Australian Research Data Commons

Being data savvy

What health librarians need to know

Liz Stokes, Skilled Workforce Team

Health Librarian Association Professional Development Days
18-19 July 2019, Monash Caulfield, VIC.

NCRIS National Research Infrastructure for Australia
An Australian Government Initiative

What is the ARDC?

The Australian Research Data Commons (ARDC) is a transformational initiative that enables Australian research community and industry access to nationally significant, leading edge data intensive eInfrastructure, platforms, skills and collections of high-quality data.

Australian Research Data Commons

What is the Australian research data commons?

It’s bigger than us...

A research data commons brings together people, skills, data, and related resources such as storage, compute, software, and models to enable researchers to conduct world class data-intensive research.

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Our people!

Rosie Hicks, CEO

ARDC staff

Australian Research Data Commons

ARDC Skilled Workforce team

Matthias Liffers
Perth

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Natasha Simons
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Alexis Tindall
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Gerry Ryder
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Liz Stokes
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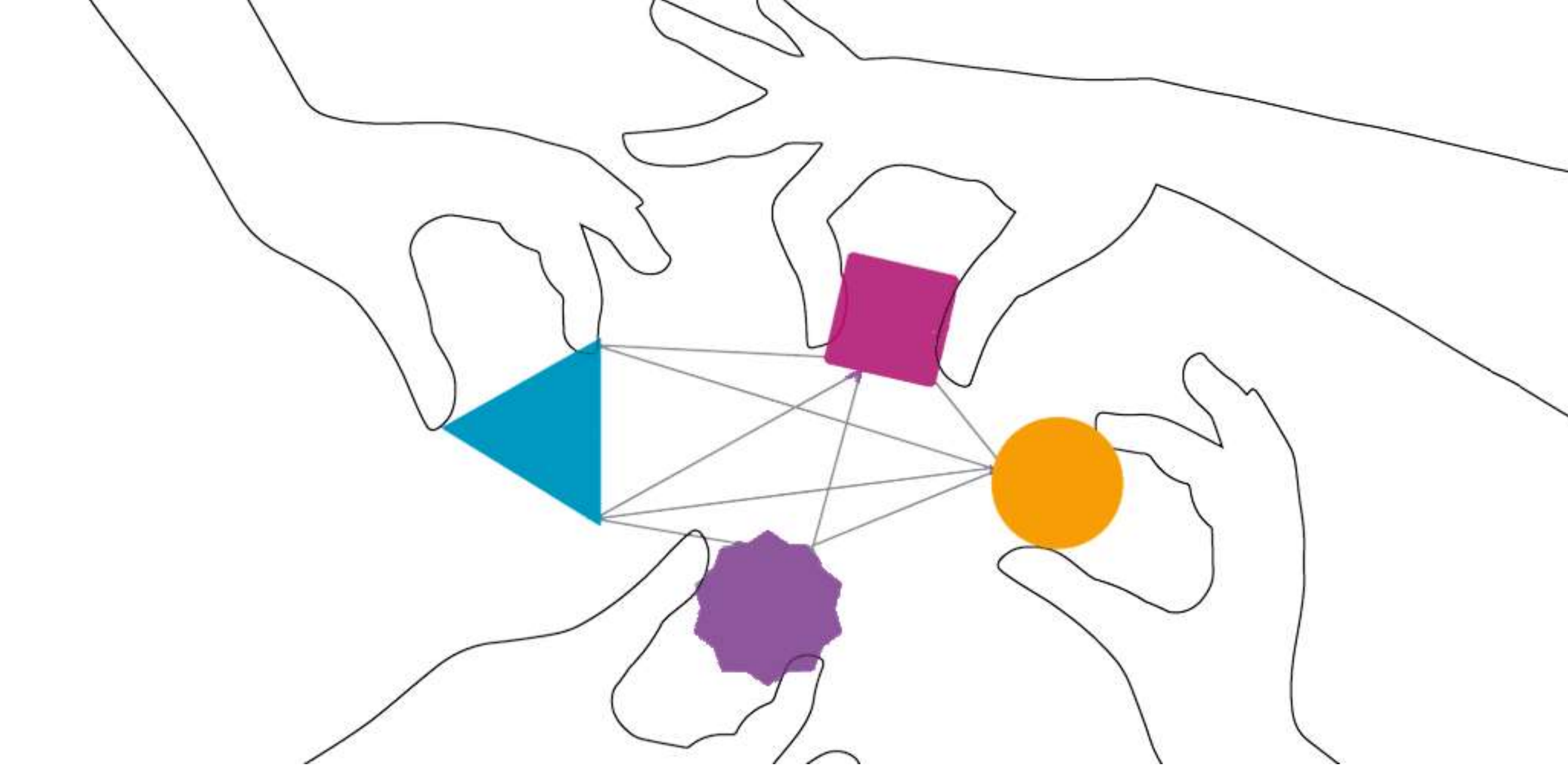

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Sharing sensitive data can be hard but it’s worth the effort.

In the name of understanding, a problem must be shared.
-Kylie.

Image: https://soundcloud.com/kyliestudio2/confide-in-me-optimus-remix

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International funders and publishers

The NEW ENGLAND JOURNAL of MEDICINE

International funders and publishers

"Publicly funded research data are a public good, produced in the public interest, which should be made openly available with as few restrictions as possible in a timely and responsible manner."

-Research Councils UK Common Data Principles

International funders and publishers

- Data sharing plans
- Data availability statements

- Trend to share data from randomised controlled trials meta-analyses.

ICMJE INTERNATIONAL COMMITTEE of MEDICAL JOURNAL EDITORS

BMJ

The NEW ENGLAND JOURNAL of MEDICINE

PLOS | MEDICINE

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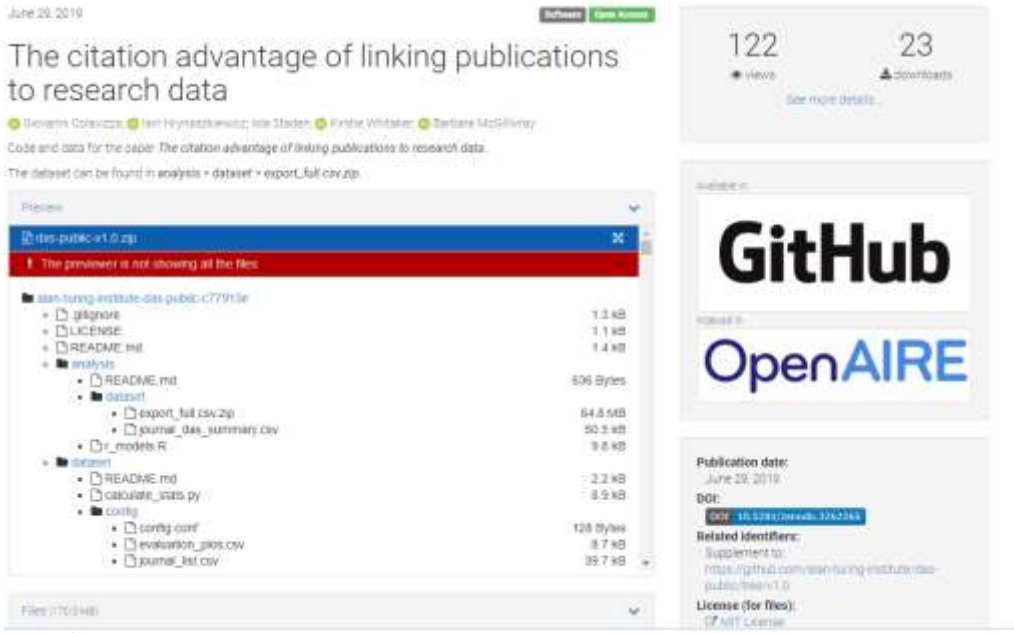
Citation advantage for linking publications to research data can be up to 25% if data availability statement links to a repository.

arXiv:1907.02565



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Australian funders

Australian Government

Australian Research Council

Australian Government

National Health and Medical Research Council

NHMRC

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Aust Code for the Responsible Conduct of Research

For Institutions

R8 Provide access to facilities for the safe and secure storage and management of research data, records and primary materials and, where possible and appropriate, allow access and reference.

For Researchers

R22 Retain clear, accurate, secure and complete records of all research including research data and primary materials. Where possible and appropriate, allow access and reference to these by interested parties.

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National Statement on Ethical Conduct in Human Research

- Updated mid 2018 – new Section 3
- Full implementation expected from 1 Jan 2019
- HREA being updated to align
- Element 4: Collection, Use and Management of Data and Information
- ARDC+ NHMRC webinar Sept 2018

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National Statement on Ethical Conduct in Human Research

3.1.50 In the absence of justifiable ethical reasons (such as respect for cultural ownership or unmanageable risks to the privacy of research participants) and to promote access to the benefits of research, researchers should collect and store data or information generated by research projects in such a way that they can be used in future research projects. Where a researcher believes there are valid reasons for not making data or information accessible, this must be justified.

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Consent for data sharing

If using repositories for re-use:

- Extended consent – for use of data or tissue in future projects closely related to or in the same general area of research.
- Unspecified consent – for any future research (3.1.36)

When seeking consent to collect info of long term value, researchers should obtain consent for perpetual retention, including any planned re-use and sharing with others (3.1.37)

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National Statement on Ethical Conduct in Human Research: Data Management Plans

3.1.45 For all research, researchers should develop a data management plan that addresses their intentions related to generation, collection, access, use, analysis, disclosure, storage, retention, disposal, sharing and re-use of data and information, the risks associated with these activities and any strategies for minimising those risks.

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Image CCBY http://archive.stats.govt.nz/browse_for_stats/snapshots-of-nz/integrated-data-infrastructure/keep-data-safe.aspx

Best Practice Guide to Applying Data Sharing Principles

Australian Government
Australian Institute of Health and Welfare
AIHW

Desai, T. Ritchie, F., and Welpton, R. Five Safes: designing data access for research. 2016. DOI: 10.13140/RG.2.1.3661.1604

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ARDC support for health and medical

Nectar Cloud services 75 NHMRC grants last year
Project support for high value collections
Interest Groups on DMPs, Library Carpentry
Sensitive data community of practice
Trusted data repositories community of practice
Run community workshops on sharing clinical data with CSIRO

Data sharing tips and resources

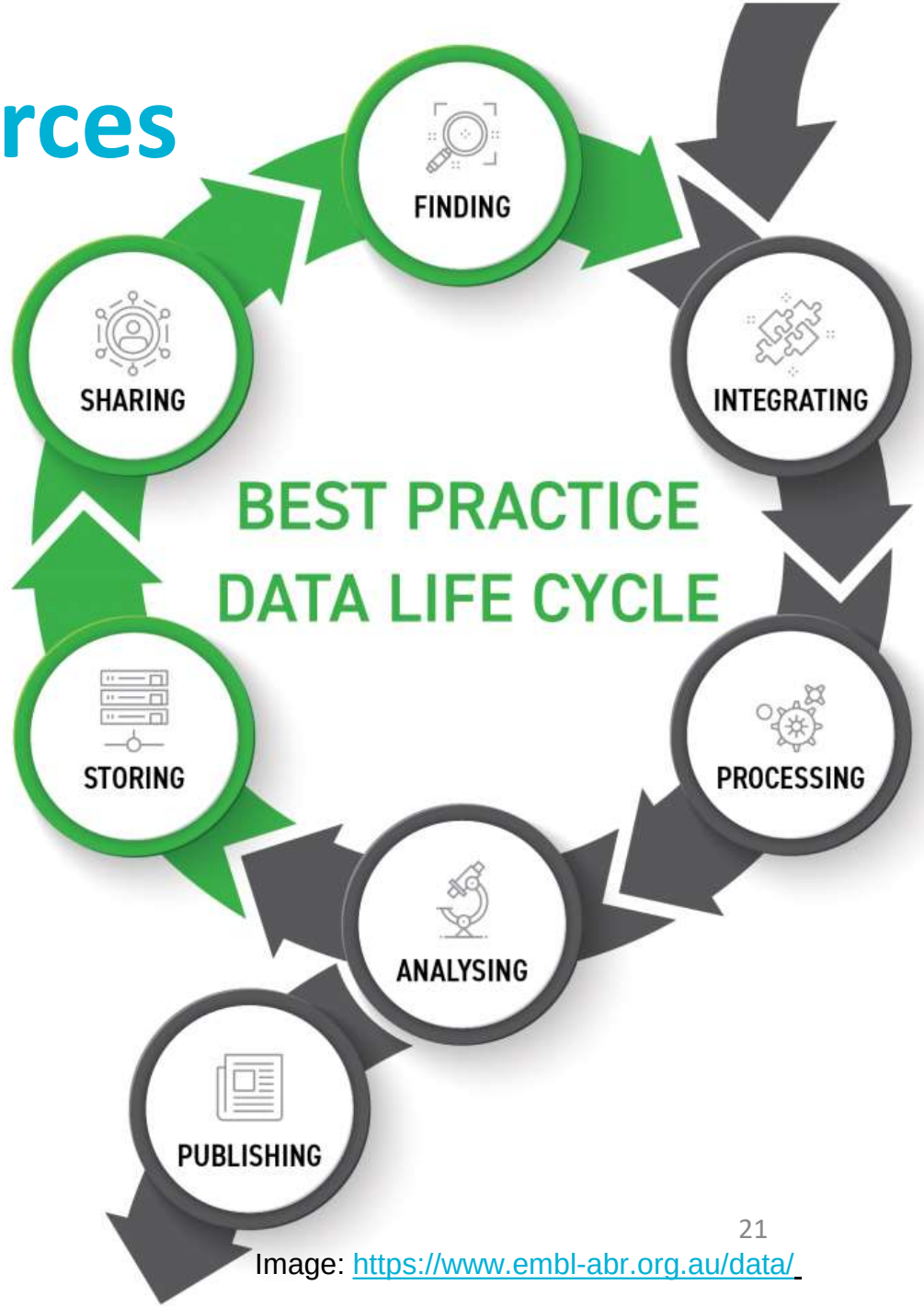

Image: https://www.embl-abr.org.au/data/

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ARDC resources

Guides – on https://ands.org.au

- Publishing and sharing sensitive data
- Data sharing considerations for Human Research Ethics Committees
- De-identification
- Research data rights management (‘the licensing guide’)

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FAIR data principles

ands.org.au/working-with-data/fairdata

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Benefits of data sharing to researchers

- *"Planning for the management of research data early in a research project can improve research efficiency, guard against data loss, enhance data security, and ensure research data integrity and replication."* QUT Library 'Managing your research data' https://www.library.qut.edu.au/research/data/
- Transparency and reproducibility
- Maximises value of investment
- Citations and impact
- Collaborations
- Secure ongoing storage
- Ethical obligation (clinical trials)
- Publications with data cited more often

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Consent for data sharing (NHMRC)

Topics that can be covered in Data Management Plan/Participant info

- Governance
- Access – during and once project is complete
- Use and reuse
- Privacy
- *3.1.31 In any information provided to potential participants during the consent process, researchers should include information on data management and storage*

Data that is re-used still needs to comply with original consent – therefore consent conditions need to be documented – metadata

Options for participants?

- Levels of aggregation or identifiability

Example wording in 'Publishing and Sharing Sensitive Data' guide e.g. "Other genuine researchers [may] have access to this data only if they agree to preserve the confidentiality of the information as requested in this form."

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Library Carpentry

- Manipulate, transform, and analyse data
- Support open research and data scholarship
- Make data-driven decisions

As a subject specialist librarian, I need an intro to data so that I can participate better in conversations with researchers

As a librarian, I need to learn OpenRefine so that I can transform and manipulate reports more efficiently

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Data savvy

- Sharing research data and preparing it for reuse are important parts of ethical and reproducible research
- Use the Five Safes framework and FAIR principles
- ARDC has communities and resources to support your learning
- Talk to me about Library Carpentry for data skills training!

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