

Australasian Science

Volume 37 | Number 6
JULY/AUGUST 2016 | \$9.95

SPECIAL ISSUE

Genomics

**Do Genome Tests
Live up to the Hype?**

**Are We Prepared for
Our Test Results?**

**Should Genomes Be
Screened at Birth?**

**Should You Share Your
Genetic Data Online?**

**Will a Genome Test Lead
to Healthy Behaviours?**

**Indigenous Questions
about Genomic Research**

**Global Biobanks: A New
Frontier for Big Data?**

**The Changing Landscape
of Gene Patent Law**

The Stem Cell "Sell"



FEATURES

- 12 Genomic Testing as a Lifetime Health Resource?**
If lives could be saved by being “forewarned” by a genomic test, should we perform genomic testing of all babies at birth?
- 15 Will Genomics Motivate Healthy Behaviours?**
Will communicating the genetic risks of disease necessarily motivate people to make healthier behaviour choices?
- 18 Indigenous Genomics**
Mistrust is a significant but not insurmountable barrier to the acceptance of genomics by Indigenous people.
- 21 The Ethics of Online Genomics Tests**
There is a significant difference between the expectation and reality of direct-to-consumer personal genome testing, creating a gap where interesting tensions and ethical dilemmas sit.
- 24 Like, Comment, Share: Should You Share Your Genetic Data Online?**
The culture of sharing our private details online is extending to health and ancestry data generated by genome testing. What are the benefits and what are the risks?
- 27 Personal Genomics: What Do Consumers Want?**
Are Australian consumers excited or cynical about the promises of personal genome tests, and are they adequately prepared for the information they’ll receive?
- 30 The Changing Role of IP in Genomics**
Recent court decisions have overturned previous rulings about genetic patents, but other intellectual property regimes are already taking their place.
- 33 Biobanks Go Global**
Global networks of depositories for biological samples open a range of scientific, legal and ethical challenges.
- 36 The Stem Cell “Sell”**
The unfettered commercial environment that has allowed stem cell tourism to flourish must be challenged, and the professionals who enable it should be held to account.



conSCIENCE

- 39 A Toxic Legacy from Firefighting Foams**
Australian communities and environmental systems adjacent to Defence sites, airports and firefighting training centres have been contaminated by toxic chemicals.



9

NEWS

6 Browse

A round-up of science news from our shores.

COLUMNS

5 Guest Editorial

This edition of *Australasian Science* focuses on the ethical, legal and social issues associated with advances in genomic science.

40 Expert Opinion

Two reports have reviewed the evidence for the safety of nanotechnologies in food packaging and food additives.

41 Neuropsy

Linguistic analysis can distinguish between genuine and falsified expressions of remorse.

42 The Fit

What if doctors could diagnose disease by what you wrote on Facebook and Twitter?

43 The Fossil File

The public are welcome to attend one of Australia's largest palaeontology conferences.

44 Directions

The mass bleaching on the Great Barrier Reef this summer is the most damaging ever recorded.

45 Out of this World

Astronomers have discovered the closest habitable planet outside our solar system, and discovered one of the biggest black holes ever.

46 The Bitter Pill

Populist TV, blogs and publications have portrayed saturated fats as healthy rather than dietary villains, but this is an oversimplification.

47 The Naked Skeptic

Scientologists argue against the existence of the mind, and therefore the existence of mental illness.

48 EcoLogic

Can automated algorithms do better than humans in conservation games?

49 Lowe Tech

The election revealed a bipartisan lack of understanding of the role of science in innovation and of the coal industry in the fate of the Great Barrier Reef.

50 Quandary

If neural lacing enables our brains to be networked, we could easily be hacked or become the tools of Google or government.

51 Australasian Sky

Your map of the night sky this month.



41



45



50

GUEST EDITORIAL

The Age of Genomics

This edition of *Australasian Science* focuses on the ethical, legal and social issues associated with advances in genomic science.

Faster and more accurate sequencing of human genomes; smaller and smarter wearable technologies; an increasingly connected world; direct access to health testing; improvements in data storage. These are just some recent innovations now influencing Australian health care and society, and this issue of *Australasian Science* focuses on their associated social, ethical and legal issues.

Some have called for the genomes of all newborn babies to be sequenced. David Amor and I take a critical look at this idea (p.12) and argue that, despite its potential benefits, genome sequencing is not yet appropriate for wide population use – on scientific, economic and ethical grounds.

We also need to learn more about the impact of genomic information. Amelia Smit and Anne Cust (p.15) look at whether people change their health behaviours after receiving individual risk information. While existing evidence doesn't show much difference, there are problems with these studies. We also don't know enough about the psychological impact of this information.

Genomic science has much to offer Indigenous Australians, yet Emma Kowal and colleagues write that poor research practice in the past has led to mistrust (p.18). The National Centre for Indigenous Genomics is fostering the development of genomics for Indigenous Australians, and is supporting Indigenous people to consider careers in genomics and promoting Indigenous Australians as partners in research.

The ease of obtaining and testing our genome has led to an expanding Australian market for personal genome testing. Jacqueline Savard (p.21) outlines her research on people's motivations for testing and the impact it may have. Kathleen Gray (p.24) looks at the phenomenon of sharing our genome information online and how this fits in with the global "quantified self" movement. Is this the ultimate in democracy or commercial manipulation? Sylvia Metcalfe (p.27) introduces the Genioz study, which is investigating the knowledge and attitudes of Australians towards these tests. While there is a lot of hype about this testing, there's also a lot we don't yet know.

Dianne Nicol (p.30) looks at concerns over patenting. While fears about gene patenting leading to exclusions in research or testing are so far unfounded, this may change. Many countries, including Australia, are starting to see restrictions on what can be patented – leading to novel methods to protect intellectual property.

This edition ends with two articles that examine the influence of a connected global world in this area. Paul Mason and colleagues (p.33) discuss biobanking in a global context, and find there is an urgent need to resolve many technical, ethical and economic issues. Megan Munsie and colleagues raise several concerns about stem cell tourism (p.36), not least being risks of harm from purchasing unproven treatments.

While these technologies are here to stay, many of their applications are not yet ready to go mainstream. The challenge is to work together to ensure that these exciting innovations are used to benefit the well-being of all Australians. This requires a national conversation. Enjoy the issue!

Ainsley Newson is Guest Editor of this edition of *Australasian Science*.



Cover Story

Advances in genetic science and related fields have created many exciting opportunities but also many ethical, legal and social issues. This issue highlights many of these aspects, and features writing from a wealth of knowledgeable Australian researchers. Image credit: Vladimir Nikitin

[@austscience](https://twitter.com/austscience) facebook.com/austscience

Reproduced from <https://www.australasianscience.com.au/category/magazine-issue/julyaugust-2016>

Australasian Science

www.austscience.com

EDITOR/PUBLISHER: Guy Nolch

COLUMNISTS: David Reneke, Ian Lowe, Peter Bowditch, Michael Cook, John Long, Tim Olds, Tim Hannan

PATRONS: *Australasian Science* is supported by Nobel Laureate Professor Peter Doherty and renowned science broadcaster Robyn Williams, representing excellence in science and its communication.

EDITORIAL CONTACTS

Control Publications P/L, Box 2155, Wattleree Rd PO, VIC 3145, Australia
Phone: (03) 9500 0015
Fax: (03) 9500 0255
E-mail: science@control.com.au
Web: www.austscience.com
Twitter: @austscience
Facebook: facebook.com/austscience

ADVERTISING:

 Steve Austin

Phone (03) 9500 0015
Fax: (03) 9500 0255
Email: advertise@control.com.au
For rates see austscience.com.au/ads

DISTRIBUTION:

Gordon & Gotch Ltd

PRINT POST APPROVED PP 331379/0032

ISSN 1442-679X *RRP \$9.95 incl. GST

The opinions expressed in this publication are those of the authors and do not necessarily represent those of the publisher.

CONTRIBUTIONS

The Editor welcomes original articles of interest to the general public written by qualified writers on fields within their expertise. Writers' guidelines are at <http://www.australasianscience.com.au/writers-guidelines>. Prospective authors should submit a summary to the Editor prior to submitting a manuscript.

© 2016 Control Publications Pty Ltd (ABN 46 006 591 304). All rights reserved. Authorisation to mechanically or electronically copy the contents of this publication is granted by the publisher to users registered with Copyright Agency Ltd. Special requests should be addressed to Control Publications Pty Ltd.

Australasian Science is published 10 times per year, with monthly publication except for Jan/Feb and July/August bimonthly editions.

JULY/AUGUST 2016 |  | 5