



Centre for Mental Health
Melbourne School of Population and Global Health

Reducing stigma and discrimination towards people with mental illness

Final summary and recommendations

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Background and aims

Discrimination against people with mental illness is prevalent in Australia.^{1,2} Reducing this is critical to improving the wellbeing of people with mental illness and their families, friends and other supporters (hereafter referred to as support people). It is widely acknowledged that it will take a sustained and collective effort to dispel the myths associated with mental illness, change ingrained negative attitudes and behaviours, and ultimately support social inclusion and recovery.

While there have been some improvements in community understanding of common mental illnesses (particularly depression and anxiety), there is still widespread misunderstanding and ignorance. In particular, low prevalence mental illness, such as schizophrenia, bipolar disorder and personality disorders, tend to be poorly understood and attitudes towards people with these mental illness diagnoses are less positive than for more common mental health conditions.³

Recognising this, Priority Area 6 of Australia's Fifth National Mental Health and Suicide Prevention Plan outlines the need for a nationally coordinated approach to reduce stigma and discrimination towards people with mental illness that is poorly understood in the community. The first phase of this work involved a review of the evidence relating to the reduction of stigma and discrimination towards people with low prevalence mental illness.^{4,5} The second phase involved consultations with a wide range of stakeholders, including anti-stigma program providers, health professionals (and students) and those working in the education, employment and social services sectors. Subsequent to these consultations, a set of draft recommendations for a nationally coordinated approach to stigma and discrimination reduction was developed. In this third phase of the project we reported on consultations with people with lived experience, either their own or as a support person. The principal aim of these consultations was to seek feedback on the draft recommendations.

In the fourth phase, we conducted consultations with Aboriginal and Torres Strait Islander people with lived experience.

A note on terminology: The language used to talk about mental illness can play a key role in reducing stigma and is constantly evolving. While we understand that views on the most appropriate terms differ, for the purposes of this project we have chosen to use the broad term 'mental illness' to reflect that used in the Fifth Plan. We also use the diagnostic terms schizophrenia, bipolar disorder and personality disorders as starting points to ensure that the focus is on low prevalence mental illness rather than on depression or anxiety. **We have also used the term 'people with lived experience' as a general term to refer to people who have experienced mental health conditions or emotional distress or have used mental health services and also to people who care for or support people with mental illness.** Alternative terms used in the report (particularly by participants) are 'consumers' or 'people with living experience' and 'carers'. Throughout this report we use stigma to refer to attitudes and discrimination to refer to behaviours towards a person with a diagnosis or experience of mental illness.

Rationale

The project plan was informed by the need for national coverage and inclusion of key groups already at high risk of experiencing discrimination as well as those whose behaviours have a major influence on people living with a mental illness and their supporters. It also drew on key national surveys incorporating measures of stigma and discrimination^{1-3,6-11} and the evidence for effective interventions.^{4,12-14}

This project is based on the rationale that an effective national plan for reducing stigma and discrimination towards people with mental illness requires consultation with a broad range of stakeholders from the following key groups:

- Group 1: People who experience stigma and discrimination as a result of their own lived experience of mental illness or through experiences as family members, friends or supporters.
- Group 2: People whose attitudes and behaviours (negative and positive) towards people with mental illness have the potential to significantly influence the lives of people living with a mental illness.
- Group 3: People who implement Australian programs to reduce stigma and discrimination and can comment on the elements of a national plan that are likely to be both effective and feasible.

We note that, in the original project plan, it was our intention to undertake consultations with people with lived experience and their support people simultaneously with those in Groups 2 and 3. However, due to Covid-19, the

project plan was revised and our interim report covered stakeholders in Groups 2 and 3, while this current report covers consultations with stakeholders in Group 1. We also note that people in peer worker and other lived experience-based roles in mental health services were involved in Phase 2 of the consultations. Therefore, there were lived experience perspectives on the development of the draft recommendations.

Methods

Phase 1: Review of Australian anti-stigma programs

Programs were identified via a search of academic databases and grey literature, and an online survey of key stakeholder organisations. Eligible programs aimed to reduce stigma towards people with complex mental illness, defined as schizophrenia, psychosis, personality disorder, or bipolar disorder; or they focused on nonspecific 'mental illness' but were conducted in settings relevant to individuals with the above diagnoses, or they included the above diagnoses in program content. Key relevant data from programs identified from the literature search and survey were extracted and synthesized descriptively.

Phase 2: Consultations with key stakeholders

In phase 2, we conducted online video interviews with 234 stakeholders from the following groups: advocates (who were often people with lived experience as consumers or carers), anti-stigma program providers, mental health peer support workers, health professionals, health professional students, people with 'broad expertise' (who held multiple roles relevant to the project) and those working to support people with mental illness in employment, education and social services settings.

Phase 3: Consultations with people with lived experience

In phase 3, we conducted online video focus groups with 117 people with lived experience, either their own or as family members, friends and other support people. Participants were asked to provide feedback on the draft recommendations developed in Phase 2 of the project.

Phase 4: Consultations with Aboriginal and Torres Strait Islander people with lived experience

In phase 4, we conducted consultations (mostly face-to-face) with 28 Aboriginal and Torres Strait Islander people.

In all phases, focus groups were recorded, transcribed and analysed to identify key themes.

Key findings

Phase 1: Review of Australian anti-stigma programs

We identified 61 programs or initiatives currently available in Australia. These included face-to-face programs (n=29), online resources (n=19), awareness campaigns (n=8), and advocacy work (n=5).¹⁵ The primary target audiences for these initiatives were professionals (health or emergency), people with mental illness, family or carers of people with mental illness, and members of the general population. Most commonly, programs tended to focus on stigma towards people with non-specific mental illness rather than on particular diagnostic labels. Evidence for effectiveness was generally lacking. Face-to-face programs were the most well-evaluated, but only two used a randomised controlled trial design.

This study identified areas of strength and weakness in current Australian practice for the reduction of stigma towards people with complex mental illness. Most programs have significant input from people with lived experience, and programs involving education and contact with a person with mental illness are a particular strength. Nevertheless, best-practice programs are not widely implemented, and we identified few programs targeting stigma for people with mental illness and their families, or for culturally and linguistically diverse communities, Aboriginal and Torres Strait Islander communities and LGBTIQ people.

Phase 2: Consultations with key stakeholders

Participants agreed that stigma and discrimination towards people with lived experience of mental illness are widespread. They reported that attitudes vary according to the type of mental illness, with people with diagnosed bipolar disorder typically seen as less stigmatised than people with schizophrenia, and people with borderline personality disorder being perceived as more likely to experience discrimination in health services than in other settings. There was strong support for a national strategy to address stigma and discrimination towards people

diagnosed with schizophrenia, bipolar disorder and personality disorders. Participants also noted the need for a long-term approach as well as for ongoing evaluation of effectiveness.

The most common theme related to ensuring that people with lived experience are central to any strategy, including in leadership, co-design, delivery and evaluation roles. Many participants noted the need to provide opportunities and support for people with lived experience to share narratives of their experiences of living with mental illness in a range of settings. They noted that these stories need to be told in ways that create empathy and challenge stigmatising attitudes, notably those relating to people being seen as entirely defined by their diagnosis, as dangerous or unpredictable, or as unable to recover and live full and meaningful lives.

While there was a consensus that language around mental illness is important, there was no consensus on the use of diagnostic terms in approaches to addressing stigma and discrimination, with many participants noting both advantages and disadvantages of various approaches.

Key settings and populations

Interviews explored views on key settings for interventions and programs to reduce stigma and discrimination, and the most frequently nominated were health services, workplaces and the media. Many participants noted the need to target the general community; family and friends of people experiencing a mental illness; police and the justice system; policymakers and the education system (both schools and tertiary education institutions).

Participants noted the need to tailor activities for Aboriginal and Torres Strait Islander and culturally and linguistically diverse communities. Interventions involving these communities should incorporate culturally appropriate understandings of mental health, be delivered in a range of community languages, be community-led and engage community leaders in design, delivery and evaluation.

(1) Health services

Many participants noted the need to address stigma and discrimination in health services. They talked about the need for structural reform, considering the biomedical paradigm on which the mental health system is based to be fundamentally discriminatory, because of the lack of agency afforded to people with lived experience of mental illness. Lack of services, particularly in rural and remote areas were also seen as contributing to discrimination due to inadequate treatment, escalation of symptoms and people with mental illness being seen as a 'burden'. Other participants talked about the need to address attitudes and behaviours of health professionals through education. Mental health peer support workers were seen as having a key role in reducing stigma and discrimination in the mental health system.

(2) Workplaces

Workplaces were seen as a key setting for interventions, due to the importance of paid work for social and economic wellbeing and the role of discrimination in reducing participation in the workplace. As in other settings, recommendations for reducing stigma and discrimination in workplaces included strong organisational leadership and the involvement of people with lived experience in sharing positive accounts that challenge prevalent beliefs that people with mental illness are a burden in the workplace. Some participants noted the need for narratives to go beyond education about managing and supporting people with mental illness to those that emphasise the value that people living with a mental illness can bring to a workplace.

(3) General population

Many participants talked about the need to educate the broad Australian community, with a focus on 'demystifying' and 'normalising' mental illness. Media campaigns, including those in traditional media (which was seen as particularly useful in reaching rural or culturally and linguistically diverse communities), digital and social media were often nominated as important in challenging stigmatising attitudes.

(4) The media

The media itself was also seen as influential in shaping attitudes to mental illness. Negative and stigmatising portrayals of people with mental illness were perceived as common and as undercutting efforts to promote positive attitudes, particularly by stoking community concerns around crime. Improving the quality of media reporting on mental illness, in the context of violence and crime was viewed as essential for stigma reduction.

(5) Educational institutions

Efforts to reduce stigma in educational institutions was viewed as necessary to create generational change in attitudes. Mental health education in schools, provision of support for young people with mental health difficulties and their families, as well as education and support for staff were seen as important in improving mental health in young people, with flow-on benefits to stigma reduction, through offering positive narratives of hope and recovery.

Phase 3: Consultations with people with lived experience

There was broad agreement that the recommendations were appropriate and comprehensive. In many cases, these discussions were wide-ranging, encompassing topics relating to broad health system and societal changes. However, we have focussed our changes to the recommendations on those more closely related to the project aims. A number of participants reiterated the urgent need for action, measurable goals with clear timelines and accountability. Limitations include relatively limited participation from people whose first language is not English, with low literacy levels, poor access to the internet or other factors that prevented them for participating in online focus groups.

Phase 4: Consultations with Aboriginal and Torres Strait Islander people with lived experience

Key themes included those relating to the importance of addressing the social determinants of Aboriginal and Torres Strait Islander health, including social disadvantage, racial discrimination and trauma (including intergenerational trauma). In contrast, a number of participants raised themes relevant to the role of traditional knowledge, and connection to country and culture in social inclusion and healing. These themes point to the value of a strengths-based approach that acknowledges the importance of the cultural determinants of mental health.

Other themes related to the need for culturally competent mainstream mental health services and healthcare professionals, and their potential for more collaboration with Aboriginal Community-Controlled Health Services (ACCHSs). Furthermore, there is a need for community health education and anti-stigma campaigns driven by grass-roots organisations that incorporate culturally appropriate understandings of social and emotional wellbeing as well as some understanding of mainstream mental health and diagnostic frameworks to support early intervention.

Recommendations

Recommendation 1: Ensure that people with lived experience (either their own or as support people) have leadership roles in the strategy, by:

- Funding a national body, either an existing organisation such as the National Mental Health Commission or a new organisation, led by people with lived experience to develop and oversee implementation of the strategy;
- Involving, and adequately funding, national and state-based lived experience advocacy organisations, both large and small, in strategy development and implementation;
- Building collaborations between community, government and non-government organisations to create a cross-sector cooperative network with a shared purpose while also accounting for diversity in cultures, perspectives, skills and experiences;
- Ensuring that there is adequate and genuine lived experience representation on boards, advisory committees, or other decision-making entities by:
 - widely advertising lived experience roles, and detailing the supports that will be provided, to ensure representation from a broad range of people, including those with less common diagnoses, those from Aboriginal and Torres Strait Islander and culturally and linguistically diverse communities;
 - appropriately remunerating people with lived experience for their work;
 - creating career paths for people in these roles through provision of support, mentoring and educational opportunities;
 - ensuring that opportunities for participation are flexible enough to suit the individual circumstances of people with lived experience.

Recommendation 2: Ensure that anti-stigma programs and activities are led and co-designed by people with lived experience (either their own or as support people), by:

- Supporting people with lived experience to share narratives of mental health and recovery in ways that allow others to move beyond a view of them as being entirely defined by their illness;
- Focusing on narratives that:
 - move beyond raising awareness that mental illness and stigma are problems without offering solutions;
 - challenge, rather than avoid, stereotypes around dangerousness, unpredictability and unreliability;
 - challenge commonly held stereotypes that a person with a diagnosis of a mental illness is a burden to society, incapable of work, participation in education or family life or of achieving successes that are possible for people without these diagnoses;
 - are realistic, acknowledging that the experience of mental illness is different for everyone (e.g., single episode, episodic, long-term and recovered from clinical symptoms), and that it comes with challenges;
 - build empathy and understanding, including a focus on mental illness as a response to trauma and a failure of necessary supports (including those in the health and mental health system) rather than blaming the individual or their family;
 - acknowledge the benefits and strengths that lived experience of mental illness can bring, including greater empathy, interpersonal skills, assertiveness, creativity, adaptability and resilience
- Providing opportunities for face-to-face contact between community members with and without lived experience of mental illness, while also maximising opportunities to use video/online content;
- Ensuring sufficient financial support and training for people with lived experience who share their experiences through adequate resourcing of organisations that run programs involving people with lived experience;
- Evaluating the impact of involvement in the programs and activities on people with lived experience themselves.

Recommendation 3: Start now and take a long-term approach that:

- Builds on successes in changing attitudes to common mental health conditions;
- Is informed by successful strategies used by others advocating for social change, e.g. the LGBTIQ+ community;
- Has adequate funding and support for large scale campaigns that may take years, or even decades to have impact;
- Involves activities that build on successes and evolve over time, with new messages and strategies to sustain interest and attention and that target sub-groups where attitude change is slow or stagnant;
- Incorporates actionable short, medium and long-term goals with clear timeframes and measurable outcomes.

Recommendation 4: Evaluate the impact of the strategy on the short, medium and long-term goals by:

- Using mixed methods approaches, including population surveys and qualitative research;
- Ensuring that people with lived experience co-design and conduct evaluations, including specification of the impact of any activities being undertaken;
- Ensuring that people from Aboriginal and Torres Strait Islander and culturally and linguistically diverse communities co-design and evaluate activities carried out in their communities.

Recommendation 5: Align key messages or elements in the strategy, but tailor to local needs, by incorporating the following principles:

- Programs should be culturally appropriate, celebrate diversity and be led by local communities;
- Use of language, including diagnostic terms, should be tailored according to program and setting;
- Further research into the impact of key messages and interventions should be undertaken to assess effectiveness in different community groups and settings and avoid unintended negative consequences.

Recommendation 6: Address stigma and discrimination in health services by:

- Implementing reforms that support, at both structural and individual practitioner levels:

- a fundamental shift away from treatment that only focuses on the symptoms of mental illness towards a focus on wellbeing, including social, spiritual and cultural aspects;
- a shift in power dynamics between practitioners and people with lived experience, including both consumers and support persons;
- moving away from approaches that offer people services and supports based on their diagnoses to those that focus on their needs and aspirations;
- Strengthening peer work as an emerging discipline:
 - through implementation of policies and processes that support their distinct role in multidisciplinary teams;
 - through comprehensive provision of career opportunities, supervision, mentoring, and training;
 - by providing fair and equitable working conditions, including parity of pay and reasonable adjustments to their roles;
 - by including peer support workers who are from a diverse range of language and cultural backgrounds;
- Incorporating strategies to address self-stigma in people diagnosed with mental illness, as well as stigma in support people, through better linkage between health services and local lived experience advocacy organisations and programs; while recognising that self-stigma is a product of the experience of stigma and discrimination in the community
- Encouraging, supporting and enabling psychiatrists, nurses and other allied health staff to take leadership roles in stigma reduction;
- Involving people with lived experience in systems-level changes in health services;
- Incorporating training in person-centred, trauma-informed care, led by people with lived experience into training for all health professionals;
- Incorporating aspects of reflective practice (including adequately funded supervision and mentoring), to allow health practitioners, senior managers and policymakers to understand their own attitudes and the impact of their work in mental health;
- Improving education for health professional students by including language guides, evidence about the harms of stigma and discrimination and positive narratives or contact with people with mental illness who have flourishing lives, to counter the impact of early encounters with people who are acutely unwell;
- Ensuring that training is ongoing to incorporate new evidence and address attitudes that may change over time;
- Implementing training and reflective practice initiatives that specifically focus on improving health professional attitudes, language and behaviours towards people with borderline personality disorder, including building skills to improve outcomes and reduce therapeutic pessimism;
- Evaluating anti-stigma initiatives in health services, including the impact on people with lived experience.

Recommendation 7: Address stigma and discrimination in workplaces by:

- Strengthening anti-discrimination policies and their enforcement;
- Promoting practices that support mentally healthy workplaces;
- Ensuring that people in senior leadership roles model positive attitudes and behaviours towards people with diagnoses of mental illness;
- Providing education including key messages that focus on the contribution that people with mental illness can make as well as on the importance of supporting people with mental illness in the workplace (including through reasonable adjustments);
- Implementation of interventions that address fears about competence, reliability, productivity and extra ‘burden’ related to employing someone living with a mental illness, by including people with lived experience telling stories of success;
- Adequately resourcing and supporting ongoing training for employers;
- Providing more access to programs for people with psychosocial disabilities to enter and be supported in the workplace, including flexible working arrangements, staying/returning to work plans, support around disclosure, mentoring, individual placement support and skills training;

- Using the momentum arising from changes in work practices caused by the COVID-19 pandemic to further strengthen access to flexible working environments, support greater openness about mental health issues and support for employees.

Recommendation 8: Address stigma and discrimination in the community by:

- Focusing on activities that demystify or normalise mental illness;
- Moving beyond a focus on the scale of the problem and what not to do, to incorporate suggestions for positive language and behaviours towards people with diagnosed with mental illness;
- Having a greater emphasis on symptoms or experiences (e.g. distress), rather than on diagnostic categories;
- Conducting media campaigns, including traditional media that reaches rural or culturally and linguistically diverse communities, digital and social media;
- Supporting grass roots events tailored to local community needs, including creative arts, food and sporting events (particularly in Aboriginal and Torres Strait Islander, LGBTIQ+ and culturally and linguistically diverse communities) that offer opportunities for positive interactions between community members with and without mental illness;
- Ensuring that Interventions intended for a mainstream audience also reflect the cultural diversity of the Australian population.

Recommendation 9: Address stigma and discrimination in the media by:

- Improving the quality of media reporting on mental illness, particularly that relating to violence and crime by:
 - encouraging the Australian Press Council to work with lived experience advocates and media organisations to improve practice for coverage of mental illness and crime;
 - encouraging media professionals to improve their mental health literacy (through accessing information resources or undertaking training);
 - implementing interventions for media professionals (including journalism, film, television, and communication students) that encourage them to:
 - ♣ regularly consider the impact of media reports and language on public attitudes and people living with mental illness;
 - ♣ report all relevant risk factors that contribute to violence and crime, including failings in the mental healthcare system and factors that are not related to mental illness;
 - ♣ use non-stigmatising language and images;
 - ♣ use social media responsibly when sharing or engaging with news content involving mental illness and crime;
 - strengthening monitoring of media reporting on mental illness and violence, e.g. through SANE Media Watch;
- Encouraging social media influencers and celebrities to improve their understanding of mental illness and how to use their platforms to support reductions in stigma and discrimination;
- Encouraging people with lived experience, advocacy bodies, and TV and film production companies to work together to improve portrayals of people with mental illness;
- Introducing segments on children’s television programs that can start to appropriately introduce concepts of mental health and diversity of experiences from a young age

Recommendation 10: Address stigma and discrimination in educational institutions by:

- Providing ongoing mental health education in all schools and tertiary education institutions, that includes positive narratives of a diverse group of people with lived experience of low prevalence mental illness;
- Providing early intervention and support for students with mental health problems, particularly for international students and students at times of transition;
- Improving funding and standards for professional development and support for staff in schools and tertiary education institutions;
- Ensuring that staff who regularly provide mental health support in educational institutions are appropriately trained in person-centred, trauma-informed practice.

Recommendation 11: Address stigma and discrimination in police, social services, justice and welfare professionals, by:

- Implementing training led by people with lived experience that takes a trauma-informed approach, incorporating an understanding of the social determinants of health, and including narratives of hope and recovery;
- Adequately resourcing and supporting ongoing training;
- Incorporating peer-support workers or advocates into social and welfare services to assist clients in navigating these complex service systems.

Recommendation 12: Address stigma and discrimination towards Aboriginal and Torres Strait Islander people by:

- Ensuring that Aboriginal and Torres Strait Islander people have leadership roles in the Strategy;
- Ensuring that any actions taken under the national strategy:
 - are inclusive of Aboriginal and Torres Strait Islander peoples;
 - do no harm, and actively reduce underlying systemic disadvantage and inequality through addressing the social determinants of health;
 - take a trauma-informed approach that recognises intergenerational trauma and the trauma caused by colonisation and systemic racism;
 - take a strengths-based approach by protecting and promoting cultural determinants of health including traditional knowledge, family, culture and kinship by:
 - incorporating Aboriginal and Torres Strait Islander conceptions of social and emotional wellbeing;
 - drawing on family and kinship support structures, while ensuring there is greater access to support;
 - drawing on Aboriginal and Torres Strait Islander cultural strengths by taking an Inclusive holistic approach to healing;
 - emphasising the role of culture and connection to country in promoting good mental health (e.g. yarning, men's groups, arts and associated activities that enhance and utilise cultural connection and practices)
 - draw on previous successful Aboriginal and Torres Strait Islander health promotion campaigns;
- Ensuring access to culturally competent health services by:
 - addressing structural racism in health services (including harmful stereotypes about substance use);
 - implementing policies and procedures to ensure accountability for instances of racism, injustice, breaches of confidentiality and substandard care;
 - increasing participation of Aboriginal and Torres Strait Islander people at all levels in the mental health workforce (including healthcare professionals, Aboriginal Liaison Officers and peer workers);
 - ensuring health providers and social service providers receive training to improve cultural competence;
 - ensuring that culturally informed practices and methods are available in addition to clinical responses;
 - building on successes achieved in other areas of Aboriginal health, including in Aboriginal Community-Controlled Health Services (ACCHSs) which are underpinned by holistic perspectives of social and emotional wellbeing;
 - listening to, acknowledging and supporting the critical roles played by carers;
 - designing health services in collaboration with local communities to include outdoor spaces, Aboriginal art and to allow local cultural practices, including rituals or celebrations.
 - Scaling up evidence-based mental health education and carer psychoeducation programs tailored to and delivered by Aboriginal and Torres Strait Islander people.
- Implementing programs that educate non-Indigenous people about Aboriginal and Torres Strait Islander people's understandings of social and emotional wellbeing and healing;
- Implementing education and anti-stigma programs in Aboriginal and Torres Strait Islander communities that:
 - are led, co-designed and delivered by Aboriginal and Torres Strait Islander people from local communities;

- build on the strengths of Aboriginal and Torres Strait Islander people in their culturally-based inclusivity and support for all family and community members (including those with symptoms, behaviours or diagnoses of mental illness);
- focus on bridging Aboriginal and Torres Strait Islander and mainstream understandings of mental health to empower community members to intervene early when someone becomes distressed.

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Research team

University of Melbourne

- Prof Nicola Reavley PhD, Centre for Mental Health
- Ms Judith Wright, Centre for Mental Health
- Ms Anna Ross, Centre for Mental Health
- Dr Karen Block, Centre for Health Equity
- Dr Claudia Marck, Centre for Health Equity

LaTrobe University

- Prof Lisa Brophy
- Dr Catherine Brasier

Charles Sturt University

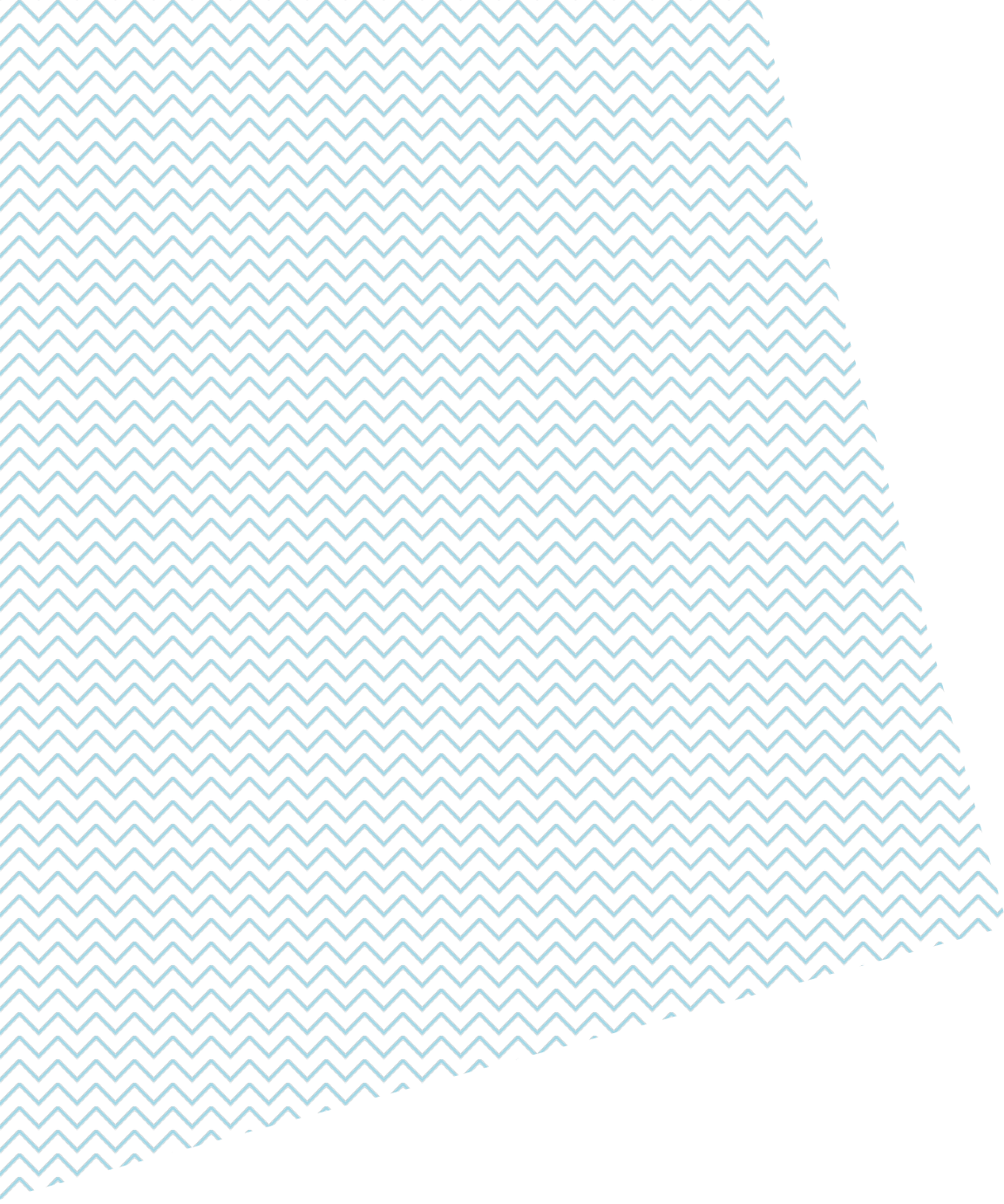
Prof Deborah Warr

Origin Communications

- Mr Justin Noel
- Ms Isabelle Adams
- Mr Frank Proctor

Kate Kelleher Consulting

- Ms Kate Kelleher



Prof Nicola Reavley. Email: nreavley@unimelb.edu.au, Ph: 03 9035 7628