

## Summary from the Phase 4 Consultation Workshop

4 March 2020 – University of Sydney

Our thanks to all workshop participants for your enthusiasm and considered feedback. We have copies of all your table notes, and further notes by the project team which capture the richness of the consultation workshop. This has been collated into this summary document of the feedback provided by the group collectively on the day.

While we present the summary below, we will continue to analyse the feedback as we attempt to integrate as many points raised as possible within the scope of the document. Please let our National Project Officer know if anything that is included below has been mis-represented or misunderstood, or if there is anything significant that you believe is missing. Email:

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We look forward to continuing to work with you on this important initiative.

### Purpose of the Workshop

This workshop was part of a staged consultation process to develop the National Eating Disorders and Translation Strategy.

**Phase 1** involved broad national consultation with over 440 individuals representing over 80 organisations, resulting in broad consensus on the direction of the Strategy

**Phase 2** involved national workshops with people with a lived experience and families and carers identifying their specific issues

**Phase 3** involved broad consultation on the draft framework for the Strategy and consultations with jurisdictions

**Phase 4** involves bringing together the expert eating disorders research group across Australia, key eating disorders expert clinicians and service providers, people from the lived experience expert Research Advisory Group

This workshop was part of Phase 4 consultations and the purpose was the first step in consolidating the draft vision, strategies & actions. The workshop included reviewing the draft vision and strategies and identifying research & translation actions.

### Participants

The workshop was attended by expert researchers (senior, mid and early career), people with a lived experience, senior clinicians and service providers and was externally facilitated by Brad Rillat from Leadership Gold. There were 44 participants in the workshop.

Participants were allocated to tables to ensure diversity of experience and expertise across all tables.

## Summary

Table notes were transcribed and collated, and themes were identified by a post doc researcher and the project team. Results are presented below under specific headings.

### Overall feedback from the workshop

General feedback was that it was a very useful exercise and useful to have a diverse group of people with different perspectives at each table with the opportunity to have collaborative discussions. There was a clear structure with manageable tasks and a good amount of time allocated to discussion. Suggestions for what would have helped was a briefer introduction from the facilitator, more clarity about the purpose of the Strategy and the audience it was addressing, and input from other fields.

#### **In Response:**

The feedback has been taken onboard and the final document will have clearly outlined who the target audience is and the purpose of the Strategy.

### Overall comments about the document

Feedback that was deemed to be relevant to the whole document included:

- Having clearer language and definitions throughout
- Improved document structure
- Clearer link to research
- Clearer direction on who the strategy is targeting
- Clearer integration of lived experience/ Co-design as a goal/feature in all elements
- Broaden definition to include wellbeing/prevention

#### **In Response:**

The document had been checked and revised for clarity around language, spelling out the link to research and will incorporate clear definitions as well as ensuring the integration of the lived experience across all sections of the document.

### The Vision

The feedback identified that would strengthen the vision are included under the following themes:

- Clearer meaning, plain English
- Inclusivity
- Clear research focus
- Include policy, education, access

#### **In Response:**

Feedback from the workshop has now been incorporated into the new Vision, which has been approved by the Advisory Committee:

*To establish and sustain an exceptional research culture in Australia that generates innovative co-designed research to transform practice, inform policy, and meaningfully impact the wellbeing of all people at risk of developing or living with an eating disorder, their families and carers.*

## The Strategies

The feedback identified that would strengthen the writing of the strategies are included under the following themes:

- Clearer language and definitions
- Reduce overlapping strategies
- Clearer direction for the strategies
- Clearer link to research

Specific issues identified that the Strategies needed to address included:

- Culture of research
- Support for research at all levels
- Clarity and importance around research translation
- Reflect collaboration, diversity in research and evidence base
- Advocacy
- Funding
- How we integrate research into clinical practice
- Raising awareness and education
- Workforce development

It was also identified that the document needs to acknowledge the difficulty to be faced in the implementation of the Strategy.

Many of the suggestions made during the Strategies section of the workshop are included below in the Actions as they fit as actions attached to the broader strategies.

### **In Response:**

The Advisory committee are reviewing the recommendations around the Strategies and will take into account all feedback. They will ensure the Strategies are relatively free from overlap, are clearer in their direction and reflect how they relate to research.

The development of clinical services is an important element of the research and translation pipeline and this will be highlighted in the document. However, some Strategies and actions that purely focused on clinical/service development may sit outside the scope of this document.

We will collate all 'clinical' and 'service' feedback from all consultations and if the Advisory Committee determine, will share this with NEDC in the development of the National Strategy for Eating Disorders.

## The Actions

The actions identified that would support the strategies fell under the following key themes:

- Eating disorders research as a national priority
- Funding
- Research policies
- Research culture
- Research quality and innovation
- Prioritising research
- Data and digital technology
- Collaboration
- Workforce Development

- Integrated research environments
- Integrating evidence with practice
- Communication
- Clinical issues

Please see below for a list of all the actions that were proposed on the day under these key headings. These will then be mapped to the final key Strategies.

Actions relate to...	ACTIONS identified at workshop
Eating disorders research as a national priority	<ol style="list-style-type: none"> <li>1. All eating disorders included in all existing national public health data collection processes</li> <li>2. Eating disorders identified as core business for all national agencies with research remit</li> <li>3. Advocacy for fast tracked eating disorder research like it's a state of emergency</li> </ol>
Funding	<ol style="list-style-type: none"> <li>1. Update economic modelling on the actual and hidden cost and social cost of eating disorders, including the diverse range of people living with eating disorders.</li> <li>2. Government funding allocated to eating disorders research commensurate with disease burden.</li> <li>3. Public funds to be invested in broad-scale interventions (from prevention to treatment) where an evidence-base for the intervention has been established.</li> <li>4. Develop a fundraising strategy to establish research funding from novel sources e.g. private companies, philanthropy, free treatment options.</li> <li>5. Funding for research through lived experience organisations</li> <li>6. Advocacy around eating disorders research funding with competitive funding schemes and national funding bodies, and international collaborations.</li> <li>7. Advocate for targeted research calls for eating disorders</li> <li>8. Lobby for minimal quota budget for national funding of eating disorder research</li> <li>9. Establish incentives public/private health sector to do research</li> </ol>
Research policies	<ol style="list-style-type: none"> <li>1. Establish policies around research that guide funding of public health interventions and services</li> <li>2. Establish strategies &amp; policies to develop, maintain and support the research workforce, including the peer workforce</li> <li>3. Establish policies to include research by people in private practice</li> <li>4. Require data collection of core elements of treatment by practitioners providing treatment through the Eating Disorder Medicare funding mechanisms</li> <li>5. Require evidence-based treatment and outcome monitoring in all public health services</li> </ol>
Research culture	<ol style="list-style-type: none"> <li>1. Establish Research Centre of Excellence in <ul style="list-style-type: none"> <li>• prevention and obesity/health promotion</li> <li>• evidence-based practice</li> <li>• practice-based research</li> </ul> </li> <li>2. Elevate the profile of our research leaders</li> <li>3. Establish Chairs of Eating Disorders Research in each State/Territory</li> <li>4. Reverse the brain sink by establishing a research culture that attracts great researchers to Australia</li> </ol>
Research quality and innovation	<ol style="list-style-type: none"> <li>1. Develop research principles/standards that are endorsed nationally – best practice research framework/guide</li> <li>2. Establish lived experience research network so research teams could call on that group for input</li> <li>3. Establish a centralised eating disorder ethics committee</li> </ol>

<p>Prioritise research that...</p>	<ol style="list-style-type: none"> <li>1. Research priorities are integrated through all national mechanisms and bodies</li> <li>2. Prioritise research and translation design practices that change the way we do things</li> <li>3. Prioritise research development in lived experience, minority and non-stereotypical groups, carers and family</li> <li>4. Prioritise research that: <ul style="list-style-type: none"> <li>• is co-designed and co-produced</li> <li>• fills knowledge gaps</li> <li>• is innovative, agile and cost effective</li> <li>• improves early identification and first point of contact experience e.g. in general practice, headspace, schools, sporting organisations</li> <li>• responds to the individualised medicine approach to treatment</li> <li>• focuses on transition periods</li> </ul> </li> </ol>
<p>Data and digital technology</p>	<ol style="list-style-type: none"> <li>1. Establish a National Minimum Data set</li> <li>2. Establish clinician research tools to capture data at point of care</li> <li>3. Establish a National Registry/ National Surveillance System</li> <li>4. Establish a national universal data collection hub linked to other data (e.g. health department)</li> <li>5. Less onerous data collection and systems</li> </ol>
<p>Collaboration</p>	<ol style="list-style-type: none"> <li>1. Establish a National Eating Disorder research network/ state-based research networks</li> <li>2. Establish an online register of eating disorder research</li> <li>3. Establish clinical trial networks and multi-site research systems</li> <li>4. Research teams more diverse ensuring co-design at all levels</li> <li>5. Build and support international teams conducting research and translation, and establish knowledge exchange/scholarships with researchers overseas</li> <li>6. Lived experience and Researchers working in partnership (and co-located) with all treatment hubs nationally</li> <li>7. Collaborate with innovators and disruptors to build new integrated research environments</li> <li>8. Work across disciplines, institutions, communities, sectors and countries to capitalise on specialist skills and different perspectives</li> <li>9. Harness interaction points between professional practice, research and education, as research opportunities</li> <li>10. Public health messaging, in particular around living in a larger body, language around food and body, and what constitutes healthy eating should be evidence-based, consider the potential harm in terms of eating disorders and be developed collaboratively with input from both perspectives.</li> <li>11. Establish systems for universities to support clinicians to undertake research</li> </ol>

Workforce development	<ol style="list-style-type: none"> <li>1. Establish a Hot House Program where a talented and diverse cohort of graduates and post docs work together with people with a lived experience, seasoned academics and expert and novice clinicians to pursue fundamental questions and translate ideas and research into action.</li> <li>2. Formulate a clear set of skills that postdoc eating disorder researchers develop during this stage in their career.</li> <li>3. Funded grants/scholarships for post docs, early career researchers, clinical fellowships, that provide time for reflection, planning and career enhancing experience and ensure maintenance/fidelity strategies like supervision and support are provided.</li> <li>4. Establish models where Post Docs linked to clinical roles</li> <li>5. Developing a best practice research workforce: training and research workforce development, including peer researchers and the clinical workforce</li> <li>6. Clinician and lived-experience funded time for research involvement</li> <li>7. Advocate for eating disorder research training (including translational research) to be included in undergraduate and postgraduate health training programs</li> <li>8. Develop postgraduate online training in eating disorder research skills for multiple disciplines</li> </ol>
Integrated research environments	<ol style="list-style-type: none"> <li>1. Research conducted and applied in real-world settings (co-location) from community and primary care settings (including private practice), through private practice, secondary and tertiary services.</li> <li>2. Enhance capacity of the health sector to address gaps in services and improve service delivery through synthesis, dissemination and utilisation of the evidence by ensuring all state specialist treatment hubs embed research with sufficient FTE allocated to drive research implementation, evaluation and innovation.</li> <li>3. Co-location of research and clinical services to help innovate treatment</li> <li>4. Establish research coordinators in major tertiary hubs, networked with each other and lived experience research workforce</li> </ol>
Integrating evidence with practice	<ol style="list-style-type: none"> <li>1. Open access resource repository for evidence – based pathways and protocols for all clinicians in all settings - including exemplar models of research translation (in any field)</li> <li>2. Develop a National Eating Disorders Strategy</li> <li>3. Develop National Practice Standards for Eating Disorders that include standardised tools and documentation, valid and reliable measures of treatment quality, health outcomes and economic impact.</li> <li>4. Translation included as a key measure of research output and promotion</li> </ol>
Communication	<ol style="list-style-type: none"> <li>1. Establish a research communication strategy that educates the community about eating disorders to improve understanding and promote early intervention, reduce stigma and that supports people with lived experience to build confidence to be involved in the research process at all stages</li> <li>2. Ensure feedback to the community and to people with a lived experience of research results and outcomes.</li> <li>3. Develop exemplar models of research and translation to demonstrate how it could work (e.g. how private clinics could link with universities)</li> <li>4. Ensure communication of strategy in plain language</li> </ol>

	<ol style="list-style-type: none"> <li>5. Use ambassadors and influencers</li> <li>6. Position paper for IJED/JED on research strategy, collaboration, lived experience</li> </ol>
<p><b>CLINICAL ISSUES</b></p> <p><b>Note:</b> The development of clinical services is an important element of the research and translation pipeline. This will be highlighted in the document. Actions purely focused on clinical/service development may sit outside the scope of this document. We will collate all ‘clinical’ and ‘service’ feedback from all consultations and if the Advisory Committee determine, will share this with NEDC in the development of the National Strategy for Eating Disorders.</p>	<ol style="list-style-type: none"> <li>1. A National Strategy for Eating Disorders</li> <li>2. Change model of care delivery – emphasis public versus private</li> <li>3. Address medical model</li> <li>4. Develop Best Practice Framework – mandated by Departments that EB practice occurs and client feedback required</li> <li>5. More specialist services – infrastructure to do this</li> <li>6. Grow the clinical workforce</li> <li>7. Building clinical skill capacity across general practice, primary care (private practitioners), public health services</li> <li>8. Addressing stigma, raising awareness across the community, recognition of people who don’t meet stereotypes by GPs and others – every community member has knowledge about eating disorders</li> <li>9. Increase access to treatment for all – rural and metro</li> <li>10. Improve the person’s experience of treatment at every point of contact – not just with specialist workforce, but with GPs, with school counsellors etc.</li> <li>11. Eating Disorder representation in all mental health planning and service delivery</li> <li>12. Tie accreditation process to EBP around eating disorders</li> <li>13. Adequate treatment available across the continuum of care</li> <li>14. Specialist providers – doctors nurses psychologists GPs also need to improve their knowledge and skills</li> <li>15. Every member of the community have literacy around eating disorders</li> <li>16. Declare state of emergency similar to the DV advocacy</li> <li>17. Increase bed availability in public hospitals with embedded evaluation re pathways of care and economic evaluation; and where service payment is tied to accreditation in eating disorders which is based on evidence-based practice</li> <li>18. Embed eating disorder knowledge/skills into undergraduate and postgraduate health training courses to raise awareness, knowledge and skills, and address stigma and discrimination against people with eating disorders.</li> <li>19. Advocating within relevant professional education and training programs (education, sports) to include eating disorders</li> <li>20. Engage people with lived experience to contribute to education of health professionals and others.</li> </ol>