Australian Government
Chief Scientist

DR ALAN FINKEL AO

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Keynote Address

The Human Factor

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Let me begin today with a reflection on our newest Academy.

It's hard to believe it's just four years old.

I've had particular insight into the Academy's work through its role in the Horizon Scanning Reports – a series commissioned by the Prime Minister, through my office.

These reports are built on a simple premise. If we can see something happening in the world of science and technology, and we know it's going to affect people's lives – maybe not today, but absolutely in the next decade – then policymakers need to know about it.

So we turn to the five Academies, who have worked together to produce most of the reports thus far.

When the Academies say "expert working group", they really do mean "expert working group" – the leading authorities, on that subject, in this country.

One of the first reports we commissioned was on precision medicine, to which this Academy's contribution was significant. This report is providing the intellectual framework for policy development.

It was launched by Minister Greg Hunt earlier this year.

And, as is the custom, my office has now prepared an Occasional Paper, summarising the evidence for a broader audience.

Coincidence or not, we released it this morning.

And I want to use my speech today to pursue some of the hard questions we've put forward: about the community's expectations for genetic research.

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Let's imagine for a moment that we're not sitting in the Walter and Eliza Hall Institute, hearing from some of the most celebrated names in research, and surrounded by our fellow scientists.

We're at a family barbecue in Uncle Bob's backyard.

And you know what's about to happen.

The topic will turn to family history... and someone will mention their ancestry profile... and suddenly we're all comparing notes on what percentage of our genome is Neanderthal DNA.

Yes, it's 2018 – and direct-to-consumer genetic testing is here to stay.

It's already a $100 million global market – and on some estimates, it will climb to at least $300 million in just five years' time.

That growth has been kicked along by some very determined marketing.

My staff even spotted one company advertising a Father's Day Testing Kit Special – perhaps not thinking through *all* of the possible consequences.

The same company has now entered into a partnership with Spotify – so now with your results, you also get a playlist, with your very own ancestral music.

But it's not just enthusiastic family historians diving in.

If you're trying to lose weight, you can go to the chemist and pick up a diet spit kit. Just send it off for a diet plan for *your* DNA.

If you're looking for romance, you can access "genetic match" dating services.

If you've run out of humans in your family to test, you can pay for a genetic profile of your pet.

And it all begs the question: how is direct-to-consumer genetic testing changing the perception of genetic research – and the willingness of Australians to support it, to be part of it, and ultimately, to benefit from it?

In 2018, *what do people think?*

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Now obviously, as scientists, we like to assume that everyone can easily tell the difference between – for example – the genetic research done at the Walter and Eliza Hall Institute, and the "DNA match" service offered by a company called "DNA Romance".

But for non-scientists, I suspect it's not so clear-cut at all.

Remember, the organisations they're likely to hear from first are those with the loudest marketing.

Try it. Type "genetic test' into Google. You'll be directed to companies: ancestry tests, diet advice and yes, DNA dating.

If you click on a link, you'll go to a website with lists of papers apparently published in actual scientific journals.

You'll also find tabs for "Frequently Asked Questions", defining terms like "variant" and "genome sequencing".

So the science is explained to you by companies. And it may well be the only user-friendly explanation you've ever received.

Now a cynic might conclude that some companies are more interested in *looking* like science... than actually *doing* it.

But that's by the by. What *is* clear is that the more credible companies do have a very obvious interest in legitimate research.

We got some idea of what that interest might be in July this year, when the pharmaceutical giant GlaxoSmithKline acquired a $300 million stake in the genetic testing company 23andMe.

In exchange, 23andMe handed over exclusive rights to its customer database for GSK to use for drug discovery.

Other genetic testing companies are looking to cut similar deals.

And if 23andMe is any indication, that link to research is something that customers are actively seeking.

To 23andMe's credit, it's made very clear on their website, and in their consent form.

I'll quote it: *"on average, a customer who chooses to opt in to research contributes to over 230 studies on topics that range from Parkinson's disease to lupus to asthma and more."*

So 23andMe clearly doesn't see a tension between doing research and recruiting customers – it's using the research as an attraction of buying the service.

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Now that's one direct-to-consumer genetic testing company, choosing to be upfront – there are many more of them out there, just waiting to be Googled.

And let's be honest: not everyone in this business is going to be scrupulous, or transparent.

So we have to assume that there are people forming their perceptions and making decisions *right now*, on the basis of information gleaned from the internet that is inaccurate, unhelpful, or incomplete.

I worry about what happens when some of those people are inevitably burned.

Today, we can say that most Australians are very trusting.

We have the evidence of Research Australia's recently published survey.

75% of respondents said they would be willing to use genetic testing to identify the most effective drug to treat their condition.

22% would need more information to make a decision. And only 3% gave a flat out no.

Of that 75% who would be willing, 95% said they would be willing for their results to be used to improve the treatments for future patients. 95%. Just 1% said no.

That says something deeply encouraging about human beings. We really do care.

And it signals something else that's encouraging, as well: Australians have learned to trust researchers.

They see a sector that conducts itself as it does in this country: with integrity, with transparency, and most importantly, to brilliant effect.

But that hard-earned trust is easily abused.

And we've seen it so many times before. A scientific field becomes genuinely exciting – and instantly, the legitimate research is jostling for space with snake-oil.

I'm thinking of stem cell research – and the number of clinics that just leapt at the chance to take people's life savings for treatments that were at best unhelpful... and often, much worse.

As an old neuroscience PhD, I'm thinking of brain stimulation. It's genuinely interesting for the clinical treatment of Parkinson's. It's *not* particularly useful to buy what's basically a tennis headband with batteries and electrodes, from a dodgy company that tells you that zapping your brain will magically boost your intelligence.

But people buy it. And legitimate research suffers the collateral damage.

The next big scandal might not be a company selling nonsense.

It might a start-up that's careless with data security.

Or it might be a consumer who takes a genetic test in good faith, possibly from an overseas provider, without awareness of the possible implications under Australian law.

I am thinking in particular of the possibility that genetic data could be requested by life insurers.

As I understand it, *health* insurers cannot adjust their premiums on the basis of genetic information.

But *life* insurers can request and require disclosure, and they can discriminate by raising the premium or denying coverage altogether, as long as there is a reasonable justification.

Is this a problem?

We know that life insurance is not a trivial consideration for people who might make the choice to be tested.

We have the evidence of a Victorian study that looked at people's willingness to be tested for a marker of Lynch syndrome – or colorectal cancer.

When life insurance was mentioned on the consent form, the number of people declining the test increased from fewer than a fifth to nearly half.

As a research community, we obviously have to think about what information we owe to anyone who participates in a genetic study as part of our duty of care.

But we also have to think very hard about the larger framework, because if others aren't ethical, and people suffer loss, then we're just as exposed to the blowback.

The UK has had a moratorium on the use of predictive genetic test results by life insurers for close to two decades.

Canada has gone a step further, prohibiting insurers from requesting or requiring disclosure of past or future test results, by legislation.

In Australia, the Parliamentary Joint Committee set up to inquire into the life insurance industry has called for the same approach in Australia – looking first at the

industry Code of Practice, and then, potentially, the changes that might be necessary in law.

The research community has led this discussion from the outset.

And as you've recognised, whatever decisions we come to, what matters is to be on the front foot – not waiting for a crisis.

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And that brings me to this Academy, and the health and medical science community more widely.

What is our role?

In particular, what should we be advocating when it comes to the collection and use of genetic data in *any* context: be it clinical, direct to consumer, in a research project, or in building a biobank?

Let me suggest that before we even *think* about a specific model, we start with a basic question.

What do we need to do to earn the community's trust?

I want to emphasise those words, "earn trust".

I've read many documents called "outreach strategies" over the years. And I often get the impression that their aim is to "persuade people" – which isn't the same as earning trust.

"Persuading" implies that there's a perfect set of words that will suddenly make everything clear for all those people who just think the wrong way.

But there's never a perfect set of words. And that's because it's not about eloquence – it's about people's lived *experience*.

We earn trust when people can see that we're delivering the outcomes we promise – and *they* are benefitting.

There are three basic principles that I think are helpful to keep in mind.

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The first and most important is – don't be greedy.

Don't ask more from people than they're comfortable to accept.

That was the lesson that Iceland learned with genetic data in the early 2000s.

At the time, my company Axon Instruments had just gone to market with a DNA micro-array scanner called GenePix, for scanning and interpreting gene expression arrays.

In that context, my awareness was high when buzz started building around a promising Icelandic start-up, called deCODE.

Its CEO had worked out that Iceland could be extremely attractive as a hunting ground for genetic factors.

Icelanders are a “founder population”: geographically isolated, and genetically homogenous.

The people know a lot about their ancestry. They’re famous for it.

And the public sector was sitting on extremely detailed health records going back to the nineteenth century.

A data goldmine!

So deCODE said to the Prime Minister of Iceland: wouldn’t it be a great idea to build a national health sector database, and sell the access rights to companies and institutes all over the world?

And sweeten the deal for investors by integrating *all* the health records, *all* the genetic data, and *all* the genealogical information?

And run it on a model of “presumed consent” – with all the records of dead people automatically included, because by definition, at that point they couldn’t refuse?

And hand over the exclusive contract for building it and operating it to deCODE?

Now Icelanders had grown very comfortable over the years with the idea of the government holding their health records.

But this was a model that many just wouldn’t stomach – and the project fell apart when citizens took the matter to court.

It was eventually reassembled in a more modest form – but by then, the damage was done. And it wasn’t confined to Iceland.

To this day, health bureaucrats point to Iceland when anyone proposes to consolidate health records.

Here Be Dragons.

The *better* lesson to take is that it’s better to let trust build up with familiarity, over time.

Sometimes that means scaling back our ambitions, and accepting that we can’t take full advantage of the expansive tools at our fingertips.

We know that our Australian researchers overwhelmingly do the right thing: they will pull themselves up short, even when the rules might technically allow them to do something that they know is inconsistent with their fundamental duty of care.

But we can’t assume that everyone will be as scrupulous. And we can’t ask the community to take our assurances on trust.

So if the protections in the system today are implicit, then we have to go the extra mile to make them *ex*plicit: spell them out.

We also have to be humble enough to give ourselves time: time to understand just what new risks we might create when we transition to a new model.

So many times, I see project teams excited about the potential of centralising data, and making it searchable, and ensuring it's easy access, and maximising the coverage.

All good things – but they come with different challenges that need to be anticipated and managed.

That includes the magnifying effect of AI – artificial intelligence.

With AI, you don't just have a myriad of data points on a given person. Now you've got the capacity to join up the dots, at speed, and at scale, in ways that the people who compiled the data simply didn't anticipate.

It only takes one breach to make a big reform untouchable – for years, if not decades. And it's that much harder to rally the troops and try again.

So we need to be prepared to rein in the excitement, to find a level of protection that gives clarity to real scientists doing ethical research, and confidence to the community.

So that's one important principle: don't be greedy.

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The second principle follows on from the first: make the benefits visible.

Iceland broke this rule, too: they designed the database to be as appealing as possible to foreign venture capitalists.

They succeeded – but the foreign venture capitalists weren't the problem.

It's a pattern we've seen many times before.

Again and again, we lose the argument because people don't see benefits for themselves.

Take GM foods.

Who benefits from a tomato that lasts on the shelf for a month – instead of a week?

It's the growers, and the retailers – not the consumer.

And you can bet that no supermarket on Earth will tell its customers that – thanks to science – they can now enjoy month-old tomatoes.

So customers may be 99% sure that GM foods are safe... but why would you accept *any* risk, if *you* carried the risk, and someone else is getting the return?

Compare GM foods to IVF.

On the surface, IVF seems much more confronting.

It's about the production of human beings.

So why are we so comfortable with IVF, and so divided on GM?

It's simple: we saw healthy babies.

And the families of those babies shared their stories: not presenting their children as freaks or curiosities, but simply raising them in the knowledge that they were just like everyone else.

Sometimes the benefits of research are so intuitive to researchers that we forget they're not so intuitive to everyone else.

Articulating those benefits has always been the challenge for big shared platforms like the My Health Record.

People aren't persuaded by appeals to their inner economist, like "cost" or "efficiency"; or the abstract proposition that more data equals better research.

But we know that they *will* tick the box marked "I consent to have my data used in research" when they're asked by a company like 23andMe.

And that's because they really do have the sense that they're making a meaningful personal contribution, to projects that 23andMe explains with great clarity.

If 23andMe can do it, then so can we.

But people need more than generalisations – they need examples.

You've got them – so let's all help to share them.

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And the third principle is one I've shared before, but it's always worth repeating: if you see an information gap, then jump right in.

We don't want people to type "genetic test" into Google, and click on the company that pays the most to show up at the top of the search results.

We want people to be able to look at the search results, and see the names of Australian universities, Australian medical research institutes, Australian government agencies, that they trust.

Or better still, they'll type the names of those organisations into the search field – because they know that their websites are genuinely useful.

And not just good at explaining their own research. Good at developing basic primers, that respect people's intelligence, and help them to make decisions, without assuming knowledge they just don't have.

I think of the materials on vaccination produced by the Academy of Science, or the primers on neuroscience by the Queensland Brain Institute.

And I think of the people like Jane Tiller and Paul Lacaze, from Monash University, who've done great work through outlets like the ABC and The Conversation.

Of course, there are others. And as a former science publisher, who knows that good science communication is rarely given the credit it deserves, I say to everyone who's making it a priority: thank you for your service to quality research.

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So, three principles worth remembering: don't be greedy, make the benefits visible, and jump into the information gaps.

And let me finish where I started – at that backyard barbecue with Uncle Bob.

The aunties, and the grandpas, and the cousins have finished discussing their ancestry profiles.

They're talking now about their expectations for medicine in the next twenty years.

And they're all looking ahead with optimism: proud of Australian research, proud that their data is contributing, confident in all our researchers – and glad to be alive in 2018.

So I'll finish with a final call to AAHMS – however you spell it.

May the Force be with you.

THANK YOU