


Victorian Senior Practitioner Seminar

5 December 2024

A multidisciplinary approach to reducing chemical restraint – pilot project


- Connie Wu, Clinical Consultant VSP
- Erin Leif, Senior Lecturer, Monash University

Dec 2024



We acknowledge the Traditional Owners of Country throughout Victoria and pay respects to their Elders past and present.

We acknowledge that Aboriginal self-determination is a human right and recognise the hard work of many generations of Aboriginal people.



Background

Joint Statement on Psychotropic Medicines (2022):

- Released by ACQSC, NDIS Commission, and ACSQHC in November 2021.
- Highlighted inappropriate use of psychotropic medicines for managing behaviors in people with disabilities and older people.
- Recognised overprescription and overuse as safety and quality issues in health care.

Key Concerns:

- Individuals with intellectual disabilities are at higher risk of behaviors of concern.
- Behaviours of concern can hinder social inclusion and lead to overprescribing of antipsychotics (Deb et al., 2009).
- Lack of evidence that psychotropic medicines are effective in managing behaviours of concern (Joint Statement, 2022), whilst leading to 'diminished wellbeing and quality of life in people with disability and older people'.

Background

Reducing psychotropic medication use in people with intellectual disabilities requires collaboration across health and disability sectors.

Current known barriers to interdisciplinary collaboration include lack of knowledge and training, limited time and resources, negative experiences, siloed service delivery and attitudes.

Purpose

Overall Goal:

- Promote a multidisciplinary approach to reduce inappropriate psychotropic medication use in people with intellectual disabilities.

Objectives:

- Equip support workers with basic knowledge about behaviours of concern, psychotropic medications and alternatives to medications.
- Address GPs' knowledge gaps through educational visits and interdisciplinary collaboration.
- Develop and implement a multidisciplinary practice model to improve care team communication.
- Facilitate the creation of high-quality fade-out plans with detailed reduction schedules and response strategies.
- Assess the impact of these initiatives on psychotropic medication reduction and participants' quality of life.

GATHER DATA

Home Medication Review:

- Identify polypharmacy related issues.
- Identify potential side effects
- Formulate fade out plans and prioritise the order of
- medications to be withdrawn according to clinical appropriateness.

PLAN DEVELOPED

SPECTROM Training

Team meeting:

- Pharmacist, behaviour support practitioner and support workers.
- Go through the medication review checklist (SPECTROM)
- Prioritise medication related issues.
- Prepare a list of questions for the GP.
- Ensure all relevant data have been collected and recorded (and pass onto GP if requested)

GP appointment

GPs are upskilled in the use of psychotropics for behaviour management, and are familiar with SPECTROM resources.

REDUCE MEDICATION

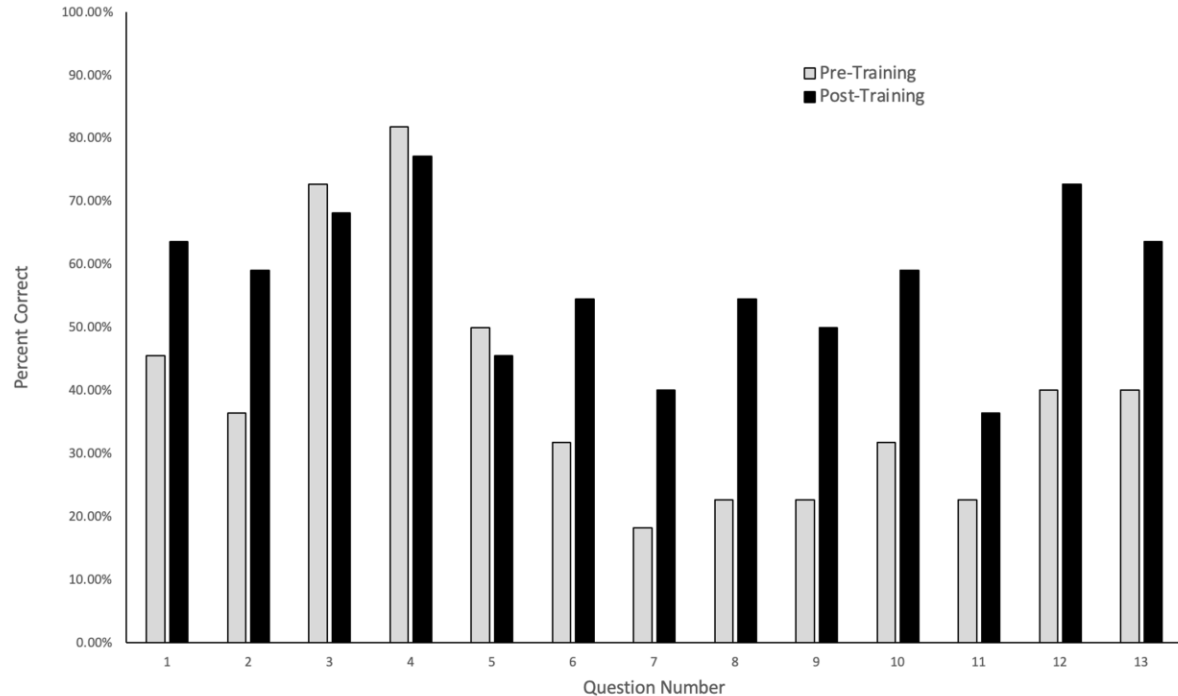
SPECTROM TRAINING

- Short-term Psycho-Education for Carers to Reduce Over Medication (SPECTROM, Deb et al 2021)
- Support workers from three organisations participated
- Participants completed two questionnaires before and after the training:
 - Psychotropic Knowledge Questionnaire
 - Management of Aggression and Violence Attitude Scale

SPECTROM TRAINING – KNOWLEDGE PART 1

Knowledge of medication and its purpose

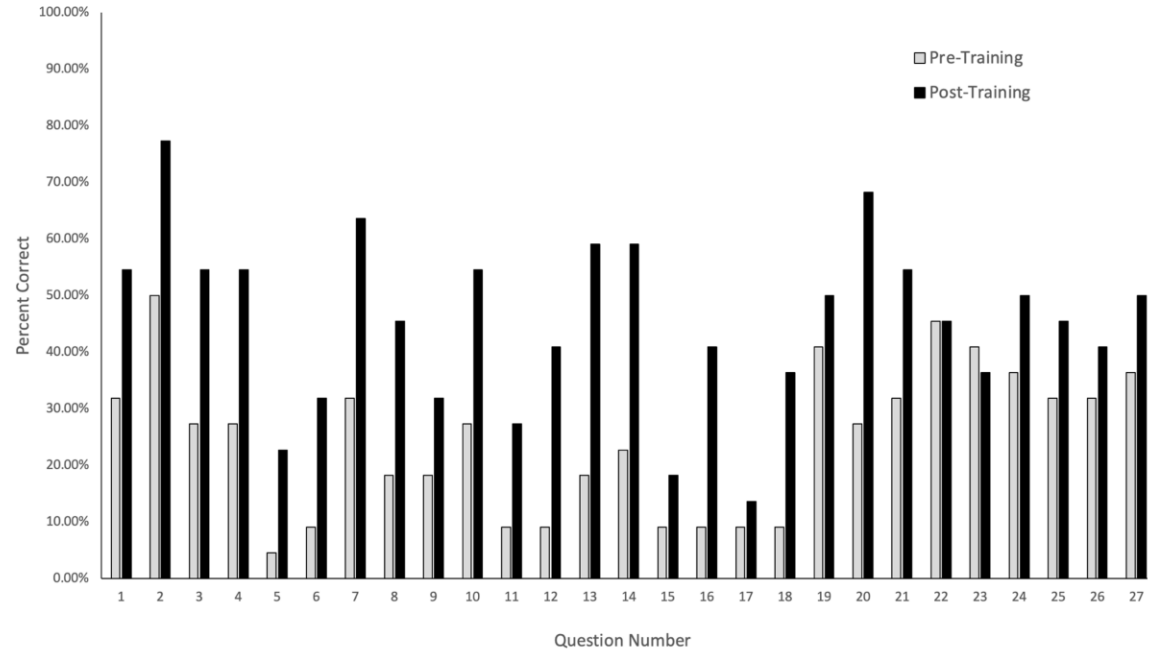
Percent Correct Responses on the Psychotropic Knowledge Questionnaire Part 1 (n = 22)



SPECTROM TRAINING – KNOWLEDGE PART 2

Knowledge of medication side effects

Percent Correct Responses on the Psychotropic Knowledge Questionnaire Part 21 (n = 22)



SPECTROM TRAINING – BELIEFS AND ATTITUDES

Following the training:

- Trainees more strongly agreed that environment factors could influence behaviours of concern.
- Trainees more strongly agreed that restrictive environments could influence behaviours of concern.
- Trainees more strongly agreed that improved communication and relationships between the person and support staff could improve behaviour.
- Trainees more strongly agreed that support the person to develop skills could improve behaviour.
- Trainees were less likely to agree that medication should be the main way to address behaviours of concern in people with intellectual disabilities.

GP EDUCATION SESSIONS

- The pharmacist met individually with each prescribing GP for all participants to discuss psychotropic medications, prescribing practices and individual concerns.
- The pharmacist provided tailored information and resources about current guidelines and evidence for psychotropic medications, and best practice regarding non-pharmacological strategies for behaviours.

HOME MEDICATION REVIEWS

- Nine individuals participated
- The pharmacist reviewed all current medications during an initial home medication review, with a specific focus on efficacy, potential interactions, side effects and rationalisation.
- Baseline data collected on behaviours of concern (*Modified Overt Aggression Scale*) and Quality of Life (*Caregivers Concerns – Quality of Life Scale*) by the behaviour support practitioner.

MEDICATION FADING PLAN DEVELOPED

- The care team (pharmacist, behaviour support practitioner, house supervisor, family where possible) and Connie met after the medication review report was written to discuss recommendations.
- The care team agreed on the next steps (E.g. which medication to reduce first) taking into consideration of the following factors:
 - Efficacy of medication on intended BOC.
 - Side effects experienced.
 - Past experience with reduction of chosen medication (if applicable).
 - Other factors such as changes in person's life, general health status etc.
- VDDS also reviewed the reduction schedules and provided feedback as required.

Evaluation of medication changes at 6 months:

Medication change

- 7 out of 9 participants had medication reduced.
- 1 participant's dose was reinstated due to withdrawal effects
- The other 6 participants had minimal withdrawal symptoms or changes in behaviour (if any).
- 1 participant has recently moved, and will commence reduction once settled in new home.

Targeted medications:

- 5 participants had atypical antipsychotics reduced.
- 1 participant had anti-convulsant reduced.
- 1 participant had anti-depressant reduced.
- Decision on initial target medication was decided with the entire care team, including family.

Enablers for success:

- **Engagement of the entire care team:**
- Team meeting post medication review to agree on recommendations to prescriber
- Address concerns re: possible withdrawal symptoms/behaviour escalations, BPrac input re: response strategies.
- **GP education visit:**
- Reassurance to GP re: best practice guidelines
- Consent from family/participant to trial reduction
- Reassurance from BPrac re: non-pharmacological interventions.
- Dual disability psychiatrist support (VDDS and private).

INTERVIEWS WITH GPs

- In some cases, the GPs noted that medications has been **prescribed for a long time** and the reason was unclear.
- GPs emphasise the importance of **communication and collaboration** among care teams, pharmacies, and medical professionals (psychiatrists).
- GPs recognised the **challenges of implementing gradual reductions** and the critical need for monitoring patients' behaviours, especially in individuals with limited verbal communication.
- There is a shared interest in **alternative behaviour support strategies** to minimise reliance on psychotropic medications.
- GPs are cautious and deliberate about the reduction process, ensuring that it is done **slowly and methodically** to avoid adverse effects.
- GPs would be **apprehensive about continuing** medication reduction if behaviours of concern re-occurred or worsened.
- GPs raised concerns about the term "**chemical restraint**," noting differences in interpretation (e.g., its association with PRN sedatives in hospital settings).

NEXT STEPS

- Continue to progress with medication fading plans
- Home medication review to be re-done at 6 and 12 months
- *Modified Overt Aggression Scale* to be re-administered at 6 and 12 months
- *Caregiver Concerns – Quality of Life Scale* to be re-administered at 12 months

Contact details

Contact the Victorian Senior Practitioner

Email:

RIquestions@dfh.vic.gov.au

Webpage:

<https://www.dfh.vic.gov.au/victorian-senior-practitioner>

ASK project

**Addressing the sexual health
and wellbeing of people with
neurodevelopmental disability:
Co-creation of a revised
innovative version of the
Assessment of Sexual
Knowledge (ASK)**

Dr Chloe Bryant & Dr Claire Lynch
School of Allied Health
Australian Catholic University
Melbourne, Victoria

In recognition of Aboriginal and Torres Strait Islander peoples' deep spiritual connection to Country, and in continuing ACU's commitment to reconciliation, we would like to acknowledge and pay our respects to the First Peoples, the Traditional Custodians of the lands and waterways where ACU campuses are located.

We respectfully acknowledge our Elders past and present and remember that they have passed on their wisdom to us in various ways. Let us hold this in trust as we work and serve our communities.



The original Assessment of Sexual Knowledge (ASK):

Butler, J.A., Leighton, D.G., & Galea, J. (2003). *The Assessment of Sexual Knowledge: A Sexual Knowledge and Assessment Tool for People with an Intellectual Disability*. Department of Human Services: Melbourne, Australia.

- Developed following extensive evaluation for use with adults with intellectual disability.
- Developed in 2003 by the Department of Human Services & Monash University.

Identified gap:


- While the ASK is well-known and respected, use of the tool has diminished significantly due to societal and technological changes.
- Demand for an up-to-date clinically useful tool/s that can be used with a more diverse group of people including children/adolescents as well as people with various types of neurodevelopmental disability
- Demand for adequate training to accompany a contemporary tool/s.
- Need for a tool to consider a broader understanding of sexual wellbeing beyond just sexual knowledge



(ASK Picture Booklet)



**What do we mean by
neurodevelopmental
disability (NDD)?**



An individual who has a neurodevelopmental disorder and who experiences challenges with personal, social, learning, and/or occupational skills

Examples of neurodevelopmental disorders include:

- Intellectual disability
- Communication disorders
- Developmental disability
- Neurodevelopmental motor disorders
- Autism Spectrum Disorder (ASD)
- Attention Deficit Hyperactivity Disorder (ADHD)

What do we mean by sexual wellbeing and sexual safety?

Sexual wellbeing

Describes the psychological, social, biological, and behavioral dimensions of sexuality. It encompasses a myriad of factors, including sexual awareness, safety, health, opportunity, function, confidence, motivation, satisfaction, intimacy, and identity. It is an integral part of being human and is associated with greater enjoyment and overall quality of life.

Sexual safety:

Experience of reduced threat coupled with experience of actions taken to assuage vulnerability

Importance of addressing this gap:

- Overrepresentation of people with NDD in prisons due to sexual behaviours
- High rate of sexual harassment and/or assault – according to the Australian Law Reform Commission, 90% of women with intellectual disability experienced sexual abuse
- People with NDD are often neglected from sexual education which is delivered to people without disability as part of national curricula, therefore increasing vulnerability.
- Research shows sexual education and support leads to improved sexual safety and overall health and wellbeing
- Sexuality & intimacy are key aspects of being human.
- Education and sexual expression are both human rights.
- Lack of support & education for sexuality is ableist and discriminatory.
- Limited support & education contributes towards decreased social participation and can prevent people from engaging in safe and meaningful relationships.

National Priorities

Key national science & research priorities:

Priority 2: Supporting healthy and thriving communities

- **Work with communities and individuals to develop the technologies, tools and techniques** for more Australians to enjoy healthier lives from birth well into old age... **Australians with disabilities will benefit** from advanced technologies and societal supports...improved preventive health through new **screening, diagnostic and treatment techniques** and models of care

Key national health & research priorities:

- 1. Consumer-driven research**
- 2. Translation and commercialisation**
 - Tools and technologies
 - Collaborations between sectors
- 3. Preventative & public health research**
- 4. Priority populations**
 - People with a disability
 - LGBTIQ+ people
 - Children and youth
 - People with rare conditions



Australian Government

State Priorities

This research aligns with key state initiatives, strategies, policies and reports:

1. Inclusive Victoria – State disability plan 2022 – 2026
2. Pride in our future: Victoria's LGBTIQ+ strategy 2022-32
3. Victoria's gender equality strategy and action plan 2023-2027
4. The Family Violence Reform Implementation Monitor

<https://www.vic.gov.au/strategies-and-policies> - Last updated 27 November 2024



Vision

An inclusive accessible, and safe Victoria that upholds the rights of people with disability, celebrates our diversity and pride, and expands our opportunities to belong and control our lives

Driving Purpose

Overall purpose of improving the sexual wellbeing and sexual safety of people with neurodevelopmental disability





PROJECT AIMS

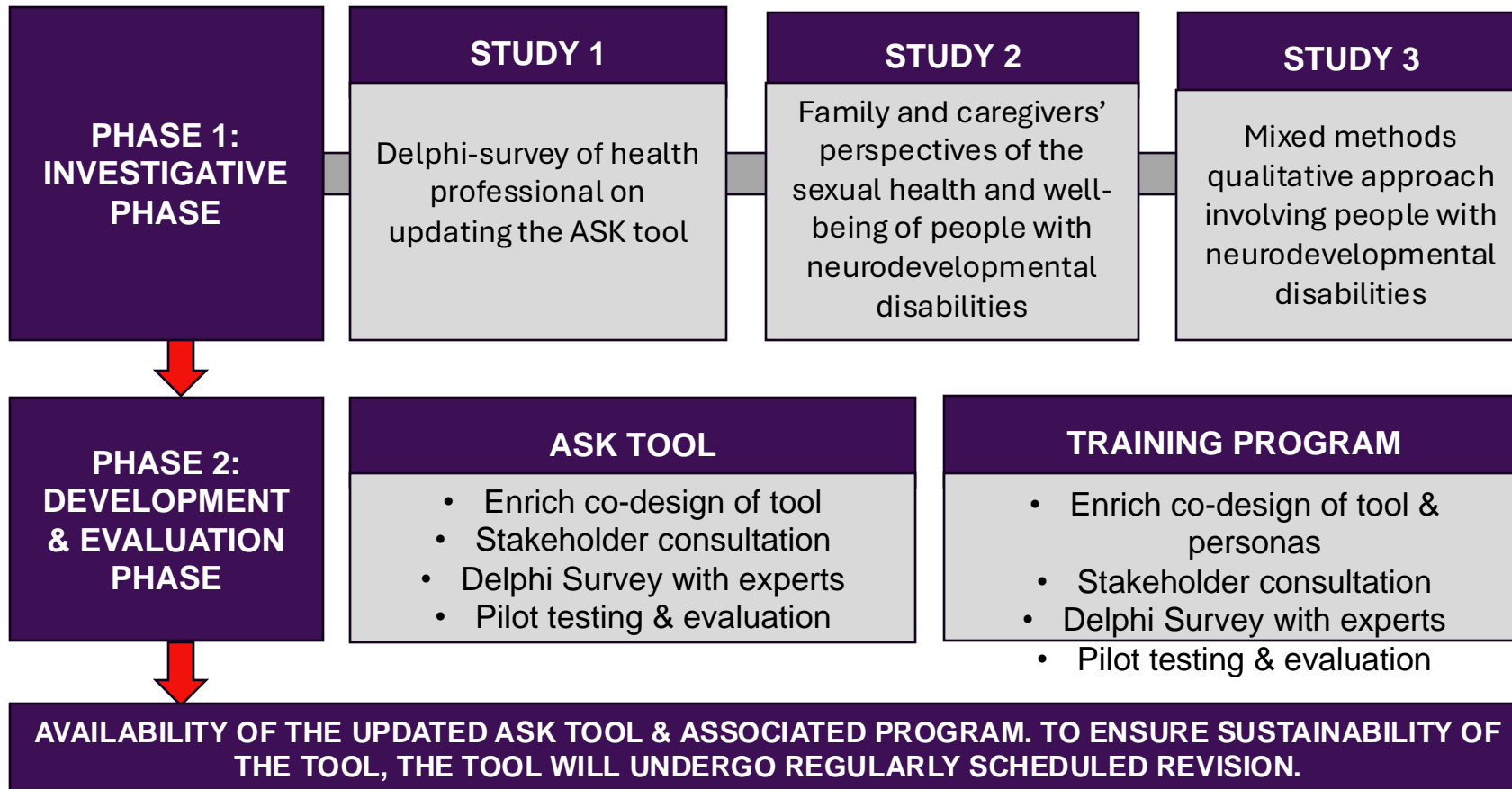
Aim of the project

To codesign an updated version of the ASK and an associated training program to:

1. Address the identified **gap in practice**
2. Ensure all research phases are conducted according to **consumer involvement and engagement** principles
3. Reflect the **diversity of modern society**
4. Respond to **technological advances**
- 5. Broaden criteria** to include children/adolescents and people with other neurodevelopmental disorders
6. Ensure there is a **clinically useful assessment tool for NDIS planning**
7. Enable an **individualised and standardised approach** to assessing sexual wellbeing
8. Ensure professionals who administer the tool are **adequately trained**
9. Enable a **sustainable approach** is undertaken to ensure the clinical useability of the tool is maintained



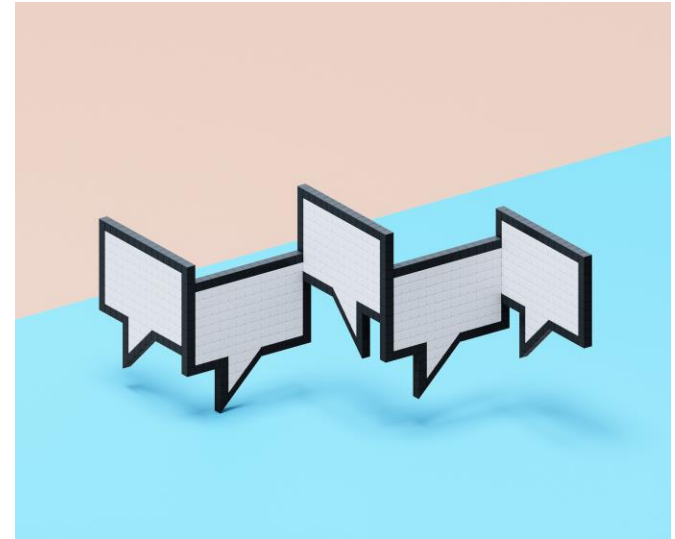
PROJECT PLAN



Consumer Involvement

Guiding consumer involvement principles:

- Effective involvement of consumers in decision-making.
- Trust and respect for all parties.
- Equitable partnerships where consumer expertise is valued.
- Communication and information that is easily accessible and understandable.
- Accountability and transparency with research outcomes reported to consumers.
- Adding value through consumer involvement.
- Diversity of consumers.
- Involvement of consumers from the beginning.





RESEARCH TEAM

Research Team Structure

Primary Investigative Research Team:

- Dr Chloe Bryant – Australian Catholic University
- Dr Claire Lynch - Australian Catholic University
- Dr Annette Joosten – Australian Catholic University
- Dr Monique Huysamen – Manchester Metropolitan University
- Andrew Gurza – Lived Experience Co-Researcher
- *Seeking additional lived experience co-researchers*

Industry Partner:

- Department of Families, Fairness, and Housing (DFFH)
- Sexual Education Counselling & Consultancy Agency (SECCA)

Steering Group:

- Daniel Leighton – Office of The Public Advocate
- SECCA Representatives
- Victoria Health Department Representative/s
- Rubix Support Representatives

Consortium:

Academics from national and international universities with expertise.



1,880 posts 25.7K followers 7,498 following

andrew Gurza they/he

@andrewgurza6

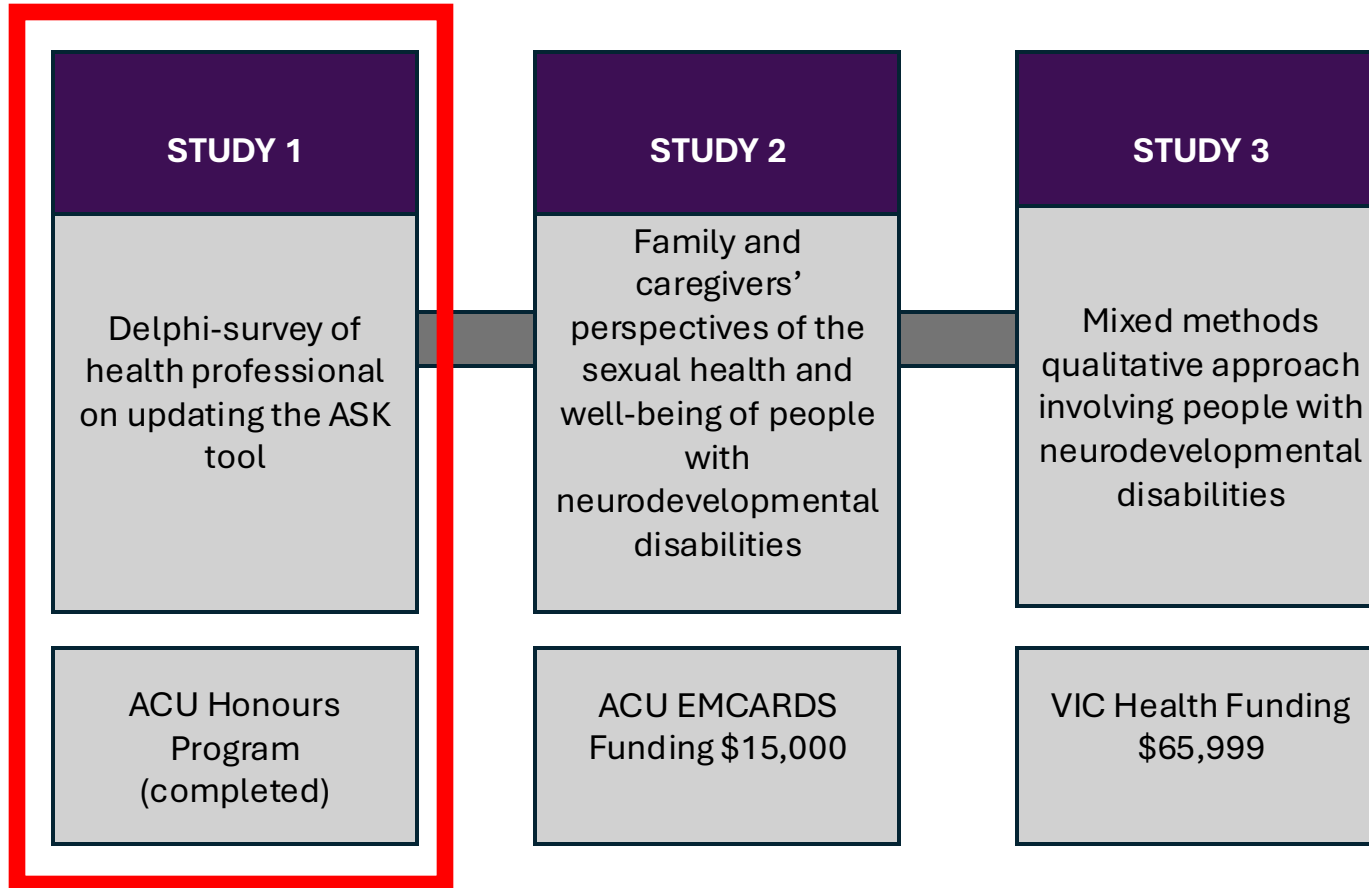
Digital creator
 Disability Awareness Consultant / Severely Disabled





PHASE 1: STUDY 1

Delphi Survey with Health Professionals



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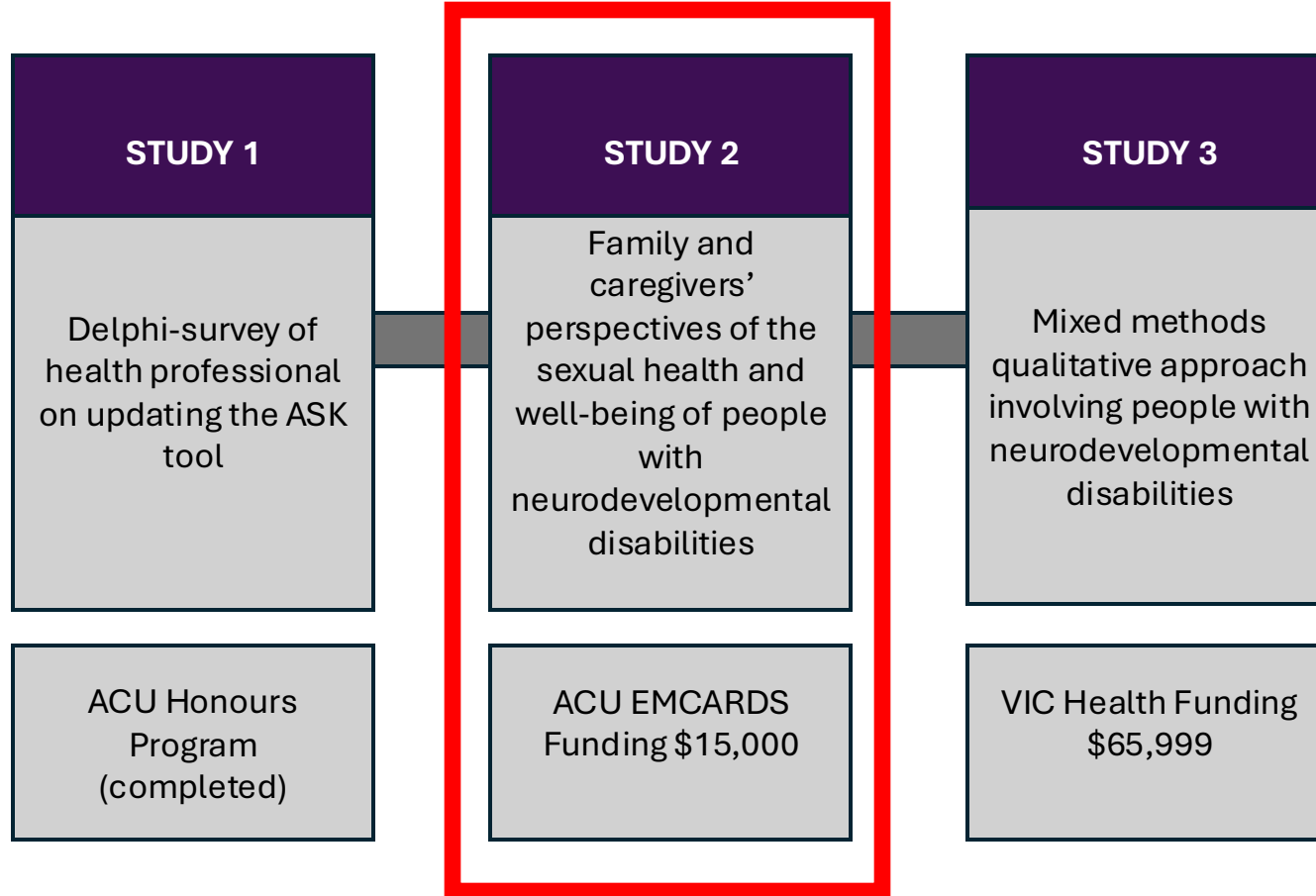
Delphi Survey Key Findings

- To sensitively and accurately conduct a complete (i.e., long) version of the tool, a short screening tool should be administered to understand:
 - *Cultural background*
 - *Religious beliefs*
 - *Gender identity*
 - *Sexual orientation*
 - *History of trauma*
- Language and content changes are needed to ensure the ASK assesses more contemporary aspects of sexual knowledge including consent and legislation.
- The ASK needs updating to be inclusive of all gender identities.
- A separate version of the ASK is required for children and adults.
- Online and paper versions need to be adaptable

Lynch, C., Bryant, C., Joosten, A., & Abel, D. (Under Review)



PHASE 1: STUDY 2



OF

Families and/or Caregivers Perspectives

Progress to date:

Data collection and preliminary analysis is underway. Data collection will cease shortly however volunteers interested in participating are still more than welcome to get in touch.

Participation involves:

~ 1-hour online interview

Eligibility:

Over 18 years of age and identify as a family and/or caregiver of an individual with a NDD i.e. an individual who experiences challenges with learning, communication, social and/or motor skills.

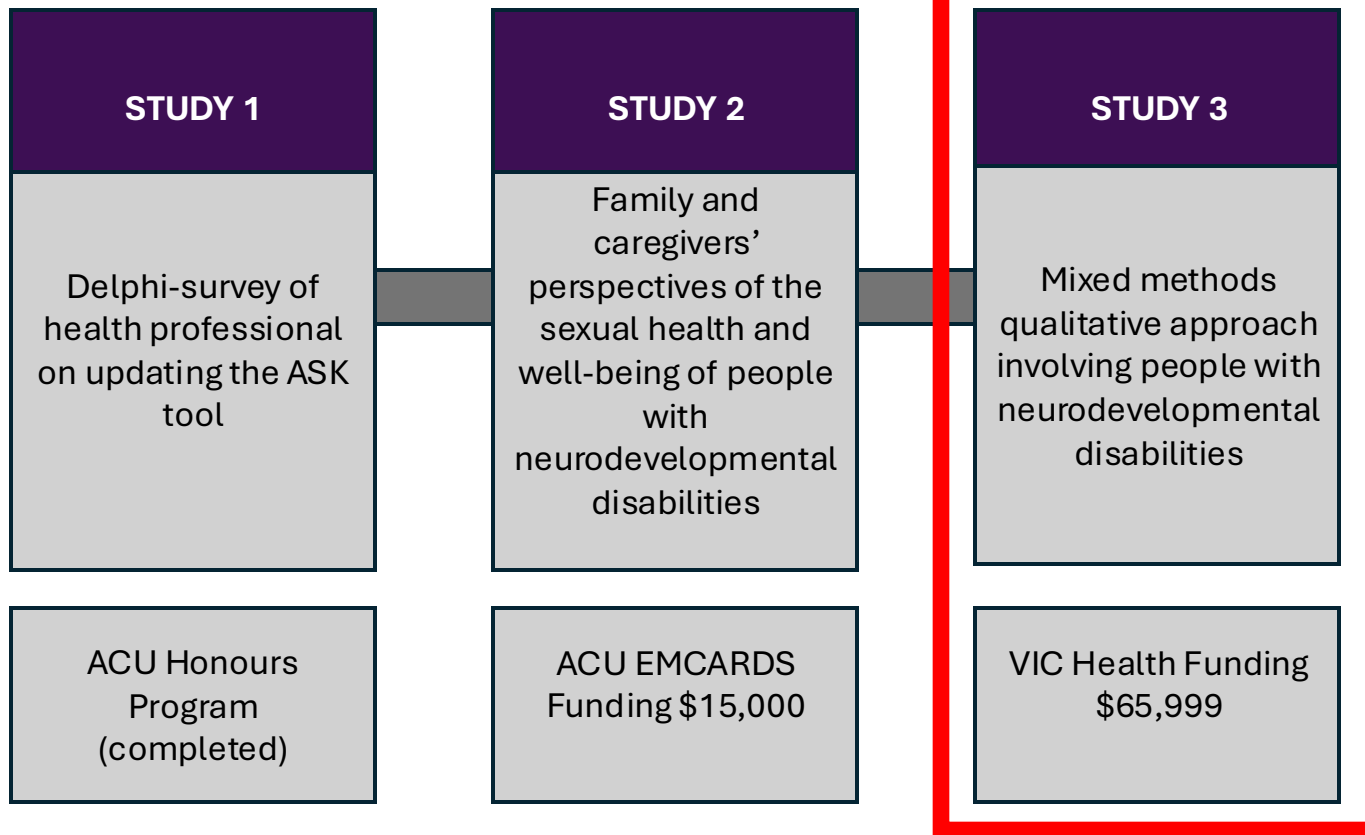
Contact: claire.lynch@acu.edu.au.

ACU Ethics no: 3638





PHASE 1: STUDY 3



All three studies will be finalised by June 2025

Parallel Mixed-Methods Qualitative Design

Aim:

Based on the perspectives of people with NDD and disability advocates, this mixed-methods study aims to understand how professionals should assess the sexual wellbeing of people with a NDD, and to understand how best to engage in a codesign method to develop a clinically useful and up-to-date assessment tool.

Study 1 – Interviews with people with NDD

Understanding how health professionals should assess and provide support for sexual wellbeing with people with NDD: Interviews with people with lived experience

Study information:

- Semi-structured interviews with ~10 people online individually or with a support person present (whichever is preferred by the participant). Data will be analysed using IPA
- Eligibility:
 - Adults with a NDD who are able to provide informed consent (OR) adults with NDD who express ongoing interest in participating in conjunction with the informed consent of their legal representative
 - Communicate (verbally or non-verbally) in English
 - Victorian residents

Parallel Mixed-Methods Qualitative Design

Aim:

Based on the perspectives of people with NDD and disability advocates, this mixed-methods study aims to understand how professionals should assess the sexual wellbeing of people with a NDD, and to understand how best to engage in a codesign method to develop a clinically useful and up-to-date assessment tool.

Study 2 - Deliberative Workshop

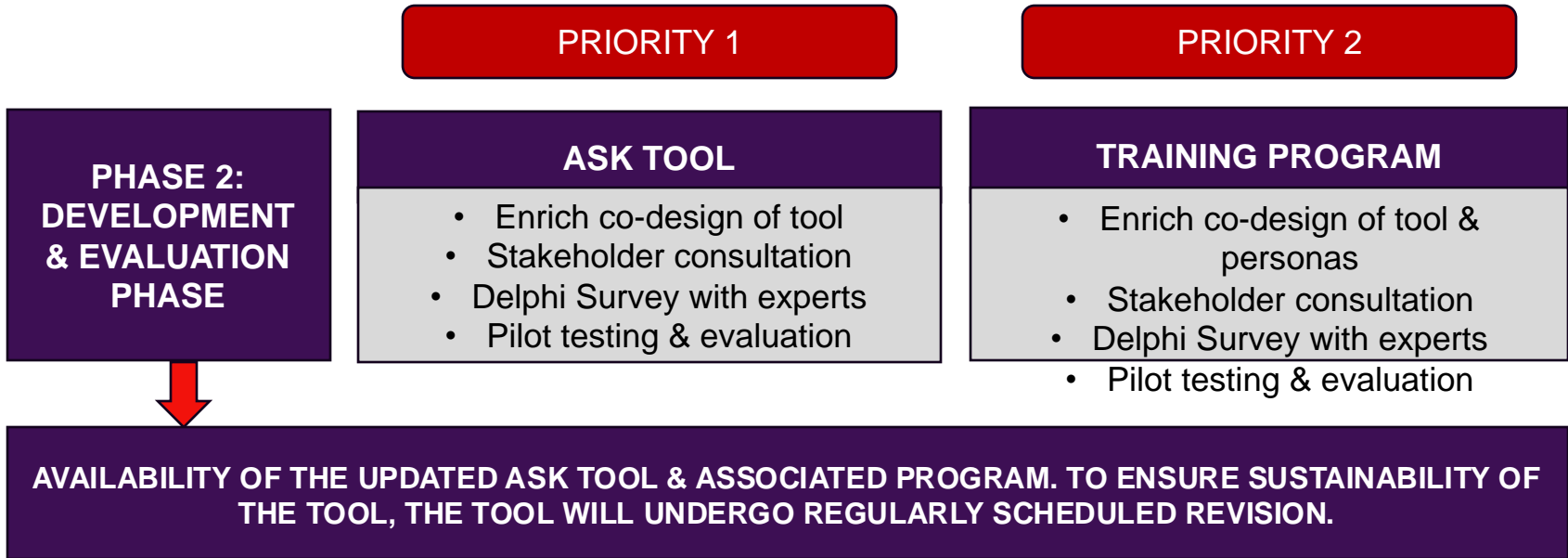
Collaborating with disability advocates to understand how to codesign a sexual wellbeing assessment tool for people with NDD: Deliberative Workshop

Study information:

- An ~2.5 hour in person workshop organised with a panel of disability advocates who are affiliated with a Victorian disability organisation. Preparatory materials will be provided in advance. A series of questions will be asked during the workshop to ascertain the panels' perspectives on various aspects of the research including:
 - Terminology
 - Possible barriers and facilitators
 - Preferred methods and important considerations of codesign research



PHASE 2: DEVELOPMENT & EVALUATION PHASE



PHASE 2: DEVELOPMENT & EVALUATION

PRIORITY 1
UPDATED TOOL



ASSESSMENT OF SEXUAL KNOWLEDGE 2.0

LOGIN

PASSWORD





PHASE 2: DEVELOPMENT & EVALUATION

**PRIORITY 2
TRAINING PROGRAM**

Thank you for
listening,
any questions?



Contact Details:

Dr Chloe Bryant chloe.bryant@acu.edu.au

Dr Claire Lynch claire.lynch@acu.edu.au

Lunch

1:15pm – 2:15pm