



# Patient-reported experiences measurement: people with intellectual disability

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# Acknowledgement of Country

THE ARTWORK CIRCLES OF THE NIGHT SKY IS CREATED BY PROFESSOR LIZ CAMERON,  
DHARUG WOMAN AND MACQUARIE UNIVERSITY ALUMNUS



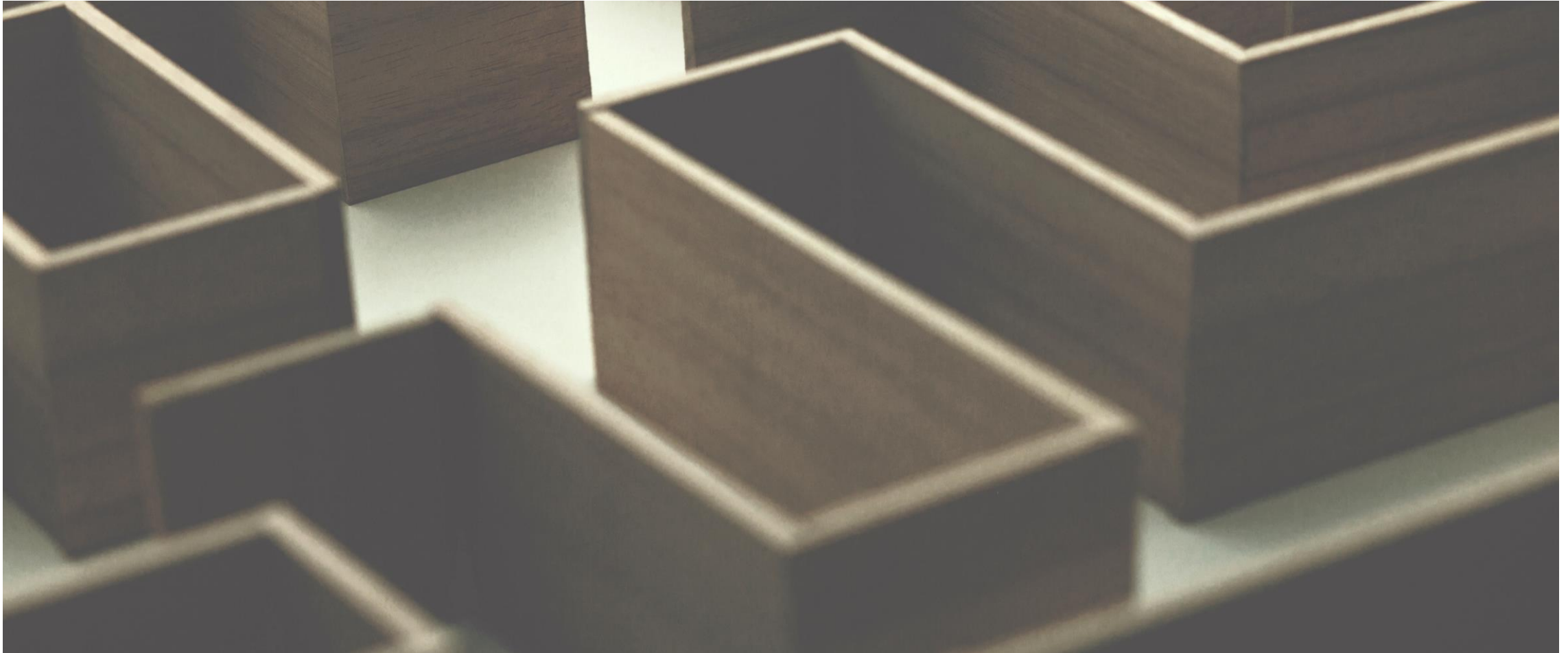
I acknowledge the traditional custodians of the land we are meeting on today, the Wurundjeri Woi-wurrung and Bunurong / Boon Wurrung people of the Kulin nation, whose cultures and customs have nurtured, and continue to nurture, this land, since the Dreamtime.

And pay my respects to Elders past, present and emerging.

# Background to the review



# People with intellectual disability often don't get the healthcare they need



# People with intellectual disability often experience poorer health outcomes



**Royal Commission**  
into Violence, Abuse, Neglect and  
Exploitation of People with Disability

# Patient centred care

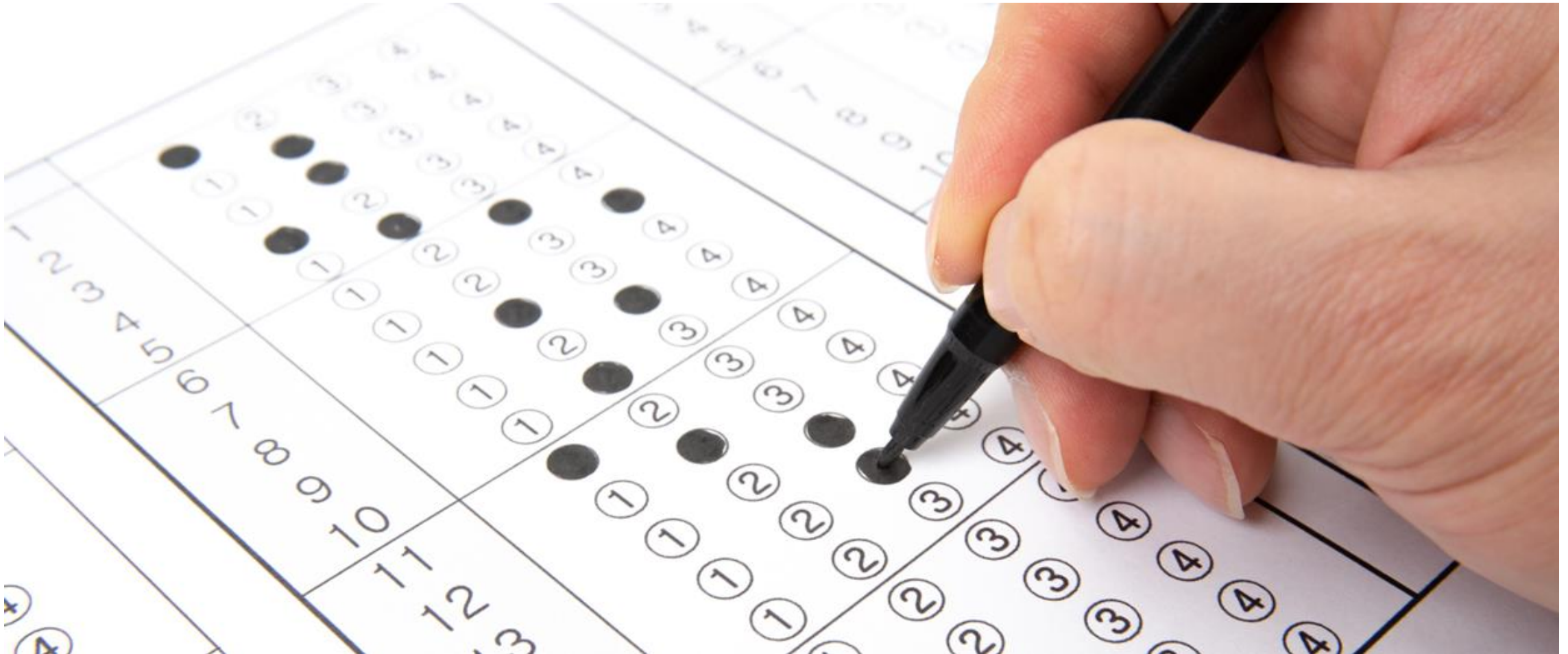


# Patient Reported Experience Measures (PREMS)



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# Patient experience measures don't suit everyone



- Explore how researchers and service providers gather patient-reported experiences from people with intellectual disabilities.
- Summarise what this means for patient reported experience measures (PREMS).

# Methods: Rapid Evidence Appraisal (REA)

## Eligible articles

- Tools / Items
- Approaches
- Methods
- Peer-reviewed
- Grey literature

## Search & selection

- Electronic search
- Grey literature search
- Team-based screening

## What was excluded?

- PROMs
- Needs analysis
- Not focused to people with intellectual disabilities

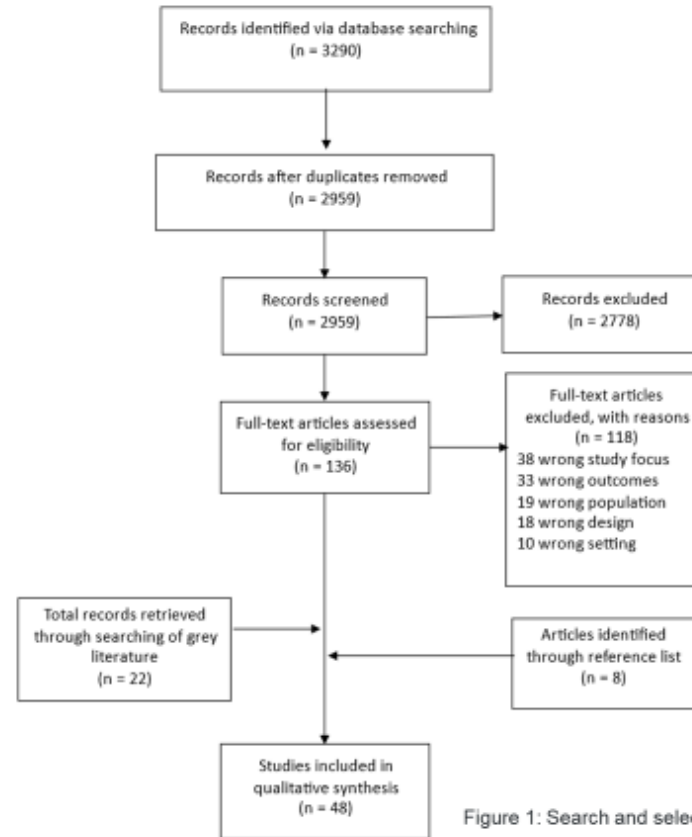


Figure 1: Search and selection process: People with Intellectual Disability

# Included Articles

Country of Origin	Peer reviewed Studies	Grey Literature
United Kingdom	13	7
USA	4	3
Canada	2	-
The Netherlands	2	-
France	1	-
Australia	1	10
Ireland	1	1
Hong Kong	1	-
Spain, Holland, Estonia, Germany, Norway and Catalonia	1	-
Norway	-	1

# Findings: Lack of system-wide data collection



# Findings: Predominantly qualitative, service specific data



# Findings: Considering individual needs and preferences was effective





# Implications: Incorporating relationships of support in data collection is important



# Implications: People with intellectual disability need to co-create and evaluate PREMS



# Implications: Data collected in PREMS needs to inform care



# What next?





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## Q&A

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