

Melbourne Data Analytics Platform
(MDAP)



Data Governance in Australian Stem Cell Research

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MRFF Enabling Openness in Australian stem cell Research (EOAR)

- ▶ Increasing urgency for crafting replicable, open, and trustworthy science including in stem cell field
- ▶ Focal question: how can these goals be accomplished?
- ▶ Use of various disciplinary approaches including consultative and deliberative approaches to generate policy recommendations
- ▶ Key issue: how to manage data/information particularly associated with historic cell lines



Clear need for better data oversight & management!

We asked 46 stem cell researchers around Australia:
“How do you find the stem cell resources that your research needs?”

Vic	18	Female	18	25-34 y.o.	4
NSW	13	Male	28	35-44	21
Qld	8			45-54	10
WA	3			>55	12
Tas	3				
SA	1				

Make them myself

Word of mouth

Publications

I don't know where to start

Informal sharing

Dan Santos



Mengqi Chi-Chi Hu

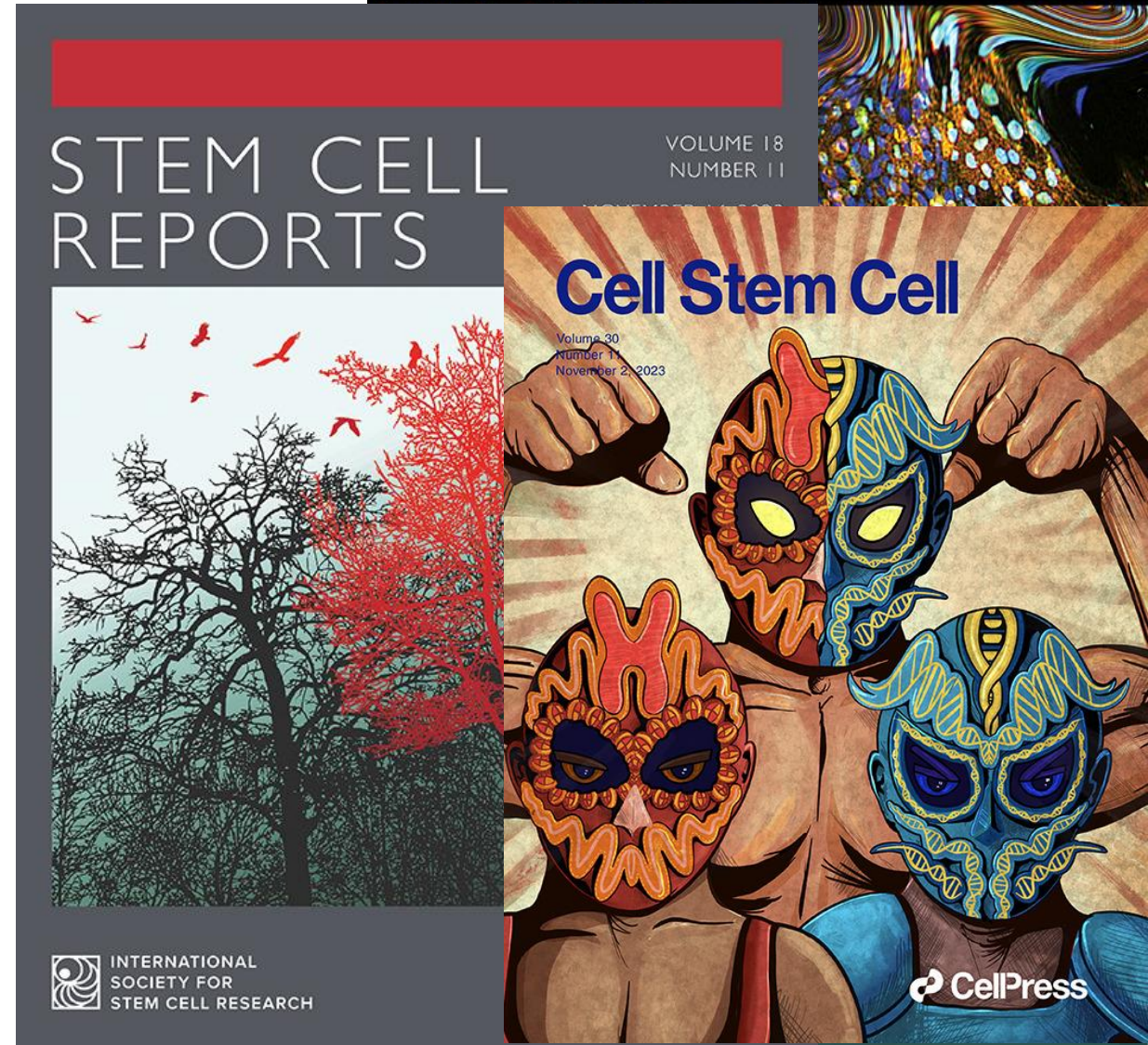


What's the current state of play?

Our analysis to date has recorded 1500-2000 Australian-made iPSC lines...

- lines from different labs have similar/same names without confirmation of equivalence
- naming of lines changes over time and across publications
- nested references to methods makes provenance difficult to track

Hu et al. (2024), Australian researchers' perceptions and experiences with stem cell registration, *Stem Cell Research*



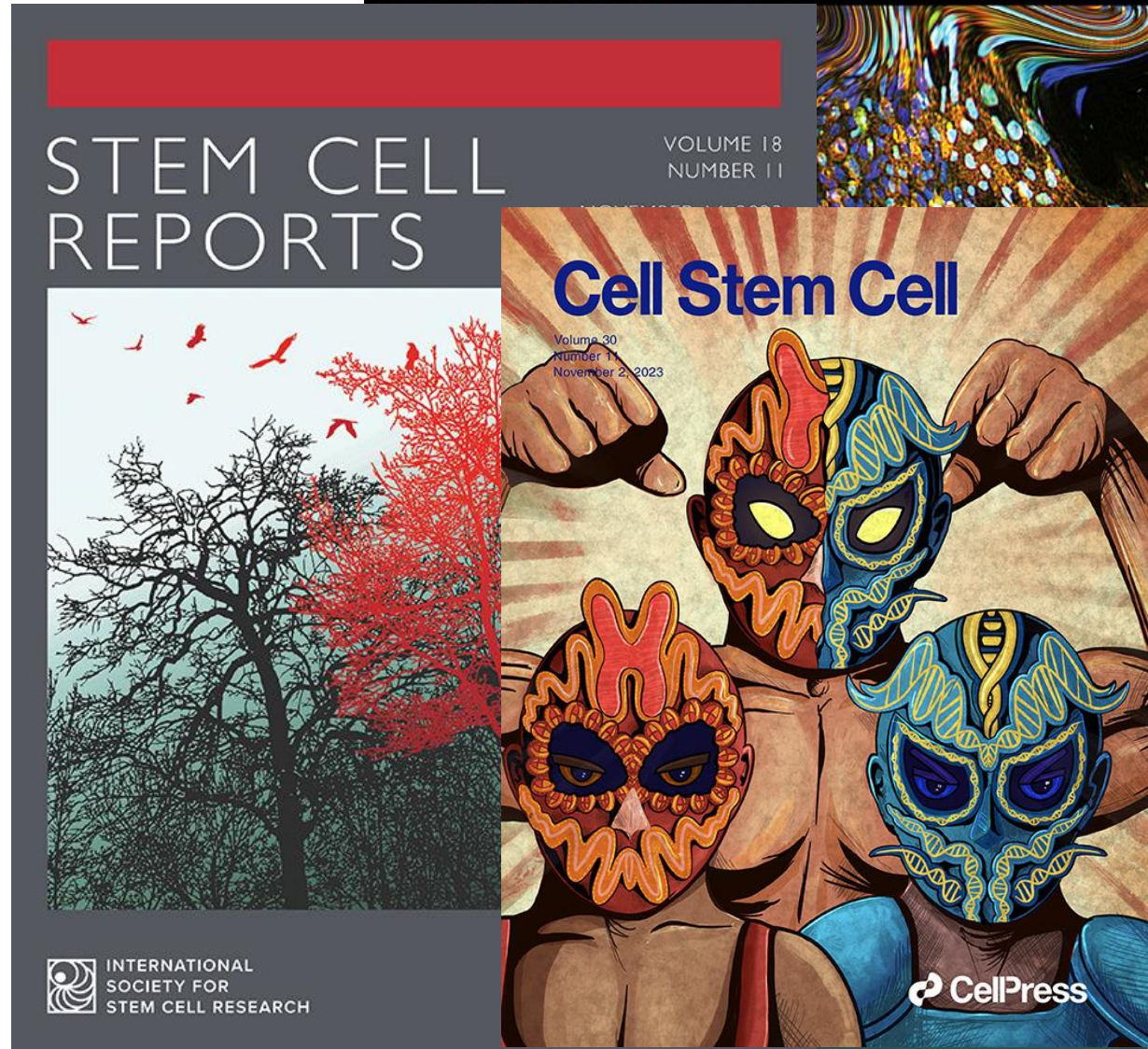
What's the current state of play? (con't)

- lack of ready access to lab contacts and movement between labs
- recharacterisation rarely occurs
- use of international registries (hPSCreg) is limited or simply instrumental
- lots of assumed/tacit knowledge!



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STEM CELL RESEARCH



Need stem cell registries to combat silos & inconsistent practices

- ▶ Stem cell lines are physical entities but need to be registered
- ▶ Registration provides unique and persistent identifiers to link phenotypic data to lines
- ▶ Critical to have data on provenance and conditions associated with consent
- ▶ If research is to be a collaborative endeavor, sharing and re-use of cell lines and associated data is necessary for downstream research translation
- ▶ **Only as good as the inputs: currently user-generated cell line names are often not unique, stable, or persistent**

Christine Wells



See Wells et al. (2024), Guidelines for managing and using the digital phenotypes of pluripotent stem cell lines, *Stem Cell Reports*

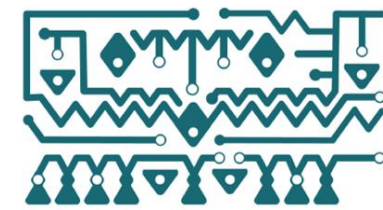
Registries can address FAIR principles

Findable: data/resources can be found along with associated data/metadata including using machine learning

Accessible: users can find out how to access the lines and associated data

Interoperable: data are consistent and integrated with other data sources

Reusable: ultimate goal! metadata and data should be well-described so that they can be replicated and/or combined in different settings



But what about CARE?

Limited use of CARE principles in stem cell domain
(more extensive in genomics)

- ▶ Collective benefit
- ▶ Authority to control
- ▶ Responsibility
- ▶ Ethics

Goal is Indigenous Data Governance including
Indigenous-led research—needs much more attention
in stem cell domain!

How should stem cell governance better account for consent & diversity?

Preliminary findings from our recent deliberative forum:

- ▶ Need transparent, publicly agreed governance mechanisms for Australian cell lines and data
- ▶ More attention to provenance particularly consent for different uses
- ▶ Establishment of ‘consent to governance’ approaches at national and/or state levels
- ▶ Consideration of ‘CARE’ style principles for diversity more generally? (may not be fit to purpose given goals of CARE)
- ▶ Greater attention to research priorities and fostering more diverse contributions to cell lines in ways that are ethically and culturally appropriate





Enabling Openness in Australian stem cell Research (EOAR) is an interdisciplinary research cluster which is interested in ways of building trust in stem cell-based research and therapies

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For more information, please see <https://www.eoar.com.au/>

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