



## WITNESS STATEMENT OF DR MELISSA PETRAKIS

I, Dr Melissa Petrakis, Senior Lecturer, of 900 Dandenong Road, Caulfield East, in the state of Victoria, say as follows:

### Background

- 1 I am a Senior Lecturer and Course Coordinator in the Department of Social Work, Faculty of Medicine, Nursing and Health Sciences at Monash University. I have been a lecturer at Monash University since January 2011.
- 2 I am also:
  - (a) the Group Director of the Social Work Innovation, Transformation and Collaboration in Health (**SWITCH**) Research Group at Monash University. My work is located in the Department of Social Work, at Caulfield Campus. The department sits within the School of Primary and Allied Health Care (**SPAHC**), Faculty of Medicine, Nursing and Health Sciences. The research group brings together 12 industry-partnership research studies, led by myself as Chief Investigator. The studies include innovative practice-based research in health and mental health services and sectors, including senior clinician co-researchers and partnership organisations. The studies currently undertaken under SWITCH include the involvement of four health networks, three universities, two mental health community support services, 12 practitioners and 12 research students – including two who identify as having lived experience;
  - (b) a Senior Research Fellow within the Mental Health Service at St Vincent's Hospital, Melbourne. I have held a research role in the early psychosis program and in strengths-based recovery-oriented practice there since July 2008. In this role I am Chief Investigator of a number of studies into evidence-based early psychosis treatment. I have conducted practice-based research (**PBR**), fostered practitioner-researcher opportunities for skilled clinicians, and co-produced with emerging consumer and carer researchers. For the last 10 years I have researched best practice in education and support with families when a loved one first experiences psychosis and encounters the mental health system, drawing on family members' expressed needs, preferences, feedback as to what helps, and feedback as to how and when best to receive information and support in the hospital and community; and

- (c) the Chair of the Board of Tandem Inc. (**Tandem**), the Victorian peak body representing family and friends supporting people living with mental health issues.

3 I have previously held the following roles:

- (a) I have been a guest lecturer and regular tutor at the University of Melbourne in its Department of Social Work across a nine-year period; and
- (b) I have worked in various mental health services, including at the Substance Use Mental Illness Treatment Team (**SUMITT**) within Melbourne Health; the Western Area Suicide Prevention Strategy (**WASPS**) within Western Health, where I was the Program Manager and a Senior Clinician with the Western Area Suicide Prevention Strategy (2003-2006), a National Suicide Prevention Strategy innovation project; and at MIND Australia, when it was Richmond Fellowship of Victoria, where I managed Southern Respite Services.

4 I have a Doctor of Philosophy (PhD) from the University of Melbourne, supervised across the Departments of Social Work and Psychiatry. My thesis was titled '*Suicide relapse prevention: recovery outcomes from an innovative model of client-centred assertive counselling, community linkage and monitoring, developed within one Victorian hospital Emergency Department*' (conferred August 2009). I also have a Master of Social Work (research), Bachelor of Social Work, and Bachelor of Arts (majoring in Psychology and Research) from the University of Melbourne.

5 I have worked in the area of mental health for over 20 years. I have authored over 70 publications and delivered over 80 national and international conference presentations in the areas of recovery-oriented practice, mental health services, family caregiving, program evaluations, psycho-social interventions, social dimensions of health and illness, suicide prevention and post-vention, care pathways in clinical practice, and early psychosis treatment.

6 Attached to this statement and marked 'MP-1' is a copy of my CV.

7 I am giving evidence in my personal capacity. I have also been nominated by Tandem to provide a statement on its behalf and I am authorised to do so in my role as Chair of its Board in 2020.

8 Exhibited at 'MP-2' of this statement is a list of resources to which I refer in this statement.

### **My own experiences in advocating with mental health carers**

- 9 In addition to having worked in the area of mental health for over 20 years, in addressing the questions in this statement I am drawing on my own experiences in having contact with the service system as a layperson and in attempting to engage in advocacy.
- 10 Growing up in the 1970s and 1980s, mental illnesses were often termed a 'nervous condition', and by comparison there was more stigma than there is today; needs were still more cloaked (in shame) and hidden. Families from migrant/culturally and linguistically diverse (CALD) communities, attempting to join the dominant culture and assimilate as was the expectation in those times, particularly were challenged if experiencing mental illness.
- 11 Across 20 years, I have supported family, friends, colleagues and undergraduate and Masters' students to access much needed assistance from a variety of services, ranging from emergency departments, crisis services, telephone counselling, in-person support services, practical and material aid, clinical services, rehabilitative services and residential services. I/we have experienced the service system as unduly complex and fragmented. The system lacks integrated procedures, paperwork, services and care.
- 12 More recently, I have had people close to me who have experienced challenges accessing supports with many services moving to reduced face-to-face contact under COVID-19 restrictions.
- 13 I mention these experiences because I draw on them in formulating my views about certain matters in relation to the mental health system. I am a researcher, and I've worked in adult mental health for many years, but I am also a person who has accessed the system. I find it important to note that people might be mostly confident and articulate, but – when in a lived experience role, be it as a consumer or a carer – the person may become disempowered by the mental health issues, and be very much in need, and much of that confidence and articulation may fall away. As workers in a clinician/worker headspace we might be aware of the system issues and resource limitations, and be working to do things much more quickly than is typical, to help individuals and families. We need to be mindful though that when a person is in acute distress, and/or a family member is, and/or when mental ill health is severe and persistent, our attempts to help will likely be experienced as slow and bureaucratic, and empathy we may feel towards people is not necessarily how it feels for a consumer or family member who is on the receiving end of the care. Frustration with limitations to helping should be expected and understood.
- 14 As a result of both my work in research – particularly working 12 years at St Vincent's Hospital – and my own personal lived experiences, I have been drawn towards understanding consumer experiences and supporting consumer researcher-led

initiatives, as well as drawn towards working with clinicians engaged in carer research rather than medication-oriented research. For more than 10 years now, I have looked at carer group work and family interventions to think about what carers need. And for the past two years, I have been involved with Tandem, including currently as Chair of its Board.

## **Families and carers and innovative practices**

### ***The physical, emotional or economic impacts on people caring for someone experiencing poor mental health***

- 15      Primarily, what I have been told repeatedly, and what is reported in international literature, is that carers find the mental health system confronting and challenging to navigate. Carers have spoken about the terminology being confronting, and in particular they find the use of certain language, and the use of inconsistent language across different services, difficult to understand. Services are like franchises operating in different ways rather than a system – each mental health service has its own names for things. Even something basic like where to go if a loved one is unwell and has been taken to hospital is confusing – the place where the loved one is might be called an inpatient unit; an acute inpatient unit; an acute inpatient service; or it might be referred to as a mental health ward. There's all this language for the same thing. It is often spoken in shorthand, by busy workers in the system, familiar with the terms. So you may be advised to attend the AIS. This is confusing and may increase feelings of distress and powerlessness for carers themselves, who may also worry about adding confusion for the person experiencing the illness.
  
- 16      In addition, carers in Victoria have spoken to me about each hospital or each access point within the system having its own triage processes; its own interfaces; and differently built environments – and carers have said they find this confusing and confronting. At the same time, carers feel as if they should be able to understand these things – they're not the ones who are unwell compared to their unwell relative; they're the ones who are 'supposed' to be able to navigate things. But sometimes they don't have prior experience in how, and they don't have a sense that they are entitled to speak for their loved one.
  
- 17      I have also witnessed carers do all that they can not to think about the burden on them when someone is unwell in their house; they are desperately concerned about that person's welfare, and they may believe that, if they don't do something, the person will get sicker, or may be suicidal, or they themselves are somehow being negligent. So my experience is that there is a lot of fear and anxiety for carers in not acting, but when they do act, they have told me, and I have witnessed, that they are historically and in many contexts not given much information (Day & Petrakis, 2017). Some of this is legitimate – I appreciate the genuine concerns around consumer confidentiality and privacy – but it is

something that has an impact on carers, and impacts their ability to do their relationship-based job well in caring.

- 18 A separate impact that is often felt by carers is the stress and distress they feel when caring for their loved one. Sometimes, people are admitted for seven or eight days in an acute admission in a hospital facility, and then they are medically cleared to be managed in the community. But it is often the case that the person is not well enough for the carer to care for them and support them 24/7. In a psychiatric unit we don't expect one person to, in isolation, manage someone who is still acutely unwell – we never do, and these are highly trained individuals. In such a hospital unit there are nursing teams, security teams and doctors who come and go and are available on call. Carers don't have that – they *feel* they are, and indeed they truly and *objectively* are, expected to do it all themselves.
- 19 In terms of economic impact, my experience is that often carers don't label themselves as 'carers' when accessing social benefits, because they don't want to be seen as benefitting from someone they love who is unwell. They have told me that it feels morally wrong. It is only when financial pressures impact to the point they cannot provide adequate care to their unwell family member that they relent and register their caring role. The Australian Bureau of Statistics noted in October 2019 is that there were 2.65 million carers, representing 10.8% of all Australians, and 3.5% of all Australians were primary carers (ABS, 2019). Mental health carers are a proportion of this group. Estimates drawn together in 2019 are that 976,000 people were mental health carers in 2015, or 4% of Australians and 36% of all carers (Productivity Commission, 2019, p. 459).
- 20 Numbers that we have about the number of carers are in my view grossly underestimated. That these are estimates and from 2015 indicates something about the priority given by government, researchers and (then by extension) service providers to carers' experiences, their roles and their needs.
- 21 In addition, I have heard carers say that they don't want to be a burden on the government or on taxpayer resources, particularly if that money could be used instead in aid of their loved ones. Carers would rather that money be spent on things like psychotherapeutic options that are not available such as counselling, or more nurses in inpatient units, so they tend not to access benefits for themselves in coping in their household, hoping money will then be available for what is 'most needed'.
- 22 The Productivity Commission (2019) noted that, with regard to family-identified needs, changes for successful intervention in mental health requires:
- (a) mental health professionals who are skilled and supported to provide family-focused and carer-inclusive care;

- (b) carer support services that are accessible, effective and designed with input from carers;
  - (c) removal of barriers that affect mental health carers' access to Carer Payment and Carer Allowance; and
  - (d) a more effective service system for consumers that allows carers more choice about how much care they provide (p. 457).
- 23 The Mental Health Carer Support Fund (CSF) is a Victorian Government fund administered by Tandem designed to support mental health carers with costs associated with providing informal support to someone living with mental health issues. Carers supporting consumers registered with an Area Mental Health Service (AMHS) can apply for funds related to costs incurred because of their care relationship. Guidelines written by the Department of Health and Human Services stipulate 'reasonable prices' for goods and services.<sup>1</sup> Due to its broad scope, the CSF is effective at providing practical assistance for carers connected with AMHSs who are most likely to be experiencing the most acute economic, social and emotional distress. Feedback from staff who access the fund say that it is a highly valued resource in the toolkit to deliver practical support to people who need it and engage carers in their own self-care.
- 24 As the total spend for the CSF has remained static for a decade, while need has increased many times over, many AMHS's have set internal caps on fund applications in an attempt to be equitable amongst all families and over the full year. Each application has a recommended cap of \$850 with a maximum of \$1,100 incl. GST per financial year. The reality is that in the 2019-20 financial year so far, the average amount per application has been \$474.70 incl. GST. The CSF is allocated to 31 AMHS's, and the allocation formula has not been reviewed since 2009. The total amount provided to Tandem for distribution was set in 2009 at \$1,578,953 and despite the number of consumers growing by over 50%, it has not been reviewed since.
- 25 Tandem in its advocacy to government has recommended that, given the substantial growth in population in Victoria since 2009, the Victorian Government's implementation of its Carer Strategy 2018-22 and the reflections made in the Interim Report of this Royal Commission, it is timely to review the level of support provided to family and friends via the CSF. Tandem calls on the Victorian Government to support an immediate increase in the investment currently available to families and carers through the CSF, and believes an investment of \$1 million to the fund from \$1.6 million to \$2.6 million would restore its currency and would assist an extra 2,000 mental health carers engaged with clinical mental health services in crisis. This would improve the CSF's overall capacity to provide

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<sup>1</sup><https://www2.health.vic.gov.au/about/publications/researchandreports/Mental-Health-Carer-Support-Fund-Guidelines>.

assistance from 3,000 to over 5,000 mental health carers and is consistent with overall annual demand over the last three financial years.

***Varying impacts on carers depending on the nature and extent of care provided***

- 26 In my view, the impacts vary depending on the nature and extent of the care provided.
- 27 To provide context, mental illness is episodic: different things can trigger acute episodes. A person working in an acute centre can only see a person when they are unwell, but not during the times that they are well – all the days in between those acute episodes.
- 28 A carer, though, is in a different situation. A loved one can be well for months and months on end, and a carer wouldn't think of themselves as such – they're a family member, and that's the capacity in which they engage with their loved one and so the role is not viewed as burdensome (in using the word 'burdensome', I am conscious of the research on carer burden. Whilst carer burden is real, carers don't like the term, because they believe that what they do is natural and what anyone would do for a loved family member when they are unwell). A family member can also at times be very severely and persistently unwell for days, weeks or months at a time, at a distressing level for the person and those around them yet assessed as sub-threshold to access tertiary referral services (how our system is currently set up for treatment). So at times the role is not burdensome; at other times it is very burdensome, and over a long period that depletes everyone's coping resources.
- 29 Tandem explicitly describes itself as a peak body for family, carers and friends. It's broad on purpose, because the research suggests that not all people like the label of 'carer'. When I conducted a survey with a Carer Consultant colleague, asking people about their carer experience, our experience was that the majority did not respond (Scanlon & Petrakis, 2012); speaking with carers since, I have been advised that if a person is asked about their family role, or how it is caring for a loved one, they are more happy to talk about it and fill in such a survey.
- 30 A further thing to add about impacts on carers is the physical and emotional impacts. There is clear literature about many possible negative outcomes and high comorbidities experienced by carers including fatigue, high blood pressure, distress, anxiety, and depression (Lowenstein et al., 2010; McCann & Lubman, 2014; Petrakis, Bloom, & Oxley, 2014; Riley et al., 2011). If someone has a severe and persistent mental illness, such as schizophrenia or schizoaffective disorder, or bipolar, the carer is normally hyper-vigilant; alert all the time; frequently organising things to care for the person who is quite unwell, even if they're not living in the same abode.
- 31 What tends to happen as a result is that carers may themselves develop anxiety and depression. My experience is also the case that depression and anxiety in carers – particularly in men, or in women caring for a long time – may not present in the way the

public expects depression to look like. They may state that all is business as usual for them, where they are coping okay and are just 'stretched' or 'stressed', but if asked, they admit to having symptoms such as poor sleep, diet, reduced enjoyment in activities, increased worries and increases in a sense of both hopelessness and helplessness in the face of worrying about challenges their family member experiences due to the illness and navigating the mental health system. If a person presented like that to a counsellor or general practitioner and they weren't in a carer role, minimising their needs, they would likely be treated.

- 32 Carers therefore need to be aware of symptoms for anxiety and depression, and should get support themselves - often they don't seek treatment for that because they see themselves as 'less unwell' than the person they're caring for.

***Services or practices that provide respite relief to carers***

- 33 Recently, I attended a meeting with members of Tandem from across the state meeting with key staff from Carers Victoria, and we discussed what increased respite services might look like. As part of this meeting, I reflected on respite services that were provided by Richmond Fellowship, now MIND Australia, about 17 years ago when I managed Southern Respite Services for that organisation. There were three types of respite services that were provided for families and for the individuals themselves, and it was funded by the Federal Government. The services were funded to support anyone who was caring for someone or had a caring role – so the flexible definition could include a neighbour, friend or direct family member – and the services were provided to the individual with the mental illness.
- 34 The services provided were:
- (a) one-on-one respite for people who were socially isolated or self-isolated, and were not very confident in group settings. We matched them with a worker based on the person's own preferences, and this was often someone of a similar age and gender, and the worker would help them navigate interactions and activities in the broader community or develop social skills. They might go to the movies, go swimming or go to the beach, go shopping or do some food preparation;
  - (b) group respite services. This was particularly enjoyed by young people experiencing psychosis. We would match a small group (usually two or three people) who were interested to meet others in recovery and help them navigate rebuilding a friendship network with other people, because they often would lose same age peers who weren't unwell over time. We would initiate forming a small group of people and help them organise and attend activities such as bowling or going to the movies, or lunch at a shopping centre, and then we would step back. The benefit for carers was that they received respite because the carer wasn't

needed to attend to the individual experiencing the mental health challenges during those times; and

- (c) holiday programs. We would take consumers away for a four-day holiday each year, fully staffed and fully catered. Every second week our team took a group away on a vacation somewhere in the state. We had a site in Apollo Bay, owned by the organisation, shared with Western Respite Services and other programs, and other sites we rented. My experience was that both the consumer and the carer loved this service. It provided the carer with four days to themselves, as an annual break, knowing that the person they cared for was having an exciting and enjoyable break with nine other people and three staff members. The carers could take a trip for a couple of days themselves, and plan for it in advance (as we would plan months in advance ourselves), or they could simply have some quiet time to rest or run other errands.

- 35 In my view, these sorts of respite services are not hard to set up, and a diversity of respite services should be made available. The types of services described above work well because they consider both consumers and carers. My experience is that if an organisation provides only carer direct services, the person who is unwell may feel like they're getting fewer services as a consequence (since public resources are limited). I have also experienced carers who have dropped out of psychoeducation and support sessions dedicated to them because they don't have someone else to support their loved one while they attend, even if it's only for a couple of hours. So respite services that provide services to both consumers and carers, so that carers also get a break, are a useful model to consider.

***Better supporting families and carers to help the person they care for***

- 36 In my view, every mental health service, for every age including young people, adults, and the aged, should provide family psychoeducation. Family psychoeducation is the most evidence-based and underutilised intervention that we have in psychiatry. In a mixed-method systematic review investigating the effectiveness of psychoeducation, published in *The Journal of Clinical Psychiatry*, Sin and Norman (2013) noted then that already there were 58 articles reporting 44 research studies about family psychoeducation.
- 37 Family psychoeducation aims to improve the knowledge and coping skills within families to enable them to work together to help a person with a mental illness. Family intervention for caregivers may be in an individual or group format and it involves receiving didactic teaching, skills practice and support (Ma, Chien & Bressington, 2017). The interventions are designed to relieve caregivers' distress and empower coping more effectively with the day-to-day caregiving challenges (Chien et al., 2015). Different professionals may adopt

different strategies of family intervention, from family psychoeducation to family therapy; all comprise common means that give rise to favourable outcomes. Pharoah et al. (2015) summarised these as key process components: establishment of an alliance with caregivers, easing strained family atmospheres, and enriching caregivers' coping skills.

- 38 As noted by Palli et al. (2015), the results demonstrated that psychoeducation had a beneficial effect for family cohesion, global family burden, objective family burden, and relatives' depressive symptomatology. They observed a non-significant finding for subjective family burdens (as did we across a number of study repetitions at St Vincent's Hospital in Melbourne), which can be attributed to the possibility that psychoeducation alone does not lift the stress associated with the demands of care from the shoulders of families; economic supports and initiatives to reduce community stigma are needed too. Interestingly, linear regression models revealed that relatives of people who had suffered from schizophrenia spectrum disorders for more than ten years displayed the greatest improvement from attending the psychoeducational group. Psychoeducation was concluded to constitute a valuable non-stigmatising intervention that empowers family members of people with severe and persistent mental illness, enabling them to cope more effectively.
- 39 One of our local studies, published with Occupational Therapist Senior Clinician Julia Oxley and Social Worker Senior Clinician Hannah Bloom, involved small psychoeducation groups where 15 people attended over five weeks (Petrakis, Oxley & Bloom, 2013). Taking on a caring role is stressful and challenging, and it has been found that support and information for carers assists in their coping and reduces isolation. Our aims were to evaluate the utility of a psychoeducation group program in a public adult mental health service, for the families of people experiencing early psychosis. Methods we used involved a purpose-designed pre and post-intervention questionnaire, administered to quantitatively measure group participants' changes in perceptions of their understanding of mental illness and its treatment through attending the group. Additional qualitative items were used to determine other knowledge, benefits and any critical feedback.
- 40 Kate Day, Social Worker Senior Clinician, Rachael Starbuck, Occupational Therapist Senior Clinician, and I revisited the research and re-evaluated at the 10 year mark of the program being delivered, because the role of family in supporting service users in coping with illness and engaging in relapse prevention in early psychosis is important. Our re-evaluation showed that the group program continues to result in highly significant improvements in family members' understanding of psychosis, recovery, medications, relapse prevention and substance co-morbidities. Additional feedback reaffirmed previous findings that family members find group peer support valuable and that this reduces isolation and the experience of stigma. Conclusions drawn were that the

evaluation, conducted following 10 years of early psychosis group work, found there to be efficacy in family peer support groups and that it is important to provide family interventions in public early psychosis mental health services.

- 41 In my view it would not be difficult to incorporate family psychoeducation into mental health services much more extensively and in an ongoing manner. It would involve:
- (a) having a manager within the service supportive of staff to have time to contact families to attend groups and sessions within their workload (we were fortunate in having Graeme Doidge and Bridget Organ when setting up the program);
  - (b) keeping a register of who is new to the service, who is new to a particular diagnosis, and who the family is more broadly; and
  - (c) arranging group sessions and contacting families in a way which doesn't make people feel like they are being blamed or judged as to why they are being approached – i.e. explaining that the service runs the sessions every year and that the person is eligible to attend and they strongly recommend doing so, that it is evidence based and that testimonials from past attendees can be shared to explain the value of attending the group from a carer perspective.
- 42 My experience is that a month between sessions is too long, if a monthly open-format group is being considered (we tried that initially more than 10 years ago; Petrakis, Bloom & Oxley, 2014). People often come and go from a group and then much of the time in the next session is spent recapping things for new people. I would suggest that five sessions over five weeks, two hours a week and inclusive of some light refreshments, is a very good model. Half the time in each session could involve provision of information to the group, and half the session could involve a group discussion.
- 43 One of the sessions in family psychoeducation needs to be focussed on medication – my experience is that carers are often confused by medication and have a lot of questions they would like to ask to better understand it. They are concerned about dose; side-effects; safety of the medication; brand and generic options, and the different names of the drugs; whether any are lethal in overdose; whether, when someone is still experiencing psychotic symptoms, it should be up to the carer to hold and administer medicines and how to have conversations about that with doctors and with the consumer; and whether diet supplements make a difference or could be helpful, such as fish oil, teas, more or less caffeine; and many other such questions.
- 44 A doctor or pharmacist could attend – it makes a big difference to how people feel. Attendance by a trained expert, beyond their group facilitators, indicates to families that their family concerns are legitimate, that help is available, that the service is compassionate towards them and committed to providing information that they need, and

being able to ask questions of an expert in a group is reassuring – that it is not a trivial question since others confirm they wondered that too.

- 45 I think there also needs to be some planning around who is going to look after the loved one whilst the carer attends the session. I refer back to my point made at paragraph 35 about some carers not attending sessions because they didn't want to leave their loved one alone.
- 46 People also appreciate and value tools to take away to help them have structured conversations with medical and other treatment staff – an excellent such resource is the Carers Can Ask tool (<https://www.svhm.org.au/our-services/departments-and-services/n/nexus/carers-can-ask>) developed by Senior Dual Diagnosis Clinician Simon Kroes of Nexus Dual Diagnosis Service through a coproduction approach with family members and carers over many years. Nexus are also well regarded by consumers and families for their innovative work on the Reasons for Use Package, developed by Senior Dual Diagnosis Clinicians Kevan Myers and Simon Kroes, supporting clinicians to have conversations toward understanding and working with consumers on substance use in their lives rather than a blaming approach (Kroes, Myers, Officer, O'Connor & Petrakis 2019; Myers, Kroes, O'Connor & Petrakis 2018; Petrakis, Robinson, Myers, Kroes & O'Connor 2018).

***Examples of best practice models for family and carer inclusive practice***

- 47 I have been involved for the last two years in a research study around enhancing LGBTIQ+ responsiveness in healthcare settings (Kilicaslan & Petrakis, 2019). I am struck that a similar approach to the 'Rainbow Tick' used to denote whether a service is safe for people who are LGBTIQ+<sup>2</sup> could be useful to denote that a service is carer-inclusive, i.e. a 'Carer Tick'.
- 48 The Office of the Chief Psychiatrist in our state has developed guidelines (2018) for working with families and carers. An incentive could be that services that commence a pilot to implement changes in practice to be compliant with the guidelines, towards Carer Tick accreditation, in a plain and robust manner, could be provided with a fractional (I suggest a 0.6 full time equivalent position) 'Carer Support Worker Service Development and Evaluation' position for two years to coordinate this service development.
- 49 Tandem as a peak body is very interested in supporting a Carer Tick initiative, and our CEO Marie Piu has spoken with key stakeholders about what that might look like and how that might work. Tandem is well positioned to provide oversight to an accreditation

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<sup>2</sup> <http://www.rainbowhealthvic.org.au/rainbow-tick>.

process for services if tasked and resourced to do so. This would lend independent review towards services, and provide discipline-appropriate resourcing to the position holders.

### **Lived experience in governance (consumer, and carer and family workers)**

#### ***Structures needed to ensure people with lived experience to have a voice in decision-making***

50 I have worked in the adult mental health system for over 20 years and I have observed the use of consumer consultants and peer workers within mental health services. My experience is that there are a number of issues that have arisen in the past with engaging consumer, carer and family workers:

- (a) first, there seems to be an assumption that people with lived experience can only work part-time – and it's not an accurate assumption. Any person, whether they be a person with lived experience or not, is entitled to take leave, including sick leave, yet we don't seem to question that for a worker who is not a peer worker. If someone has a lived experience, and they have disclosed this and take leave, they run the risk of someone assuming they are becoming unwell again. So they are offered a part-time position, with managers thinking that they are protecting the staff or somehow helping them, but then that runs the risk of the person not being as entitled to certain employment rights as someone who is working full-time. In addition, a worker with lived experience who gets a job two days a week may then have to take on a second job simply because they need to pay their bills;
- (b) second, it is often the case that consultants are stretched in their roles and are not fully integrated into the team. They are expected to work across multiple programs, and attend lots of meetings (Byrne, Roper, Happell & Reid-Searl, 2019), and are not often well briefed prior. Because they are spread so thin, the person may miss a meeting, or they may not know what the meeting is about but then are expected to provide 'the' consumer or carer perspective when asked, as if there is only one and as though representativeness can be delivered without time to consult others with lived experience about the matter at hand (Daya, Hamilton & Roper, 2020); and
- (c) third, there doesn't seem to be enough money in services' budgets yet to fund the roles of peer workers. I have seen managers apply for funding, and get some funding for their services, but others don't. This builds a sense of competition between services – and then the funding is only for a short period of time. That then creates the likelihood of the peer worker taking on a new role, spending say three months to get their head around the workplace and getting to know their colleagues, and then three months to learn their role and become good at it, and

then before they know it the funding runs dry and they need to look for another job. The frequent lack of permanency in positions for peer workers (Chisholm & Petrakis 2020) is neither respectful nor sustainable for a skilled discipline group.

- 51 Instead, we should adopt a model whereby we commit to our peer workers. I have seen some good examples of good programs that try to have better governance, with commitment from management, good support from a non-peer leader and good peer worker leadership central to daily operations.
- 52 I have also seen very successful inclusion of consumer vocational opportunities embedded in and central to operations of a mental health service when St Vincent's partnered with Wellways (Petrakis, Stirling & Higgins 2019). I particularly credit Regional Manager Kate Higgins of Wellways Australia, for clarity of vision and persistence, along with the committed case managers at Hawthorn Clinic at St Vincent's and my Manager Graeme Doidge, since sustaining that work across more than 7 years was a challenge in the funding environment in Australia for vocational interventions (Stirling, Higgins & Petrakis 2018). A focus on education and employment enables many people to achieve vocational opportunities that increase income, symptom recovery and so lessen the burden of the illness, and improve personal recovery through engagement with self-directed meaningful activities, connection with others, greater hope, enhanced self-esteem and identity. A supportive environment to gain experience or a qualification prior to and upon entering competitive paid employment in the broader community is very valued by people in recovery. Peer worker roles, to share expertise by experience and support others in their own recovery journeys, can be one such avenue of competitive employment. Roles outside peer work can also be of interest to people who have experienced mental illness – to resume a previous career or to pick up an area of interest that was beyond their ability to engage in when they were unwell (perhaps due to concentration challenges, cognitive processing challenges, confidence, or the difficulty of early morning starts when highly medicated).
- 53 The Mental Health America service in Long Beach, California is one of the best examples I have seen as to how things can be run differently. I attended this service in June 2013 when I was in Los Angeles presenting at the 7th International Conference on Social Work in Health and Mental Health. I observed that the service is housed in a regular building on a regular street with no fancy signage. It's not a brand new building and there has been some thought internally as to its redesign and purpose. When you walk in, people meet you and check what you'd like; why you are there; how they can help you. It's different to what we often observe in Victoria, which is a big desk in almost all of our services in reception but is not receptive – it's almost like a guard station. You don't get in further until you've been checked that you're really entitled to be there.

- 54 The office space is open plan in Long Beach, with lots of clinician workstations, and someone can go in and find the person they are looking for.<sup>3</sup> If there is a need for a private meeting, there are meeting rooms off to the side, and there are open spaces for people to read. There are private consulting rooms, but the psychiatrists are readily available to speak to people in the open plan area, as are case workers. I spoke with a psychiatrist working there when I was visiting, wondering whether they would get bombarded with requests and questions, but he said that consumers only come up to him if they have a need, asking whether they could see him at some time today and telling him they will be waiting inside or outside, where there is a basketball ring and a paved area.
- 55 Finally, at Long Beach there is a cafeteria, and at that time about 50% of its staff had lived experience (that percentage has since increased). It's a non-clinical way of supporting people with lived experience, and is often used as a stepping stone for other work in the community if and when they are ready. Social Enterprises offered by the Long Beach service include the Village Cookie Shoppe, Deli 456 and its catering services, and Preferred Staffing Services. What I witnessed in the cafeteria was also an opportunity for a clinician or peer worker to sit with a consumer to see how they are going in a more casual way – and in my view they would get a lot more clinically useful information in that process. In my role as a social worker I would often learn more about a person driving them home from a hospital admission than I would in a formal appointment. I would therefore often put my hand up to do practical assistance in discharge work simply so I could have the opportunity for people to tell me about things in a more parallel way should they choose.

***Recent reforms that have given greater voice and roles to people with lived experience***

- 56 I am a big believer in the Prevention And Recovery Care services (**PARCS**)<sup>4</sup> and in the Expanding Post-Discharge Support (**EPDS**) Initiative<sup>5</sup>. These are excellent reforms, and the Victorian Government is to be commended for them. They are well liked by consumers, families and lived experience staff. I have learned a lot about how these can be delivered well through conversations with Liam Buckley, Senior Peer Worker and Carmen Raspor, Senior Social Worker in the inpatient setting, at St Vincent's. I have seen these services embraced by staff across disciplines and across clinical and mental health community support sector services. They have at their core principles such as person-centred healthcare, flexibility, respect, uniqueness of individual needs and recovery trajectories, an awareness of age and gender in treatment decisions, and an awareness of differences in cultural beliefs and practices.

<sup>3</sup> <https://www.mhala.org/services-and-programs/employment/>.

<sup>4</sup> <http://www.health.vic.gov.au/mentalhealthservices/parc.pdf>.

<sup>5</sup> <https://www2.health.vic.gov.au/about/publications/ResearchAndReports/expanding-post-discharge-support-initiative-report>.

57 I have seen very tangible opportunities for peer leadership in these programs that have been genuinely realised, and that have impacted service culture favourably, towards greater respect for persons. These initiatives should be bolstered, and extended. These are lessons for other programs, and these successes should be shared with other states in Australia to a greater extent since there is much potential for roll-out more broadly nationally, with some fairly minor local adaptations.

***Facilitating more service provider organisations governed and delivered by people with lived experience***

58 I think it is important to support start-ups whereby people who are skilled to lead lived experience organisations do not necessarily have to also be accountants and administrators for the organisations to commence and function.

59 I have for a long time, as a clinician and a university educator, been impressed by work from the Centre for Psychiatric Nursing at the University of Melbourne to support lived experience academic positions. I have been fortunate to be mentored by the empowering collaborative leadership of the Centre's Director Associate Professor Bridget Hamilton. I have been impressed by Cath Roper, Consumer Academic pioneer at the Centre, who – in training clinical staff around coproduction (Roper, Grey & Cadogan, 2018) – has sometimes shared the parable of the blobs and squares.<sup>6</sup> It is salient to remind ourselves not to make lived experience experts over in our own image, and that includes carer lived experience leaders. At Monash University, where I work much of my week, I have also been impressed by the work of Vrinda Edan, another consumer academic and leader in the PULSAR initiative (Shawyer et al., 2017).

60 In 2013, Melbourne was home to the 5th World Hearing Voices Congress, hosted by the Australian Hearing Voices Network (21-22 November 2013). It was very expertly organised and delivered by Voices Vic, led by dynamic Consumer Advocate Indigo Daya and a skilled team, including Judith Drake; two more women who I have admired for many years for vision in consumer-led services. It was noted about the Congress:<sup>7</sup>

*“Over 770 people attended the congress during the 3 days, making it the largest ever Intervoice World Hearing Voices Congress, and the largest ever consumer-led event in Australia’s history. Most importantly, many voice hearers have now found new ways of living with their voices, many workers now have new strategies and ideas for better supporting voice hearers, and many family, friends and carers now feel better able to understand and support their loved ones.”*

<sup>6</sup> <https://ideas-alliance.org.uk/hub/2016/06/02/the-parable-of-the-blobs-and-squares/>.

<sup>7</sup> <https://www.intervoiceonline.org/about-intervoice/world-congress/2013-australia>.

## Community based model for mental health services

### *A community-based mental health system over the next 10 years*

- 61 I respect and admire the clarity of Professor Patrick McGorry, Executive Director of Orygen, in how he has lectured and published for many years about models that involve phase and stage-specific care (McGorry 2002). In my view we want a system that has about three levels of acuity of intervention available to people, which is much more explicit than what there currently is (the current tertiary focus to treat severe and persistent mental ill health, quite separate to high prevalence disorders treated largely in primary care). In my view, we have made a pretty decent attempt toward achieving that at the moment, given the drastic under-funding relative to the level of mental health needs in the community. There is a lack of integration still though, and there is a missing middle. Headspace centres have at least been a very genuine attempt to bridge the service divides that people experience and struggle with in terms of access; and access to timely care remains a staggering problem with so little investment in mental health programs relative to disease burden and community need.
- 62 People talk about the system being broken, but in my view we don't have a broken system in terms of a badly designed system – we have just never fully realised the current system because it has not ever been properly funded since deinstitutionalisation. That saddens and angers me because I see consumers, family members, clinicians, rehabilitation workers and managers of programs struggle to stretch to make up for what has become a threadbare blanket we try and wrap around people in need who deserve better.
- 63 What we need is a system that is adequately funded and designed in a way that provides adequate responses to people who are acutely unwell, and in a safe way. We need community-based responses that support people in an ongoing way when they are in recovery, and then information and support when people have higher prevalence disorders.
- 64 At St Vincent's – under the leadership of Professor David Castle – we developed a model in a different way, establishing an integrated model of care, rather than a standalone and separate team to deliver early intervention in psychosis services. Some people experience a first episode of psychosis (**FEP**) after the age of 25, and others fall through gaps in treatment for various reasons, and they are often the most disadvantaged by socioeconomic, educational, cultural/linguistic and location factors. There are higher presentations of depression with psychotic features in people experiencing older onset (notably so for those over 40), and a trend towards greater metabolic morbidity (Selvendra, Baetens, Trauer, Petrakis & Castle 2014).

65 Understanding the needs of diverse adults is important in tailoring optimal treatment and service responses, and this has been a careful and long-term focus in the work of my colleagues, allies, Consultant Psychiatrists Ajit Selvendra and Dominika Baetens, and Senior Clinician Nurses Steve Penno, Simon Laxton and Michael Nolan. We have advocated that stand-alone early psychosis services based on age may inadvertently exclude this adult group in first episode from optimal evidence-based treatment, exacerbating disadvantage (Baetens, Penno, Dowling, Petrakis & Castle 2012). Services available to people irrespective of age of onset enable those who might otherwise miss out to at some point engage in a FEP treatment program, including a slow, thoughtful and collaborative approach to medication, intensive psychoeducation and support, collaborative practice inclusive of family/carers, and a focus on personal and functional recovery, emphasising employment and community engagement. Quality FEP practice in standard care reduces admissions, involuntary treatment, police involvement and seclusion (Petrakis, Penno, Oxley, Bloom & Castle 2012), things that matter a great deal to consumers, their family and the staff I work alongside.

### **The mental health workforce**

#### ***Barriers to Australia achieving the vision for community-based, multidisciplinary, person-centred and family-centred service delivery***

66 I recall that multidisciplinary teams were established with an expectation of a mixed caseload in terms of level of acuity and complexity, and a caseload number of about 22 consumers per full-time clinician. What I have witnessed over 25+ years is the insidious shift to only working with severely unwell people and caseloads of quite often around 30 people per clinician. It actually is about sufficient funding to realise what was a promising model of well-rounded care.

#### ***Key features of a workforce strategy to meet current demands on mental health services***

67 Speaking recently with the Chief Mental Health Nurse Anna Love at an International Women's Day breakfast hosted by Tandem, held at Orygen, I was very impressed and pleased by changes already happening to move the early roles for our mental health nurses from acute settings (historically the focus to learn to work first with acuity of presentations) to commencing in the community (in order to learn interdisciplinary teamwork and recovery-oriented practice, working with people over a longer time period). I think this move is sound and I would welcome it for our allied health and medical colleagues as well.

68 I am very excited by the potential of the Victorian Collaborative Centre for Mental Health and Wellbeing (**Collaborative Centre**). It will be important to bring together practice, education and advocacy staff across the key disciplines housed in one purpose-built or purpose re-designed setting, in order to share, compare, contrast ideas and avoid

separatist thinking and turf warfare (which occurs at times of scarcity of resources and high need).

- 69 When I refer to key disciplines I mean the following: lived experience (consumer and carer), nursing, medical, social work, occupational therapy, psychology, rehabilitation and policy. We need university/academics to collaborate with advocacy, practice and policy leaders in the space, so that evidence-based practices can be compared and contrasted and adapted and trialled to, as expediently as possible, be road-tested to devise something fit-for-purpose.

### **Lived experience workforce (including consumer, and family and carer workers)**

#### ***Necessary steps to better support lived experience workers***

- 70 My view is that we need to move away from the consumer consultant and carer consultant (only) roles, and move towards innovative peer support roles which are direct practice roles in addition to the leadership and oversight of senior consumer consultant and carer consultant positions. Peer workers should be integrated and supported like any other disciplined practice roles, working directly with consumers who are distressed or in recovery, and they should have the same rights and industrial protections as all other workers. They should be included in the relevant enterprise bargaining agreement and considered to be a true and permanent core workforce group.
- 71 There needs to be a pathway for lived experience workers – and not just a pathway out. We need good people in these roles (and the roles already attract good people), who have clearly defined position descriptions, a direct line of mentoring in role, responsibilities and have support around them.
- 72 The lived experience workforce is a crucial ingredient in achieving a less stigmatising and discriminating workplace culture, and indeed to contribute to societal shifts toward inclusivity that are happening but are slow. This group cannot lead by example unless they have critical numbers. Frankly, the government needs to more than double this workforce within two years if we are serious about a tangibly person-centred and respectful mental health system.

### **Oversight of the mental health system**

#### ***Strengthening the regulatory framework and independent oversight of mental health services to improve their quality and safety***

- 73 As discussed above, I don't perceive our system to be broken. I would suggest that Victorian staff and managers are already doing admirably given that we have such an underfunded system that is no longer fit-for-purpose; indeed that was perhaps always transitional as we moved people from asylums into what was the unknown of how the

community would or would not embrace people coming back to it. A lot of good work has been done by a lot of people over the last two decades, and we have come a long way towards enhancing the system we have. That's why I think people can see we can do more. Unfortunately we have been putting short-term patches on top of patches, and small retrofitted innovations have been added and have been nurtured to work well, then there has not been ongoing funding available for them. I welcome the government's commitment to take stock and bring more permanency to innovations that are working and others that should be there but are not yet.

- 74 As I mentioned earlier, I welcome the possibility of the key advocacy bodies – the Victorian Mental Illness Awareness Council (**VMIAC**) and Tandem – to have a role in oversight; through involvement in the Collaborative Centre and also to a system of consumer and carer “tick” processes, or something of this nature, whereby services are mandated to work towards certain competencies that can be demonstrated in their philosophies, processes, staffing and resource distribution.

***Improving responding to mental health services complaints***

- 75 I think that we should think of services as ongoing projects, rather than institutionalised responses. If we think of our services as being more agile and responsive to the needs of the community, and more of an ongoing project always in development, we could ensure we have a system that is better responsive to complaints; a learning system.
- 76 An issue with complaints, it seems to me, is that there is often a different complaints system depending on the service. In some places a complaint is made internally to the service; in other places it's internal to the broader organisation, and that is confusing for people – consumers and carers. When there is an inconsistency, there is confusion because somebody doesn't know how to file a complaint. I commend the fine work of Independent Mental Health Advocacy (IMHA) in this space (<https://www.imha.vic.gov.au/>) and would look to them for advice going forward on what to change.

sign here ►



print name Melissa Petrakis

date 11/06/2020



**Royal Commission into  
Victoria's Mental Health System**



## **ATTACHMENT MP-1**

This is the attachment marked 'MP-1' referred to in the witness statement of Dr Melissa Petrakis dated 11/06/2020.

CV for Dr Melissa Petrakis *PhD, MSW (Research), BSW, BA*

Chair of the Board, Tandem Inc.

Senior Lecturer, Department of Social Work, Faculty of Medicine, Nursing and Health Sciences, Monash University

Senior Research Fellow, St Vincent's Hospital (Melbourne), Mental Health Service

## QUALIFICATIONS AND APPOINTMENTS

### Academic Qualifications

Conferral Date	AQF Level	Degree/Award Title	Discipline/Field	Awarding Organisation	Country of Award
22/08/2009	Doctoral Degree	Doctor of Philosophy	Social Work and Psychiatry	University of Melbourne	Australia
08/03/2003	Masters Degree	Master of Social Work (Research)	Social Work	University of Melbourne	Australia
04/04/1998	Bachelor Degree	Bachelor of Social Work	Social Work	University of Melbourne	Australia
20/03/1993	Bachelor Degree	Bachelor of Arts	Psychology and English majors	University of Melbourne	Australia

### Current Appointment(s) and Position(s)

Current appointment		
Year	Position	Location
2016 -	Senior Lecturer, Monash University	Caulfield
2007 -	Senior Research Fellow, St Vincent's Hospital (Melbourne), Mental Health Service	Clarendon Community Mental Health Centre, East Melbourne
2016 -	Member, Research Academic Group (RAG), Department of Psychiatry, University of Melbourne	St Vincent's Hospital (Melbourne), Mental Health Service, Fitzroy
2017 -	FMNHS Level C Promotion Committee	Clayton
2019 -	Board Member, Tandem Inc. (peak body for mental health carers) 2020 Board Chair	Abbotsford

### Previous Appointment(s) Held

Year	Position	Equivalent Level	Location
2002 – 2010 (9 years)	Sessional Subject Co-ordinator, Lecturer, Seminar Leader and Tutor	A-> B	University of Melbourne, Department of Social Work

### Professional Awards and Distinctions (since last promotion)

In 2016 - I won The Tom Trauer Evaluation and Research Award. It is a mid-career award and was given in recognition of Academic mentoring, collaboration and co-production in mental health services research. TheMHS Awards are presented annually by the TheMHS Learning Network to recognise and encourage best practice, excellence and innovation in mental health service delivery across Australia and New Zealand.

In 2019 – I won – with collaborators Liam Buckley and Carmen Raspor – the Service User and Survivor Research award for: "Co-designing and co-producing support during and following inpatient care: mental health service users and social workers working as allies", International Conference for Social Work in Health and Mental Health (ICSW2019), York, UK.

### Career Publications

## Refereed journal articles

1. Ling, D., **Petrakis, M.**, & Olver, J. (Accepted/In press). Investigating how viewing common humanity scenarios impacts compassion: A novel approach. *British Journal of Social Work*.
2. Nolan, M., & **Petrakis, M.** (2019). Delivering family psychoeducation at the mental health acute inpatient service: A practitioner narrative. *Journal of Psychiatric and Mental Health Nursing*, 26(3-4), 101-107. <https://doi.org/10.1111/jpm.12516>
3. Kilicaslan, J., & **Petrakis, M.** (2019). Heteronormative models of health-care delivery: investigating staff knowledge and confidence to meet the needs of LGBTQ+ people. *Social Work in Health Care*, 58(6), 612-632. <https://doi.org/10.1080/00981389.2019.1601651>
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7. Wills, L. A., & **Petrakis, M.** (2018). The self in motherhood: a systematised review of relational self-construal and wellbeing in mothers. *Advances in Mental Health*, [10.1080/18387357.2018.1476066].
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10. Konidaris, M. & **Petrakis, M.** (2018). Cultural humility training in mental health service provision. *New Paradigm: the journal of the Psychiatric and Disability Support Services*, 30-33. Melbourne: VICSERV.
11. Chavulak, J., Buckley, L. & **Petrakis, M.** (2018). Recovery co-design and peer workforce development in the acute inpatient setting. *New Paradigm: the journal of the Psychiatric and Disability Support Services*, 34-39. Melbourne: VICSERV.
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13. Stirling, Y., Higgins, K., & **Petrakis, M.** (2018). Challenges in implementing individual placement and support in the Australian mental health service and policy context. *Australian Health Review*, 42(1), 82-88. <https://doi.org/10.1071/AH16093>
14. Penno, S. J., Hamilton, B., & **Petrakis, M.** (2017). Early Intervention in Psychosis: Health of the Nation Outcome Scales (HoNOS) Outcomes from a Five-Year Prospective Study. *Archives of psychiatric nursing*, 31(6), 553-560. <https://doi.org/10.1016/j.apnu.2017.07.003>
15. Day, K., Starbuck, R., & **Petrakis, M.** (2017). Family group interventions in an early psychosis program: A re-evaluation of practice after 10 years of service delivery. *International Journal of Social Psychiatry*, 63(5), 433-438. (cited by 4)
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20. **Petrakis, M.** (2015). Women in the Middle: Their Parent-Care Years by Elaine M. Brody: (2003). Springer Series on Lifestyles and Issues in Aging. New York, NY: Springer Publishing, 400 pages. *Journal of women & aging*, 27(4), 355-357.
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23. **Petrakis M.**, Brophy L., Lewis J., Stylianou M., Scott M., Cocks N., Buckley L. & Halloran K. (2014). Consumer measures and research co-production: a pilot study evaluating the recovery orientation of a mental health program collaboration. *Asia Pacific Journal of Social Work and Development*, 24, 1-2, 94-108. <https://doi.org/10.1080/02185385.2014.885212> (cited by 10)
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33. Stevenson R., **Petrakis M.**, Balla, J., Cementon E., Ording-Jespersen S., Joubert L. & Barton D. (2005). Proactive care: Assertive counselling and linkage for ED suicide presentations. *Australian Journal of Psychology*, 57 (S1), 258.
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35. **Petrakis M.**, Evans S. & Swain P. (2001), 'Multimedia Innovation and the Potential for Transnational Education: What students have to say about the use of a new project developed by University of Melbourne, School of Social Work', *Traffic: An Interdisciplinary Postgraduate Journal*, vol 1, 92-102.

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38. Aadam, B., & **Petrakis, M.** (2019). Ethics, Values, and Recovery in Mental Health Social Work Practice. In *Mental Health and Social Work* Springer.
39. Castle, D. J., Lusicic, A., & **Petrakis, M.** (2018). Early intervention in psychiatry. In D. Bhugra, K. Bhui, S. Y. S. Wong, & S. E. Gilman (Eds.), *Oxford Textbook of Public Mental Health* (pp. 399-409). Oxford: Oxford University Press.  
<https://doi.org/10.1093/med/9780198792994.003.0043>
40. **Petrakis, M.**, & Sheehan, R. (2018). Social Work Practice in Mental Health Care Settings. In M. Alston, S. McCurdy, & J. McKinnon (Eds.), *Social Work: Fields of Practice* (3rd ed., pp. 149-164). Oxford UK: Oxford University Press.
41. **Petrakis, M.** & Lethborg, C. (2018). An introduction to health and health services practice, and the social determinants of health. Chapter 1 in Melissa Petrakis (Ed.) *Social Work Practice in Health: An introduction to contexts, theories and skills*. Sydney: Allen & Unwin.
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## ATTACHMENT MP-2

This is the attachment marked 'MP-2' referred to in the witness statement of Dr Melissa Petrakis dated 11/06/2020.

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