners. They made a formidable duo. But the story that sums them up best is surely the way that Frank proposed marriage.

It was 1944. Bobbie and Frank were at the Heidelberg Military Hospital.

Bobbie was there to give classes in blood transfusion.

Frank was performing experiments on ways to control the spread of malaria.

He proposed to Bobbie in a room adjoining the lab, between experiments.

The witnesses at their marriage were a lab assistant and a nurse.

It's a rare example of a love affair that was helped along by a contagious disease.

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But today I want to begin my speech with another story, set in another hospital, in another year: the Royal Children's Hospital, in Melbourne.

The year is 1948. The war is over.

A paediatrician named John Colebatch is working with children diagnosed with leukaemia.

And it's heartbreaking work.

Everyone knew. A child diagnosed with leukaemia in winter would be gone before spring. Ten weeks from diagnosis to death. That was all.

No cure. No treatment. No hope.

But now, in 1948, in his rooms in the Royal Children's Hospital, Dr Colebatch catches a glimmer.

A doctor in Boston, named Sydney Farber, the father of chemotherapy, has treated a handful of children with an experimental drug, aminopterin.

And some of those children have gone into temporary remission.

At the time, it was extremely controversial. The drugs were toxic, the treatments were painful, and to many in the medical establishment, they simply prolonged the anguish.

It was cruel to hope. It was impossible to cure.

Dr Colebatch thought differently. He wrote to Sydney Farber, asking if he could conduct a trial. And could he please have a supply of aminopterin?

The answer came back by sea mail: *yes*.

And in that same year, 1948, within months of Sydney Farber's initial report, Dr Colebatch conducted the world's first controlled trial of chemotherapy to treat childhood cancer. At the Royal Children's Hospital, in Melbourne. Australia led the way.

And as the science progressed, and the patient support groups rallied, the medical establishment began to turn.

Weeks of life in remission became months. Months became years. Years became decades.

Now the goal was no longer a comfortable death. It was the determination to cure. It guides us to this day.

Next year we will celebrate the 70th anniversary of that first groundbreaking trial.

Today, 20th November, we mark the anniversary of Dr John Colebatch's death.

And it seems fitting to open this Symposium on Genome Engineering for Cancer Treatment, the Frank and Bobbie Fenner Conference, by reflecting on the reason we're here.

It bears repeating.

In 1948, a child diagnosed with leukaemia would live ten weeks.

In 2017, nine in ten children diagnosed with the most common form of childhood leukaemia in Australia will survive for at least five years, and many will achieve full remission.

To me, it says something very important about what it means to be Australian.

Excellence in research. Equity in access. Empathy in care.

Excellence, equity, empathy.

And so I know, as you know, that nine in ten isn't good enough. Ninety-nine in a hundred isn't good enough.

We are capable of more. And you, in this room, are the people we trust to deliver.

In your hands, we see a powerful new tool.

CRISPR.

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When I first heard about the revolutionary gene editing tool called CRISPR, I thought it was one to watch.

Since that time, I've realised that keeping track of it is like calling the hundred metre sprint.

You can't look away for a second.

By May this year, new CRISPR papers were emerging at a rate of around 50 a week.

I decided it would be helpful for my office to explain the science in layman's terms.

So we got in touch with some leading scholars and went to print with a four-page primer in late September.

And then two research papers were published in the same week, in the journals Science and Nature.

Up to that point, we thought that CRISPR was fast, cheap and precise.

Now, we're calling that era CRISPR 1.0.

CRISPR 2.0 is base editing: editing at the level of individual letters, without cutting through the DNA.

Of course, it's still very early days. But if you measure the rate of scientific progress by the half-life of Chief Scientist publications… CRISPR is developing fast.

And the implications for cancer may well be profound.

We've been speaking of gene therapies for cancer for a long time.

It seems fitting that the first human patient was an 11 month old baby girl, with leukaemia, treated with gene-edited T cells in the United Kingdom after conventional treatments failed.

The therapy was trialled in 2015. This year, the little girl was reported to be in full remission.

It was experimental, and extremely expensive.

But that was gene-editing by the older and more cumbersome TALEN method.

CRISPR makes it possible to imagine that gene therapies could be delivered safely, reliably and affordably – not in the far distant future, and not simply for the desperately sick or the extremely wealthy, but as a standard part of care: a routine clinical procedure.

And Australia will be a player.

For evidence, I look to the 78 organisations that have united in the form of the Australian Genomics Health Alliance.

It's all there: our outstanding research institutes, our national research infrastructure assets, our sophisticated biotechnology sector, our networks for clinical trials.

Earlier this month, the first National Health Genomics Policy Framework was adopted by the COAG Health Council.

It sets out an agenda – and these are magic words, so I quote: for a "coordinated, strategic approach… to embed genomics in the health system in an efficient, effective, ethical and equitable way".

And so my challenge to this conference is simple: what will we make of that opportunity to be strategic?

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I'm a relative newcomer to Canberra, but I've been involved in research advocacy for some time. I've seen big ambitions come, and go. And I've also seen agendas that worked.

Let me offer a few mantras I've acquired along the way.

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First mantra: speak human to humans.

And by "human", I don't mean humans as complex and fascinating biological systems, but humans as people, with complex and fascinating lives. People who worry a great deal about cancer.

What do they think about gene editing?

Probably, not much.

The best evidence we have is a survey from the Office of the Gene Technology Regulator, published last month.

Of those surveyed, about 17% – one in six – thought they knew enough about gene editing to explain it to a friend. The rest knew little, or nothing.

Where did they get their information about science?

No surprises: "Google". Then "shows on television".

So I thought I'd try an experiment: if I Google "gene editing and cancer", what would I find?

Gosh, it's amazing!

"*All inherited diseases could be cured within 20 years thanks to gene editing breakthrough*." That's from a UK tabloid.

"*Cancer cure can lead to brutal bioweapons*". That's from the Chief Medical Officer of the technology giant Intel.

His concern is that Joe Biden's Cancer Moonshot will, quote, "seed thousands of hospitals with exquisitely targetable cell-killing biotechnology."

Hospitals out of control! Bioweapon production in the basements! What's new?

"*Unicorns to designer babies: gene editing could change the course of evolution*". That's from Canada's public broadcaster, the CBC.

I could go on… but you've seen these headlines before.

Seen them, responded very calmly to them, seen them again. We don't win by giving them any more oxygen.

It's a curious property of that simple word, 'gene'. Wherever the conversation begins, it always ends up in unicorn bioweapon designer babies.

And Google is complicit, it directs you to the fringes: it feeds you more and more examples of the stories that you click.

Google will convince you that you're right. It won't necessarily help you to be so.

For that, we need trusted explainers: just like Dr Colebatch.

It's true: he didn't have to contend with Twitter. But nor did he have our opportunity: to cut through the noise.

In all the babble, and the nonsense, people are missing what our newspapers used to provide: trusted go-to sources.

Where can they put their trust today?

The answer is – our universities. Our research institutions!

Our research institutions can meet that basic human need for credible information on important topics.

I don't mean media releases on new discoveries: I mean materials connecting the science to the decisions we face in daily life.

Primers on the role that genes play in cancer. Basic information on what it means to be part of a clinical trial. Questions to ask before genetic testing.

Media consultants will tell you that you can't reach an audience without a clickbait headline or spraying abuse. But you don't compete in that market.

When it comes to health, people are seeking credible information, consolidated in one place.

In an ideal world, when a person types “gene editing cancer” into their search engine, they will be directed to a reputable Australian university or research institution that respects their intelligence, and speaks to them in clear terms.

Or better still, they won’t need to go through the search engine: they will automatically associate gene editing with an Australian institution they know and trust.

We have a window to act while the issue is still on the margins of the public debate. This is the time to give Australians the tools to navigate the choices ahead.

So first mantra: speak human to humans.

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Second mantra: think out to the ten year horizon.

Every time I visit a hospital I’m reminded that it’s difficult to plan for the future of healthcare.

You start with a purpose-built facility… and you end up with a maze. Side-wings. Extensions. Repurposed car parks.

You could take the cross-section of a hospital and read the history of medicine, in the way we use tree rings.

The challenge for the research sector is to help leaders think and plan ahead.

Here I want to foreshadow a report I hope to see published in the near future, from the Australian Council of Learned Academies.

The report was commissioned by the Commonwealth Science Council, the body chaired by the Prime Minister.

Its focus is the ten year horizon for precision medicine.

Ten years is important. It’s the window to act. Too far beyond, and we’re into speculation. Too near, and we’re playing catch-up.

The report from the Learned Academies is designed to help us think across the continuum: from the research agenda, to the workforce planning, to the governance and protocols, to the infrastructure, to the cost implications.

Digital infrastructure is a particular focus.

Now on that front I can report that we’ve made some progress.

Last year the Royal Australian College of General Practitioners put out a position paper.

The College has spoken! It's time to do away with fax machines.

The next stop: digital health.

Seamless digital healthcare records. Linkages across massive datasets. Artificial intelligence systems for rapid diagnosis and personalised treatments. Secure cloud-based platforms.

And people prepared to use them!

Change takes time. Change carries risk. And change has to co-exist with constant care.

That's the bottom line for politicians. It's incredibly easy to get terribly, terribly wrong.

The upcoming report on precision medicine from the Learned Academies sets our sights on the horizon. And the Australian genomics community is coming together to help government to navigate the way.

It has done the work to make it easy for leaders in government to reflect, to discuss, to decide.

I salute that vision, and I hope that other sectors will take note.

That's the second mantra: think out to the ten year horizon.

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Finally, the third mantra: regulate to facilitate.

Regulation is never a debate you want to enter backwards. Biotechnology is a classic case.

To start, we have outdated regimes written for a different era.

This is compounded by a patchwork of restrictions, moratoriums, funding blocks, labelling requirements and outright bans.

They were band-aid responses to the outdated laws. Or they were born in a moment of panic. And many regulations outlive the panics that produced them.

We end up with a bizarre conglomerate of old and new.

The path to that point is different in every country, but the outcome is always the same: confusion about what can and can't be done. Baseless fear in the community about things that shouldn't concern us. Apathy in the community about things that we really *should* be worried about. Caution amongst investors.

And the casualty is science: ethical science, quality science, reputable science. The sort that needs money. The sort we do in Australia.

A patchwork quilt of regulations might indeed be effective at protecting the safety of the public, but at great economic cost – and the unmeasurable cost of progress foregone.

The broader point of regulation is to facilitate progress.

Regulation done well is our best friend!

It gives us certainty. It rewards the quality providers. It channels our efforts to things we can actually implement.

So let's be even better at regulation.

We start from a strong position, with a record in healthcare that Australians trust: excellence, equity and empathy.

I spoke earlier of the survey conducted by the Office of the Gene Technology Regulator.

The same survey found that most respondents didn't know or hadn't thought about how gene technologies are regulated, or who is responsible.

They just assumed that someone was doing it; and most people assumed it was being done well.

Australians assume that government works.

Forget about the politics for a moment, and just think about the way we behave.

We assume that when we go to hospital, there are protocols and safeguards. We assume that the medicines we get from the chemist are safe. We assume that our researchers are proceeding with integrity.

We assume because in almost every case, it's true: the system protects us.

The most trusted organisations for the survey respondents were the research community: in particular, the CSIRO and the National Health and Medical Research Council.

The least trusted organisations were industry groups, and environmental groups.

You in the audience are the people Australians will listen to. They will look to you for guidance in the years ahead.

You have a responsibility to work with the regulators, to help them in their quest to modernise the rules to balance safety and progress.

We have the opportunity to demonstrate that we are ready to be responsible custodians of CRISPR.

I am confident that we can be an example to the world: with best-practice regulation, that ensures we advance with community understanding and support.

That's the third mantra: regulate to facilitate.

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To summarise, three mantras:

- Speak human to humans.
- Think out to the ten year horizon.
- Regulate to facilitate.

And let me leave you with a final question.

The progress in treating cancer in the last 70 years has been extraordinary.

In the 1940s, the options were radium, x-rays or radical surgery.

At best, they were traumatic and scarring.

The Cancer Councils were in their infancy.

Oncology wasn't recognised as a discipline.

Cancer facilities in the major cities were appallingly stretched.

Cancer facilities beyond the major cities were non-existent.

Chemotherapy was unknown.

CT scans and MRI were unknown.

That was the cancer ward of the 1940s.

How different the world looks today.

So my question to you is "where will we be" – where will we be in ten years' time?

Where's the horizon, and how are we going to get there?

I know you can imagine it.

This conference is your opportunity to think ten years out, sparring with the best minds in the country.

And so, enjoy the discussion… and in the immortal words of Professor Frank Fenner: WORK HARD.

THANK YOU