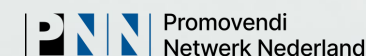


Beyond personal data

# The Ethics of Research Data and the CARE Principles

Bora Lushaj, Data Steward, ISS/ESL/EUR

8 May 2025





# The Why of Today

- To what degree can we implement CARE?
- Sharing
  - Opening the research data cycle
  - Enabling co-stewardship of research data





## Agenda for Today

- Lightning talks (until 14.15)
  - **Introduction: The Sharing of Fieldwork Data and the CARE Principles** (Bora Lushaj)
  - **Navigating the inherent uncertainty of fieldwork data and the Research Ethics Review Process** (Jing-Yi Magraw and Tijs Gelens)
  - **Legal Aspects of the CARE Principles** (Anka Mos and Rafeek-Carmelo Baloum)
- Break: 15 minutes (until 14. 30)
- **Parallel Group Sessions (until 15.45)**
  - Only one session of a little more than one hour (no break)
  - Break 15min
- **My story: what I learned in the field that school didn't teach me (until 17.00)** (Beatrice Hati Gitundu, PhD Candidate ISS)





## QR Code Rolling Notes

*[link deleted, as the rolling notes were a collaboration between the workshop attendees.]*

*We suggest reusers of the materials create their own rolling notes document]*

- Rolling Notes all in one document: for lightning talks and group sessions
- Thank you note takers!





# Why the CARE Principles

- Data is valuable and can provide benefits
- CARE Principles support and complement the FAIR principles for RDM
- CARE principles can offer guidance:
  - Research with Indigenous data and communities
  - Use of Indigenous data
  - Research with communities with collective rights: minoritized groups, geographically located communities, patient groups, special professions, consumers.



[Source](#)

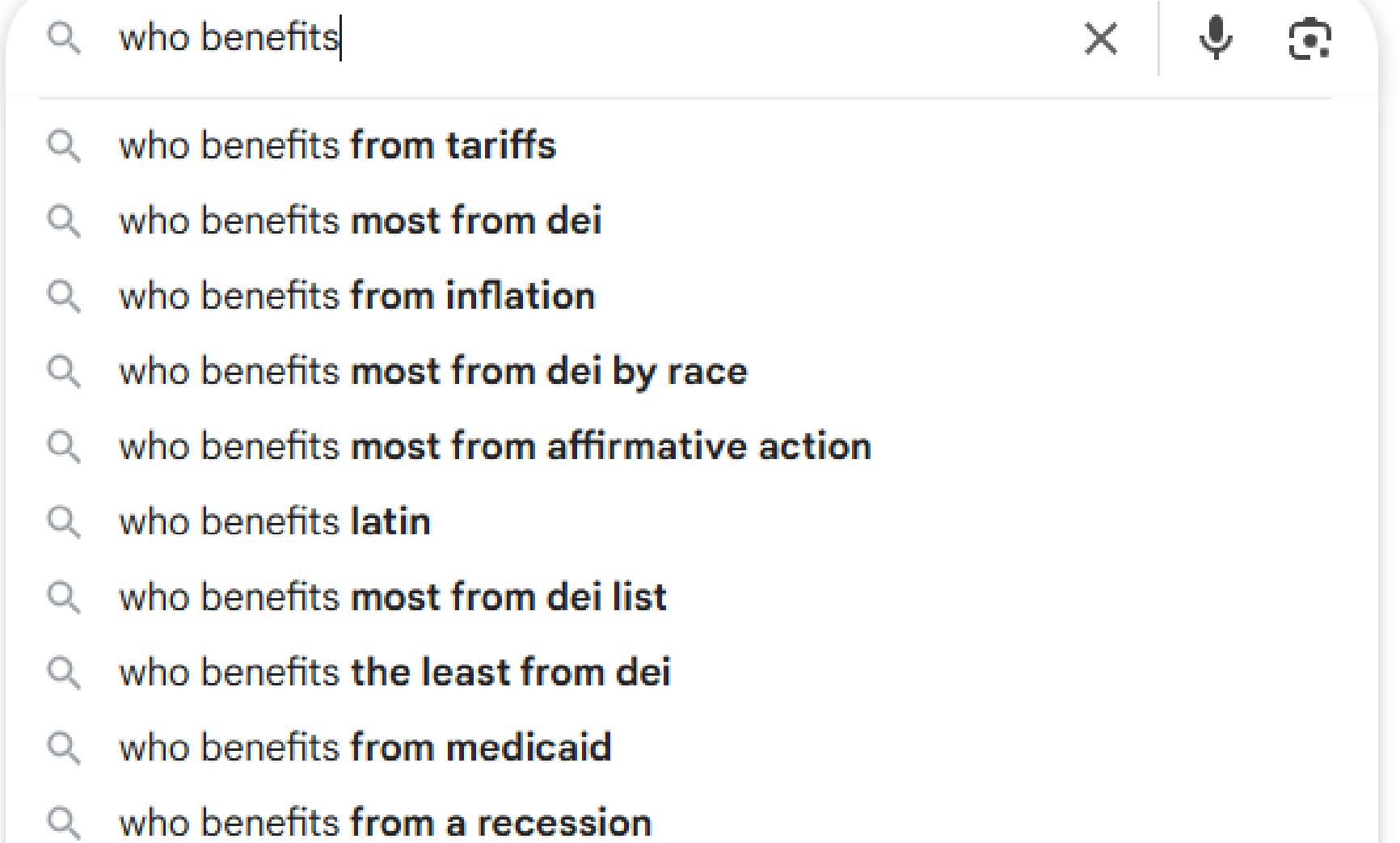
# Who benefits?

Who benefits?

- Think of a research project (involving fieldwork) that you worked on and answer these two questions:
    - Who benefited mostly from your research results? How?
    - Who benefited from your research data? How?
    - Could those benefits be extended?
- 



Google



# Background of CARE Principles

- Indigenous Data Sovereignty
- Participation to ensure proper care of Indigenous data held by non-Indigenous governments
- Grounded in Community-Developed Indigenous Data Sovereignty Frameworks (e.g., OCAP® Principles, Principles of Māori Data Sovereignty, etc.) and broadly recognized in UNRIP.
- Drafted by the RDA International Indigenous Data Sovereignty Interest Group in 2018, hosted by the Global Indigenous Data Alliance, formed in 2019.





# Rationale for CARE Principles

- Enhancing indigenous use of data for the pursuits of indigenous communities
- Complement movement towards FAIR by focusing on people and purposes for data governance
- Shift focus from regulated to value-based relationships for data governance that benefits indigenous communities
- CARE Elements are conceptually separate but interdependent



DATA PRINCIPLES						
INDIGENOUS				MAINSTREAM		
New Zealand Indigenous Data Sovereignty Principles	Australia Indigenous Data Sovereignty Protocols	United States Indigenous Data Governance Principles	Canada Indigenous Data Governance Principles	Open Data Charter Principles	FAIR Principles for Data Management and Stewardship	STREAM Properties for Industrial and Commoditized Data
Authority	Self-Determination	Inherent Sovereignty	OCAP®	Open By Default	Findable	Sovereign
Relationships	Available and Accessible	Indigenous Knowledge	Indigenous Knowledge	Timely and Comprehensive	Accessible	Trusted
Obligations	Collective Rights and Interests	Ethics	Methodology and Approaches	Accessible and Usable	Interoperable	Reusable
Collective Benefit	Accountability	Intergenerational Collective Wellbeing	Evidence to Build Policy	Comparable and Interoperable	Reusable	Exchangeable
Reciprocity	Exercise Control	Relationships	Ethical Relationships	For Improved Governance & Citizen Engagement		Actionable
Guardianship			Data Governance	For Inclusive Development and Innovation		Measurable
People oriented principles	Purpose oriented principles	Data oriented principles				

[Source](#)



# Who can implement the CARE Principles

- Researchers
- Research Institutions
- Data repositories
- Museums and Libraries



# Collective Benefit

- The data collected in research is informed by community-driven questions that address priority needs of the community
- Research data are used (and reused) to advocate for the needs of indigenous communities within or beyond the scope of the research
- Research data is used to add value to Indigenous communities



By Winfried Bruenken (Amrum) - Own work, CC BY-SA 2.5,  
<https://commons.wikimedia.org/w/index.php?curid=948868>

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# Authority to Control

- Indigenous peoples are actively involved in data stewardship and data governance protocols, whether hosted locally or elsewhere
- Data protocols and consent processes are documented and implemented
- Access limitations can apply, based on cultural values and customs (age group, gender, community review)
- Reflected in data licenses (E.g., [Kaitiakitanga Māori Data Sovereignty Licences](#)), metadata labels, terms of use, access conditions, data governance models.



## Vision

## Tuia te korowai o Hine-Raraunga - Data for self-determination

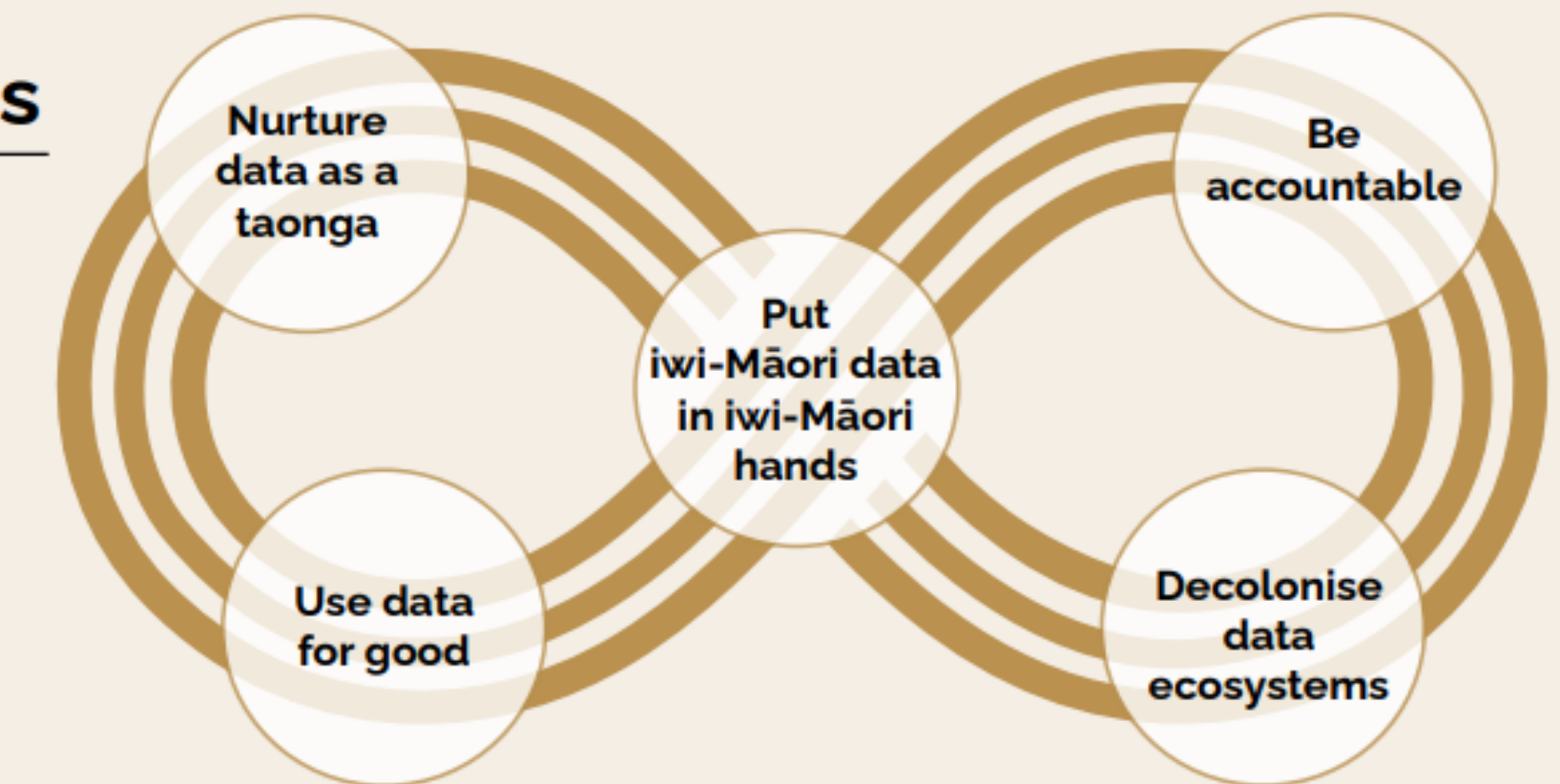
This vision enables iwi, hapū and Māori organisations, businesses and communities to pursue their own goals for cultural, social, economic and environmental wellbeing and to address inequities.

### Desirable Outcomes:

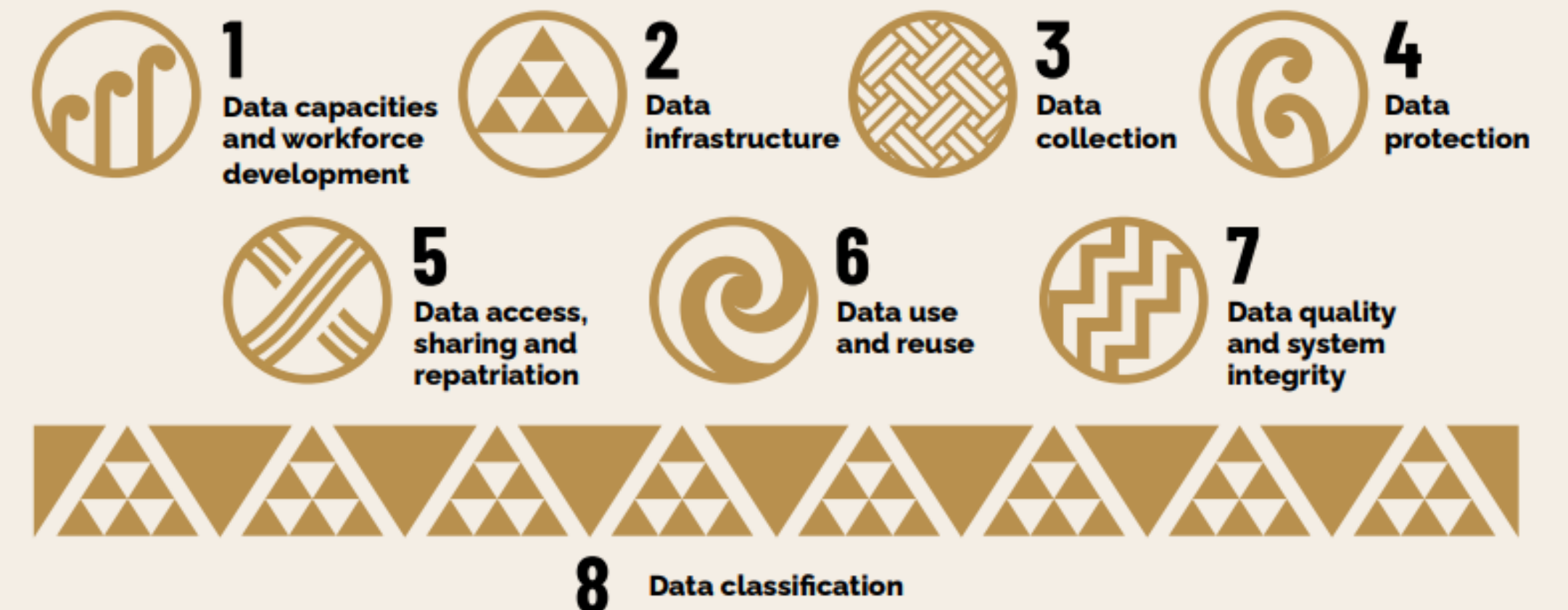
- The right service, at the right time, in the right way
- Better shared and autonomous decision-making
- A trusted and safe data ecosystem
- Data to drive iwi-Māori economies
- Supporting whānau to flourish
- Reaffirming and strengthening connections to identity, place and te reo Māori



## Values



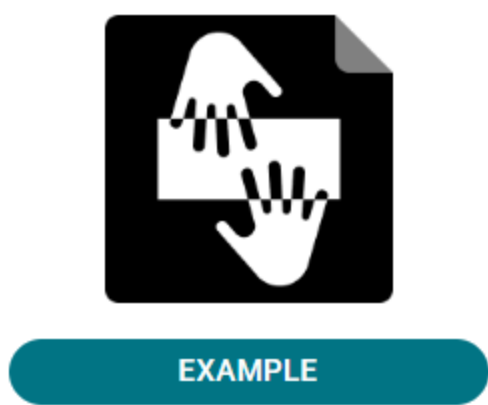
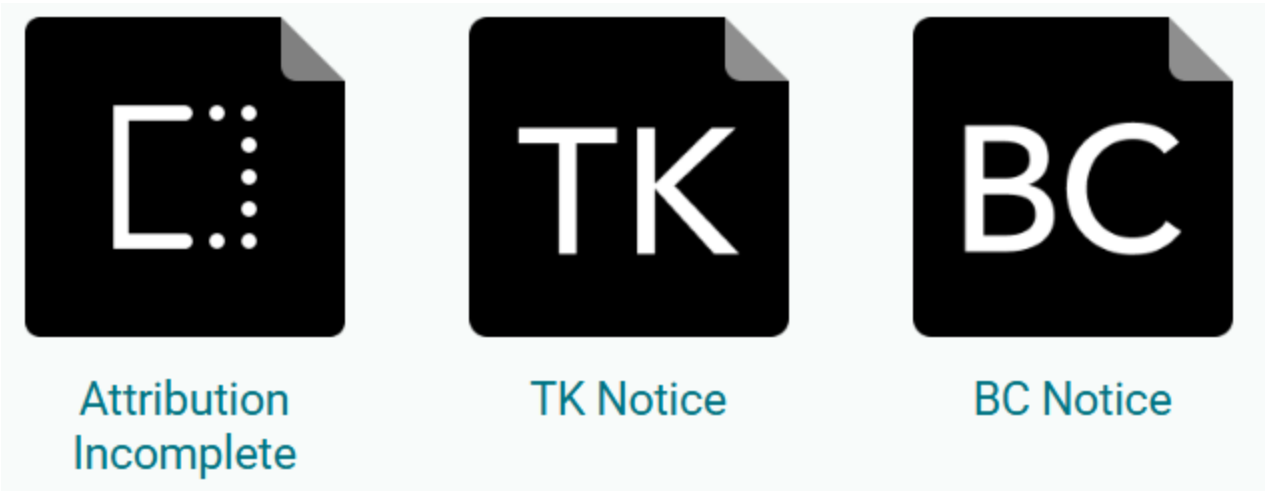
## Data Pou





# Responsibility

- Researcher contributes to expand data capacity through training, advocacy, etc.
- Researcher describes and labels data in accordance with linguistic and conceptual frameworks of indigenous communities, e.g., Traditional Knowledge (TK) and Biocultural (BC) Labels and Notices



## Open to Collaborate

### ENGAGEMENT NOTICE

#### Why use this Notice?

The Open to Collaborate Notice indicates that an institution is committed to developing new modes of collaboration, engagement, and partnership over Indigenous collections and data that have colonial and/or problematic histories or unclear provenance. This Notice indicates an institutional commitment to change and to develop new processes for the care and stewardship of past and future heritage collections.

#### Notice Text

Our institution is committed to the development of new modes of collaboration, engagement, and partnership with Indigenous Peoples for the care and stewardship of past and future heritage collections.

#### How to use this Notice

Institutions and researchers can generate and apply Notices through the Local Contexts Hub. Learn more about joining the Hub in our [Getting Started Guide](#). A Notice Style and Usage Guide is available on our [Downloadable Resources](#).





# Ethics

- Consider potential risks and harms of research and data and benefits
- Address historical injustice and contribute to future use



## One Map Initiative at the Local Level/ Inisiatif Satu Peta di Tingkat Tapak

One Map Initiative at the Local Level is a collaborative initiative to achieve a sustainable and equitable land use and planning in order to support the government to implement low-emission development.

---



# CARE Principles and Participatory Research

- Knowledge Democracy
    - Recognition of indigenous knowledges and frameworks
    - Recognition of multiple forms of knowledge and information
    - Recognition that knowledge is a powerful tool for taking action towards a fair and healthy world
-



# Key References

- Carroll, S. R., Garba, I., Figueroa-Rodríguez, O. L., Holbrook, J., Lovett, R., Materechera, S., Parsons, M., Raseroka, K., Rodriguez-Lonebear, D., Rowe, R., Sara, R., Walker, J. D., Anderson, J., & Hudson, M. (2020). The CARE Principles for Indigenous Data Governance. *Data Science Journal*, 19. <https://doi.org/10.5334/dsj-2020-043>
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  - Contracts and Agreements: Data Governace and Data Management Toolkit for Self-governing Indigenous Governments, Version 1.1, 2024. [Contracts and Contracts-and-Agreements.pdf](#)
  - Astuti, R., & McGregor, A. (2015). Responding to the green economy: how REDD+ and the One Map Initiative are transforming forest governance in Indonesia. *Third World Quarterly*, 36(12), 2273-2293. <https://doi.org/10.1080/01436597.2015.1082422>
  - Burns, D., Howard, J., & Ospina, S. (2021). Challenges in the practice of participatory research and inquiry. In D. Burns, J. Howard, S. M. Ospina (Eds.) *Challenges in the practice of participatory research and inquiry* (Vol. 2, pp. 17-34). SAGE Publications Ltd, <https://doi.org/10.4135/9781529769432.n2>
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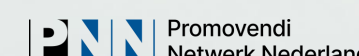
Beyond personal data

# Navigating the inherent uncertainty of fieldwork data and the research ethics review process

Tijs Gelens, Coordinator Research Ethics Review, EUR

Jing-Yi Magraw, Research Ethics Facilitator, EUR/ISS

8 May 2025





# Overview

- Introduction to presenters
- Research ethics review: the institutional perspective
- Case study
- Takeaways





# Introductions

## **Tijs Gelens - Coordinator Research Ethics Review**

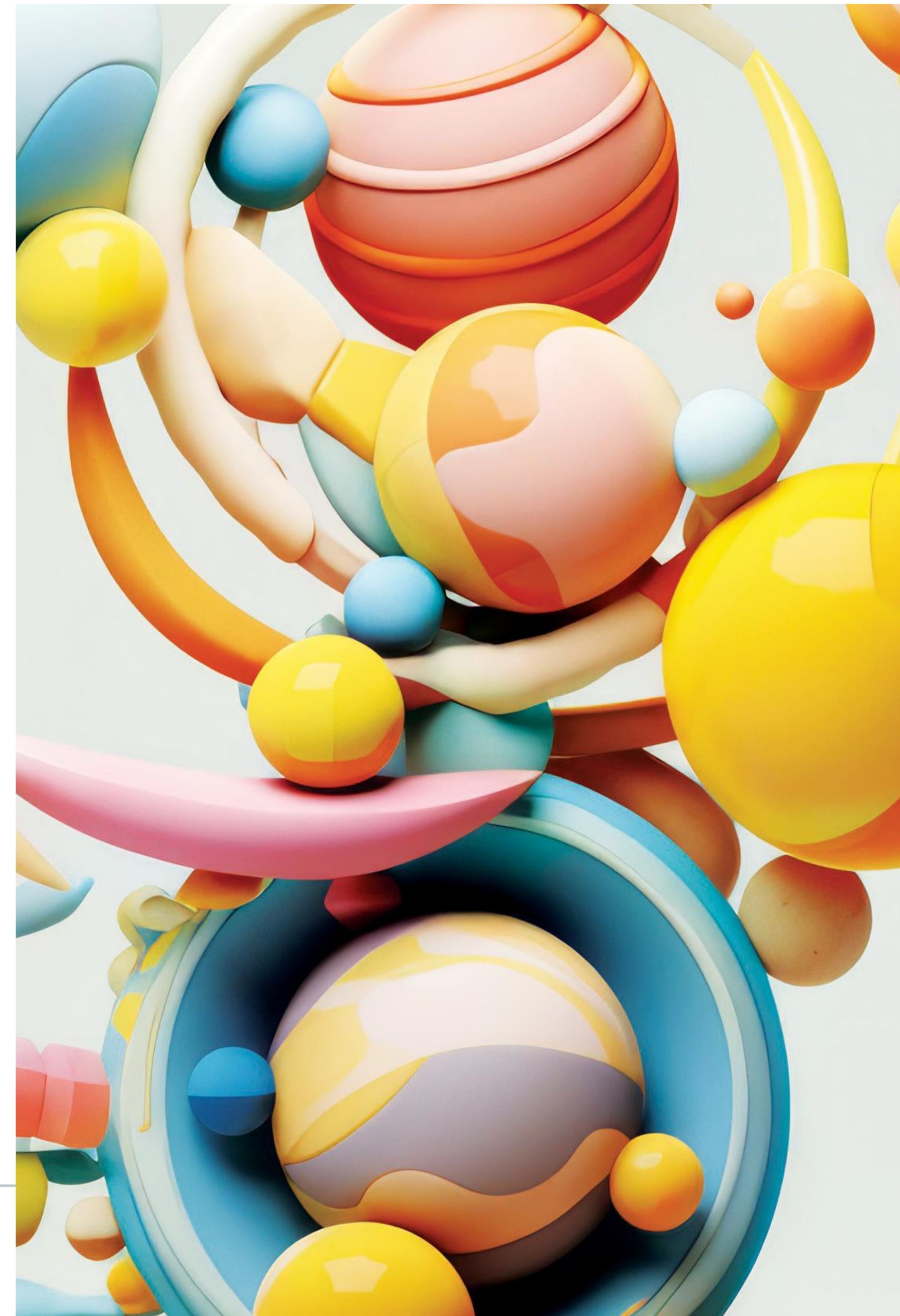
- Ethics review policy and processes at EUR
- Background in history and religious studies

## **Jing-Yi Magraw – Research Ethics Facilitator**

- Supporting the ethics review process at EUR
- Religious studies, with a focus on law

## **Why addressing uncertainty?**

- Researchers (including supervisors) have expressed doubts and/or concerns about how to formulate uncertainty about plans in an ethics application
- 





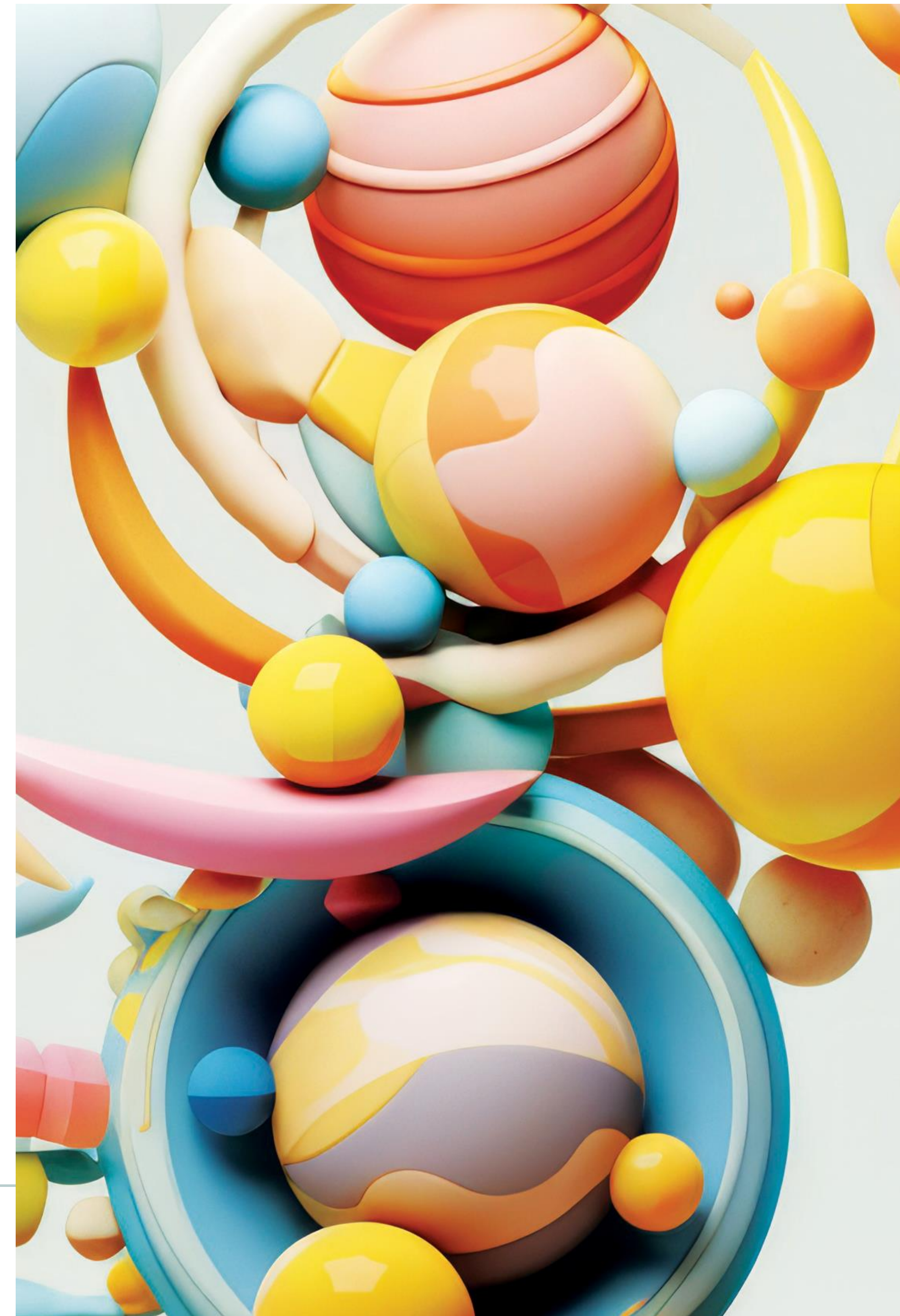
# The Institutional Perspective

## Awareness of research ethics

- Fundamental principles of research ethics: Nuremberg Code, Helsinki Declaration, Belmont Report
- Mainly grounded in biomedical research
- Ethics less formalized in other disciplines

## Need for formal processes

- The European Code of Conduct for Research Integrity (2010)
- The Netherlands Code of Conduct for Research Integrity (2018) - Duties of Care
- GDPR (2016)
- Journals and funder requirements





# The Institutional Perspective

What do we (the institution) need to have in place?

- A review process that is structured and systematic
- Based on available models, i.e., from bioethics

Challenges

- Rigid process
- Little reflection during fieldwork
- Ethics of data
- Address uncertainty in applications

How to navigate uncertainty in the ethics review process?





# Addressing Uncertainty

How do you prepare an ethics application for research that will inevitably shift in response to the situation in the field?

How can you prepare your application if you have not yet confirmed all the details for your research?

How can you incorporate the CARE principles in your ethics application?

## **Collective Benefit:**

- How can participants benefit from the research conducted?
  - Is the research team able to provide non-research related benefits to the community?
- 





# Ethics Application Case Study

2024 ISS ethics application from Stephan Bauman

- Note that different ethics committees may have different requirements

"A Participatory Action Research (PAR) study with former refugees or asylees who have resettled to Western Michigan to explore processes of meaning-making related to their migration experiences. Our research journey will be shaped and led by a team of former refugees, or "New Americans", who will facilitate, within their respective communities, processes of narrative inquiry while developing and designing a curriculum for refugee resettlement agencies and other service providers."

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# Ethics Application Case Study

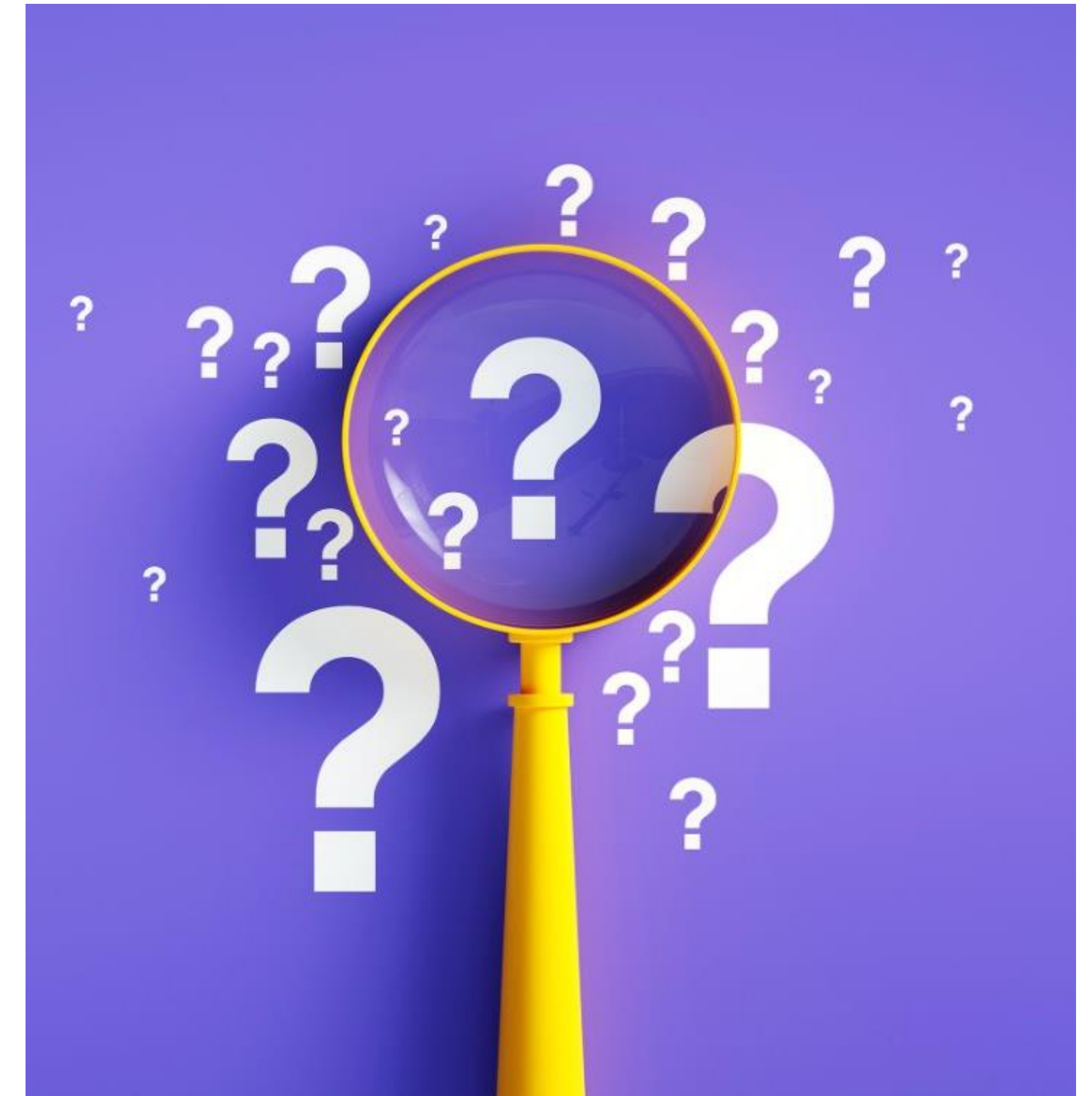
Facilitated by former refugees for former refugees (informing project design, facilitating narrative inquiry, distilling emerging themes)

- Facilitating team will be included as contributors to the research and curriculum

Perspectives and relationships explained

- Stephan and Belinda (philanthropy and educational psychology | prior familiarity with the communities)
- Facilitating Team (experience of forced migration, documented, eligible to work)

Possibility of the creation of a curriculum to combine insights from this research and to build upon a previous curriculum which "incorporated evidence-based exercises, neuroscience, and regulation techniques to introduce former refugees to aspects of the resilience process" (p.4 research proposal)





# Addressing Uncertainty

Plans can be explained with acknowledgement that these may later shift

- Uncertainty about prevailing theories (acknowledging limitations)
- Uncertainty about who final facilitating team members will be
- Mitigation of risks (i.e. careful selection of facilitating team to ensure diverse, inclusive group etc.)

"We recognize former refugee communities will experience resilience and personal growth in ways that **defy prevailing theories... These tensions between theory and praxis will serve to inform the journey**"

(p. 8, research proposal)

"We recognize that while the methodological features of this study elevate its aims, but **they also bring complexity**. Participatory research seeks to the flatten power differentials between those studying and those being studied... Still, it must be said that despite significant efforts to simplify the aims, design, and process, this project remains risky. We are prepared to **meet these challenges**, however, even as we seek to **mitigate the inherent risks**."

(p. 9, research proposal)



# Collective Benefit

Research proposal highlights the:

Expressed interest from members of the community to participate in a process that can "encourage and strengthen their communities" (p.4, research proposal)

Curriculum creation which builds upon insights from both this research and prior research to introduce "former refugees to aspects of the resilience process" (p.4, research proposal)





# Updates on Research

Now in final stages of first phase of project

- Adjustments required in pacing (to build trust, facilitate the schedules of different members)
- Political climate has changed, creating fear (i.e. threat of deportation) in the communities





# Takeaways

Don't underestimate the certainty that you do have in your research

Acknowledging uncertainty whilst providing plans/mitigation strategies is possible

Reflection on collective benefit, authority to control, responsibility, and ethics could be embedded into your application as a part of your research

## Further Questions

- What challenges have you experienced with uncertainty in fieldwork, and how did you navigate these?
- How can you embed CARE into your research?



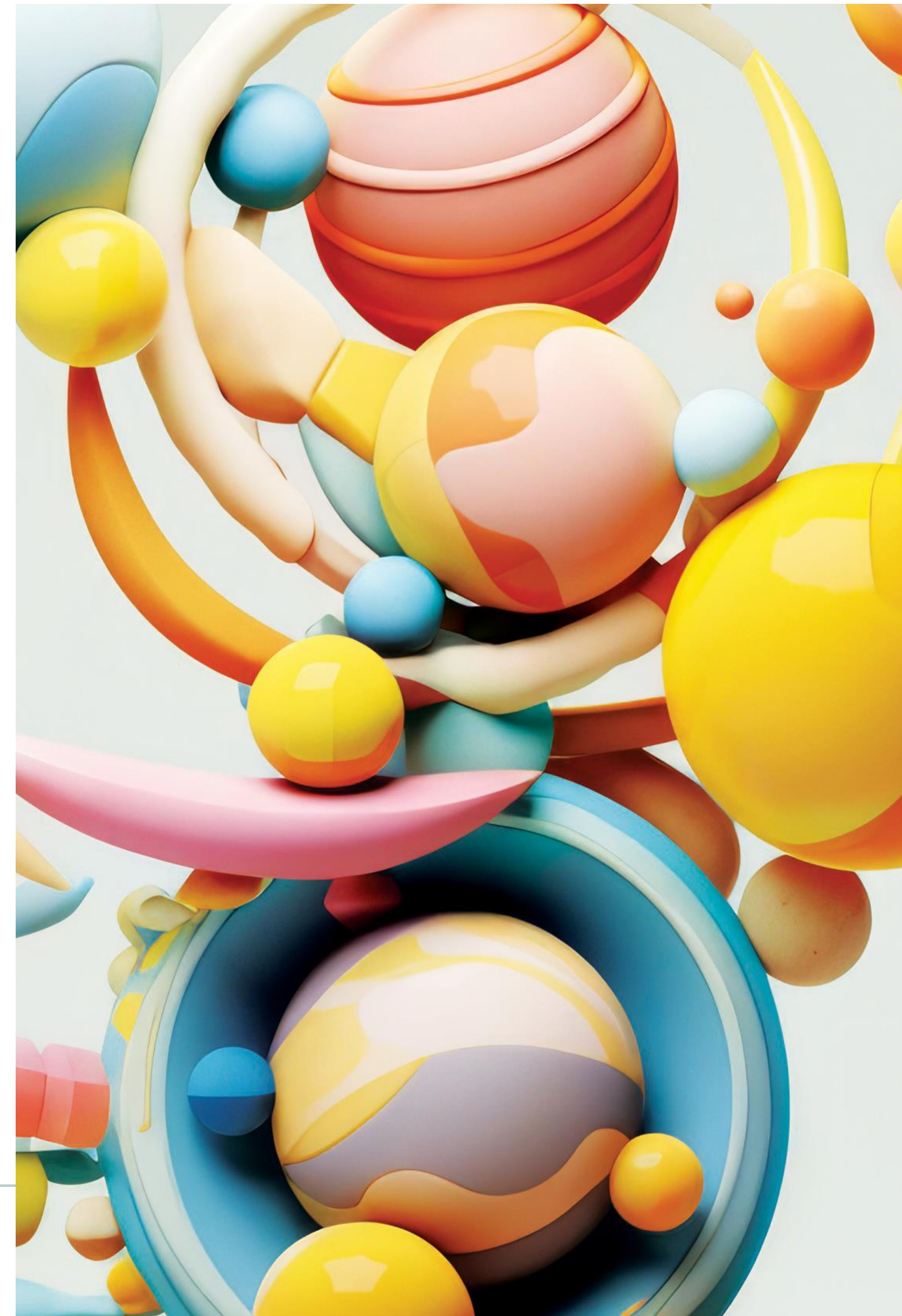


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Barsness, S., Cummins, J., Fernandez, M., James, A., Pierce Farrier K., Pringle, J., Carroll, SR. Taitingfong, R., & Wieker, A. (2023). CARE Data Principles Primer. Data Curation Network GitHub Repository.

Bauman, Stephan. (2024) When My Soul Sings: A Participatory Inquiry into How Former Refugees Construct Meaning from their Migration Narratives. Research Design Proposal.

Wittmayer, J. M., et al. (2024). Neither right nor wrong? Ethics of collaboration in transformative research for sustainable futures. *Humanities and Social Sciences Communications*, 11(1), 1-15. Article 677.  
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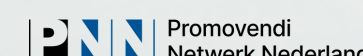
Beyond personal data

# Legal aspects of the CARE Principles

Anka Mos, Legal Counsel a.i. ERS

Rafeek-Carmelo Baloum, Privacy Officer, ISS/ERS

8 May 2025





# Overview:

- Introduction
- Contract types for Conducting Research with Indigenous Communities
- Implementing Collective Benefit
- Legal vs Moral Contract
- Governance and Data Custodianship
- The CARE Principles and Community-Level Control over Data
- Individual and Community Consent
- Conclusion and Recommendations





# Introduction

- Objective: Embed the CARE principles into legal and policy frameworks for research.
- Focus: Legal and policy frameworks for agreements between universities and Indigenous communities.





# Contract types for Conducting Research with Indigenous Communities

- **University – community representative:** Memorandum of Understanding (MOU), non-binding agreement establishing mutual expectations and principles.
  - **University – researcher of the community:** Research Agreements outlining academic freedom and integrity (including reference CARE Principles), governance (i.e., decision-making process including the community), intellectual property, publication rights, and research proposal (taking into account the CARE Principles).
  - **University – party sharing the data:** Data/Information Sharing Agreements (data use, storage and retention) based on Data Management Plan (taking into account the CARE Principles).
  - **University – researcher of the community:** Joint Controllership Agreements under GDPR (in case of collaborative research projects, where one of researchers is member of the community) based on Data Management Plan (taking into account the CARE Principles).
-



# Relevance of (Legal) Documents

- MOUs: establish good faith, mutual trust and recognizing the involvement of Indigenous Communities.
  - Research Agreements: setting out the collaboration between parties and the way the research should be conducted based on the CARE Principles
  - Acknowledging the Indigenous Community's culture and right to participate in the decision-making process.
  - Useful also when a community lacks formal legal status.
  - Legal contracts to be signed by the university (dean or CvB) and community-endorsed representative.
-



# Elements of a Research Agreement for CARE

- Academic Integrity based on CARE Principles
- Expected Advantages and Risks
- Methods to obtain consent are described in detail and in collaboration with community (including consent form)
- Description of data collection methods and quantity/types of information collected
- Intellectual Property Rights (in terms of authorships on results and datasets, how will community participants be acknowledged)
- Validation of Preliminary results for review and approval

Source: [First Nations in Quebec and Labrador's Research Protocol, 2014. p. 57](#)

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# Elements of a Memorandum of Understanding

- Purpose of the MoU or Statement of Purpose
  - Description of the parties that will cooperate for the purpose of the MoU and the structure and procedures for collaboration
  - Scope of the collaboration and agreements on what collaboration entails
  - Outcomes and outputs of the collaboration
  - Chosen method of dispute resolution (e.g. mediation)
  - Can include elements about access to data or sharing of data/results
-



# Implementing Collective Benefit

- Define mutual benefits in agreements (e.g., education, co-authorship, infrastructure).
  - Engage community early to co-design research goals.
  - Include community oversight roles.
-



# Legal vs Moral Contract

- If a community lacks a legal entity, use traditional governance structures.
  - Authorize representatives via community declaration or power of attorney.
  - Document the process of appointment and approval in writing.
-



# Governance and Data Custodianship

- Create joint governance committees.
  - Agree on data storage (duration, access, location).
  - Respect cultural restrictions on sharing and re-use of data.
-



# The CARE Principles and Community-Level Control over Data

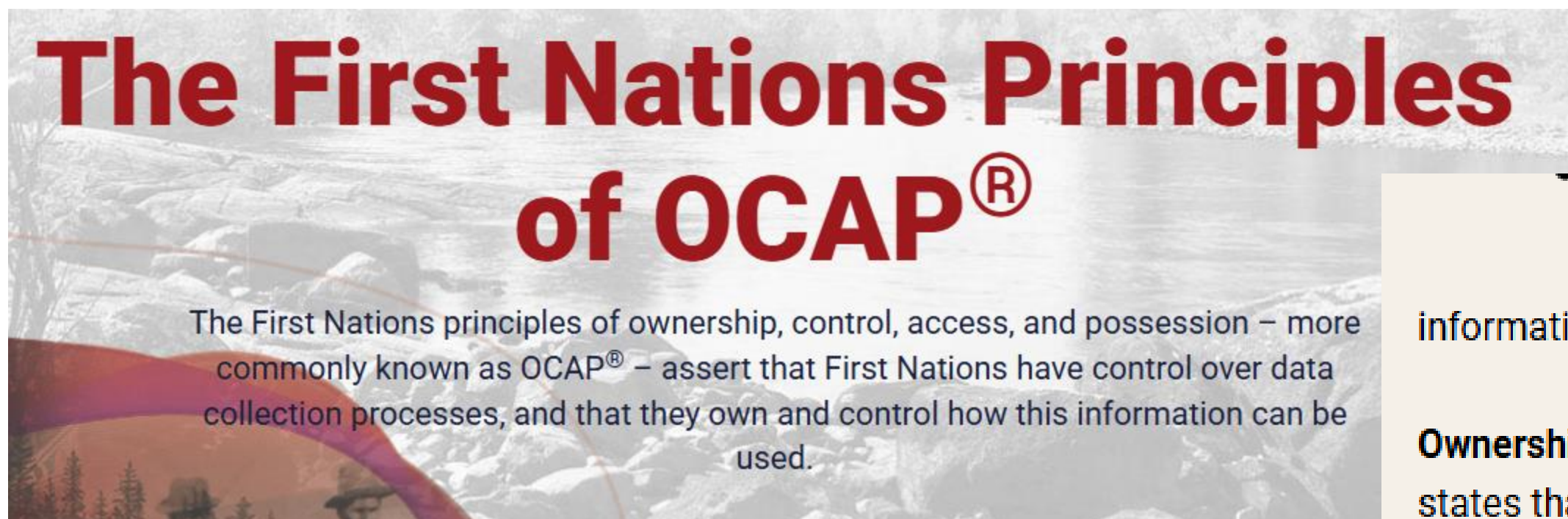
- Most national privacy laws focus on protecting privacy at the individual level and generally do not address collective or community-level privacy.
  - The CARE Principles expand control over data, typically given at the individual level, to the community level.
  - The CARE Principles do not, in themselves, create enforceable legal rights or obligations. Organizations and researchers must adopt them and incorporate them into contracts, policies, and procedures.
-



- SODA principles (adaptation of CARE principles) refer to maintaining the privacy of both Sami individuals and Sami communities.<sup>1</sup>
- Extension of protection given to individuals to the community as a whole.

4. **Responsibility:** Acknowledge the responsibility of researchers, institutions, and data custodians to ensure that Sámi research data is collected, managed, stored, and used in a manner that upholds the rights, dignity, and cultural values of the Sámi people. This includes adhering to relevant legal frameworks, ethical guidelines, and Sámi cultural protocols when handling data, as well as maintaining the privacy and confidentiality of Sámi individuals and communities.

- The First Nations Principles of OCAP®<sup>2</sup>



OCAP® asserts that First Nations alone have control over data collection processes in their communities, and that they own and control how this information can be stored, interpreted, used, or shared.

**Ownership** refers to the relationship of First Nations to their cultural knowledge, data, and information. This principle states that a community or group owns information collectively in the same way that an individual owns his or her personal information.

Source:

1 Sámi Council, Sámi Ownership and Data Access (SODA-principles) - Sámiráđđi. Available at: <https://www.saamicouncil.net/documentarchive/soda-en>

2 OCAP® is a registered trademark of the First Nations Information Governance Centre (FNIGC). For more information on the OCAP® principles, visit: <https://fnigc.ca/ocap-training/>



# Individual and Community Consent

## A1 Recognizing rights and interests

Indigenous Peoples have rights and interests in both Indigenous Knowledge and Indigenous data. Indigenous Peoples have collective and individual rights to free, prior, and informed consent in the collection and use of such data, including the development of data policies and protocols for collection.

Dual consent mechanism: two layers of protection

- i. Individual consent: Obtained directly from each participant.
  - Either ethical consent to participate in research and/or consent for the processing of personal data.
- ii. Community consent: Approval / permission from recognized community leaders, authorities, or representatives.
  - May be difficult to obtain in communities without clear representatives or governance structures.
  - Community consent adds an extra layer of protection but does not replace individual consent.

Further questions for group discussions:

- Who is authorized to represent a community in the consent process?
  - What if you have secured individual consent but no community consent? Are there situations where overriding community consent could be justified?
-



**Can you think of examples from other areas where individuals, groups or their representatives can be consulted when decisions are made about the use and sharing of their data?**

- Consulting data subjects (or their representatives) when conducting a DPIA.
  - Receiving approval or permission from organizations (e.g., companies, hospitals, schools) to conduct research on their premises.
  - Consulting patient representatives when conducting research involving patients and other vulnerable groups.
  - Involve community representatives in drafting terms of use for data sharing and reuse.
  - Involve labor representatives or unions when making decisions related to the processing of employee data.
-

# Conclusion and Recommendations

- Embed compliance with CARE principles in organisational policies, processes and procedures.
  - Embed CARE principles in research design and contracts.
  - Use MOUs and/or Research Agreements to clarify expectations when formal contracts aren't feasible.
  - Ensure that consent, representation, and governance reflect both legal and ethical standards.
  - Work closely with community leaders and professional staff at your institution throughout the process.
-



# Group Sessions Planning

- Three groups in Aula B
    - Collective Benefit: Jing-Yi Magraw
    - Authority to Control: Bora Lushaj
    - Responsibility: Tijs Gelens
  - Group sessions shorter with no break in between
  - Your experiences and perspectives will inform our guidance!
-

# Ethics of Research Data and the CARE Principles

## Group Sessions



International  
Institute of  
Social Studies



Universiteit  
Leiden

DANS



PNN Promovendi  
Netwerk Nederland

This publication is part of the project 'Beyond personal data: a new initiative to support early-career researchers with hard-to-share data' with file number ICT.TDCC.001.002, which is (partly) financed by the Dutch Research Council (NWO) via the Thematic Digital Competence Centre Social Sciences & Humanities (TDCC-SSH).

Designed by [van van Zanten](#). Pictures by [Freepik.com](#)



# QR Code Evaluation Form

[link deleted. We suggest that reusers of the material include an opportunity here for participants to evaluate the workshop]





# My Story:

## What I learned in the field that school didn't teach me



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Leiden

DANS



Promovendi  
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Erasmus Universiteit Rotterdam

[www.eur.nl](http://www.eur.nl)



Promovendi Network Nederland

[www.hetpnn.nl](http://www.hetpnn.nl)



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