# Psychopathologisation of physical illness in the Victorian mental health system: a submission to the Royal Commission

Please note: A list of recommendations is at the end of this submission.

## This submission

I provide this submission to the commission first and foremost as a survivor of multiple diagnostic errors – in which my non-psychiatric physical health conditions were misdiagnosed as psychiatric – which led to near-fatal complications, immense life-long suffering, and a permanent physical disability. I provide this submission secondarily as an advocate who, in the aftermath of my own near-fatal experience, has spent many years examining and collating evidence about erroneous psychiatric diagnosis of non-psychiatric disorders – its causes, contributing factors, impacts, and possible solutions.

I provide this submission to give a voice to the countless Victorians (likely hundreds of thousands), who have suffered, and do suffer, as a result of becoming trapped by erroneous psychiatric diagnoses or explanations for their physical health problems ('erroneous psychopathologisation'). Especially those who have been trapped in the Victorian mental health system with non-psychiatric health conditions, or abandoned by the health system altogether, because of erroneous psychopathologisation.

It is time for the mental health system to take responsibility for the **harm caused by erroneous psychopathologisation**, to act to reduce its incidence and severity, and ensure ongoing care and support for those seriously impacted by it.

## My story – how an incorrect mental illness diagnosis permanently disabled (and nearly killed) me

As a child, I suffered from incessant, crippling pain in my lower limbs. My life was agony. When I was of primary school age, my parents were variously told by doctors that it was just 'growing pains', or I was just lazy, whiny or attention-seeking. As I entered high school, and still hadn't 'gotten over it', as my parents were told I would, my mum took me to a paediatrician. In the space of about ten minutes, without examining me, speaking to me or ordering basic tests or evaluations, he confidently concluded that I had what was then known as 'somatoform disorder' – not an organic physical problem, but a physical manifestation of psychological issues.

For the next four years, I was compelled into psychological and psychiatric treatment, including psychiatric medications, to allegedly 'fix' my pain. I was vehemently and relentlessly denied other medical assistance, including pain relief, because my treating practitioners said that it would only feed my false, delusional and anxious belief that I was physically unwell. For the same reason, adults around me were instructed not to acknowledge my suffering nor show any compassion for it, as this may feed my false beliefs and encourage attention-seeking or malingering. This approach continued unabated and essentially unexamined, even as my symptoms became worse and more complex, involving multiple body systems and symptom types. I developed a multitude of new and worsening symptoms, including episodic abdominal distension, extreme constipation, poor postural endurance, severe nose bleeds and crippling period pain.

If I admitted that I wasn't getting better, this was deemed further evidence of my denial about the 'real' psychological cause of my suffering, and the psychological and psychiatric treatment was ramped up. If I pretended I was indeed getting better, it was deemed a sign of the treatment's success – and the treatment was ramped up. It was a hopeless, lonely, torturous and inescapable cycle.

A few of times I convinced my parents to take me to other practitioners. But carrying a diagnosis of somatoform disorder, no doctor took me seriously. I didn't get better. Aged 14, 15, 16, 17, it only got worse. Dramatically worse. I had become physically disabled. Years and years of my life slipped away largely unlived, stolen by unacknowledged disability, and immense suffering. Even at that age, I knew the clinical reasoning being applied was plainly illogical, and I saw the impact of the cognitive bias (particularly confirmation bias and gender stereotyping) plain as day. I knew the practitioners were wrong. But as a child, and a child now burdened by a stigmatising, credibility-destroying psychiatric diagnosis, I was powerless to save myself.

At the end of high school, out of desperation, I seized my new adulthood and flat out refused further psychological or psychiatric treatment. But the credibility-shattering shackles of the misdiagnosis still bound me. I spent years trying to escape pre-judgement and stigma from the labels in my medical records – malingerer, doctor-shopper, hypochondriac. In the end I only escaped the oppressive stigma by dumping a lifetime's worth of health records altogether and starting from scratch. Something that was possible in a pre-electronic health records era, but would be increasingly impossible for a child who is going through something similar today.

And then, the first crack chink appeared in the shackles of misdiagnosis that bound me. In my early 20s, I was finally diagnosed with surgically-confirmed stage IV endometriosis with endometriomas and extra-pelvic lesions – the worst possible form of the disease. Then, with a small amount of vindication to back my battle to regain credibility, I started shifting the dial of diagnostic attitude. Soon, another revelation, just months later. An orthopaedic surgeon found shredded ligaments in both of my extremely hypermobile hips. Scarring upon scarring upon scarring indicated that those injuries had occurred, and recurred, such that they were essentially ever-present for years. He could not explain to me how I had sustained such severe injuries without an obvious mechanically traumatic event (such as a serious accident). I required multiple surgeries on my hips to repair and reconstruct them.

In both cases, if caught early, the worst of the damage could have been contained. But it was too late. While I languished under a cloud of psychiatric misdiagnosis – trapped in the mental health system – the endometriosis had run rampant. It had advanced all the way from my uterus to my nose, invading my organs, tissues and joints along the way. The untreated hip injuries had permanently damaged nerves. My fertility and mobility were permanently ruined, and the rest of my life destined to be marred by pain.

I now had two objectively proven medical conditions that explained two of my key symptoms. And while medical practitioners did not question the veracity of my newly identified diagnoses or their symptoms, they remained openly doubtful about the symptoms that had not yet been explained. The general view was that maybe I was just a person with psychologically-derived physical symptoms who also just happened to have a few 'real' physical problems. I struggled along, without access to appropriate care, as the physical health system rejected me, and the mental health system remained a wholly inappropriate, unhelpful and indeed dangerous place for me.

And so it remained, as my condition deteriorated and level of disability increased, until I was nearly 30. In the lead-up to that day, I had been increasingly unwell. During that time, I consulted with a GP five times. He suggested a few actions on my part, but nothing worked. The prevailing theory was that grief over a recent death in the family was to blame. The old psychosomatic theory beast, which had never truly left me, had come back for another bite. After more than two weeks of this exacerbation, my abdomen swelled to an almost inconceivable size in the space of a few minutes, with acute pain and vomiting. I was certain my life was in danger.

I called triple zero for an ambulance. The call taker denied my situation was an emergency, concluding that I was over-reacting to "wind pain" and needed to "calm down". He refused to send an emergency ambulance. I made my own way to hospital. But there too, the nurse at the triage desk, then a series of doctors, told me 'constipation' is not an emergency and I should "calm down", go home and "try doing something relaxing". Spotting the red flags of misdiagnosis after a lifetime of experience, I refused.

I was abandoned in a back room, and neglected for 18 hours. I was given only oral paracetamol (which I promptly vomited straight back up) as I lay there, slowly dying from a rare and exceptionally deadly form of bowel obstruction. Once again, I had to fight tooth and nail against totally unfounded reactive psychopathologisation, by people who had barely met me, to save myself. By the time the obstruction was diagnosed, after an exhausting battle of wills, I was more likely to die than to survive. I required multiple emergency surgeries and blood transfusions to save my life, and lost a third of my bowel. I had lived under the crushing burden of psychopathologising misdiagnosis, and I came terrifyingly close to dying under it too.

That bowel obstruction was a late-stage complication of an incurable and disabling genetic connective tissue disorder. Finally, forced to go to the edge of death and back to prove the legitimacy of my physical condition, I was diagnosed. My genetic condition explains every symptom that was left to explain, from the moment I was born into a life of pain. It also explained my hip injuries. But once again, the diagnosis came too late to prevent the development of significant disability and lifelong pain and suffering.

I endured a marathon of needless suffering at the hands of the mental health system and its influence on diagnostic culture. Even though I have now been definitively diagnosed, the oppressive burden of psychopathologisation still wreaks havoc on my life and health care. Staggeringly, over 98% of people with my genetic condition have their symptoms attributed to psychiatric or psychological causes, typically for many years, before they are accurately diagnosed. Most are directed towards futile treatments for their imagined mental health condition. In Australia, the average delay in diagnosis of my condition, shockingly, is 29 years. And this is just the figure for the fortunate few who are eventually diagnosed – it is widely believed that many never are. Twenty-nine years of being tormented and tortured, physically and psychologically, by something you can't identify and can't explain, while those who are supposed to help tell you it isn't real. Twenty-nine years isn't a mere diagnostic delay - it's a third of a lifetime. And for me, it was nearly an entire lifetime.

## What is erroneous psychopathologisation (ErP)?

Erroneous psychopathologisation (hereafter 'ErP') is a common form of diagnostic error or clinical reasoning error. It occurs **when any of the signs and symptoms of a person's non-psychiatric, physical health condition are incorrectly attributed to psychological or psychiatric causes**. It is distinct from over-zealous psychopathologisation, in which reasonable emotional and psychological responses to one's circumstances, and non-pathological variations in human behaviour, cognition and personality, are unduly and excessively pathologised. While distinct, the two phenomena are both significant problems, and share many contributing factors. ErP takes on four main forms, described in Box 1. This submission focuses on ErP types 1-3. However, the fourth form is a related and equally important problem that may contribute to poorer physical health and lower life expectancy in people diagnosed with mental illness.

### Box 1: Main types of ErP

1. **Formal ErP** – in which a person is erroneously **given a formal psychiatric diagnosis** in order to explain the signs and symptoms of a non-psychiatric physical illness. This may be either a specific psychopathologising diagnosis (e.g. 'somatic symptom disorder' or 'conversion disorder'), or a more general psychiatric diagnosis (e.g. generalised anxiety disorder, major depressive disorder).
2. **Informal ErP** – in which a person's symptoms are **dismissed, minimised or explained away** as being caused, exacerbated, exaggerated or fabricated by their perceived psychological state, without a formal psychiatric diagnosis being delivered (e.g. symptoms being blamed on 'stress', 'attention-seeking', 'loneliness', 'over-reacting', or 'worry'). This psychological explanation may be shared with the person, or may simply influence the practitioner's decision-making and reasoning (consciously or unconsciously), without being overtly discussed.
3. **Substitutional ErP** – in which a person's symptoms are **given a diagnostic-sounding label** that sounds more like a physical condition, but is essentially void of scientific substance or validity (i.e. it does not correspond to an organic explanation), and serves as cynical place-holder for medical uncertainty or suspicion of psychiatric causes (e.g. 'functional neurological disorder').
4. **Secondary ErP** – in which a person has a well-founded diagnosis of a psychiatric disorder, but also has or develops unrelated symptoms or signs of a secondary, non-psychiatric, physical condition, and these **symptoms or signs are erroneously attributed to the already diagnosed psychiatric disorder**.

## ErP is an entrenched cultural problem

ErP is an ancient problem. It has evolved from its early spiritual and religious forms (e.g. notions of demon possession and bad spirits) to early medical models (e.g. hysteria) to modern codified versions (e.g. formal diagnosis with set criteria). While the modern form adopts a more scientific-looking guise, there remains little if any evidence to support the veracity of psychosomatic diagnoses. These diagnoses are little more than a dressed-up, modern-day version of hysteria – a false diagnosis which brought oppression, imprisonment, suffering and death to generations of women. While associated diagnoses are now officially not gender-specific, a large body of research evidence consistently shows that **ErP is disproportionately levelled against women and girls**.

At its heart, ErP arises from **destructive cultural forces in healthcare**. These include discrimination and **stereotyping, paternalism, victim-blaming**. It also includes a pervasive culture in medicine that prefers to avoid the discomfort of displaying and confronting the uncertainties and limitations of the profession and individual practitioners, by deflecting blame, and discrediting, stereotyping and invalidating patients who expose these limitations. In this medical culture, many practitioners choose to deliver a credibility-shattering and potentially life-destroying incorrect diagnosis, or outright dismiss a patient's request for help, **rather than say "I don't know"**. In addition, it is a culture where access to help and support hinges on the golden key of 'the diagnosis', rather than accepting that sometimes, people can and should be supported to manage their symptoms, signs and experiences in the absence of a definitive diagnosis. A culture that is uncomfortable with saying 'I don't know the answer, but here is how I think I can help you regardless'.

## ErP arises from false premises that must be challenged

Delivering a psychopathologising diagnosis or explanation is the practical enactment of the problematic culture described above. It represents a practitioner's conclusion that **'if I can't identify something physically wrong with the patient, there is, by definition, nothing physically wrong with the patient'**. Examining the diagnostic criteria for various psychopathologising conditions confirms that this is indeed the clinical logic invoked. Drawing such a conclusion logically requires the simultaneous truth of three core premises:

1. Modern medical science globally has discovered, documented and accurately explained all forms of all human pathology, and that there are no remaining unknowns or undiscovered conditions or variations.

2. Modern medical science provides the means to detect all possible human pathologies objectively, in all cases, with complete accuracy.

3. The practitioner (or the group of practitioners) who have examined/treated the individual are (solely or collectively) completely knowledgeable about the entire global body of medical knowledge described above, and can accurately and reliably recognise, detect and diagnose all forms of all human pathology in all cases.

Of course, none of these three premises is even independently true. Much less are they all simultaneously true. Time and time again, **new scientific discoveries** remind us of this, as new conditions are discovered, or old ones better explained. Two modern examples are:

1. The discovery that bacteria, not psychological stress, is the main cause of peptic ulcers (discovered in 1987, not widely accepted by the medical community until 1997).
2. The discovery of Loeys-Dietz Syndrome (a genetic connective tissue disorder) in 2005, which liberated many patients from the previous insistence by practitioners that their complex and life-threatening symptoms were psychological in origin.

In both cases, and countless others, new evidence uncovered countless people whose physical symptoms had been dismissed as psychosomatic, who were finally given the correct physical explanation for their condition. And yet, the mental health system continues to deliver, uphold and validate the brazen and definitive psychopathologisation of physical symptoms, **leaving no room to acknowledge medical uncertainty**.

## ErP can happen to anybody, but the risk is inequitably distributed

I have spent many years observing and collating research and patient stories about ErP. What is clear is that it can happen to anybody with almost any condition – from minor to serious, short-term to long term, acutely life-threatening or chronic. It can happen in the case of rare conditions, not rare but rarely-diagnosed conditions, as well as very common conditions. Thus, this is not a niche or minor issue. Strikingly, if the informal form of ErP is taken into account, evidence on medical error rates suggests **ErP is likely to happen to almost everybody at least once in their lifetime**. This is a problem that needs urgent attention

My genetic condition is not alone in exhibiting stubbornly high rates of ErP and associated long diagnostic delays. Consider, for example that endometriosis is very common (affecting approximately 10% of women), but ErP in cases of endometriosis remains very common. There do appear to be some conditions and circumstances in which ErP. Some of these reflect **cognitive biases and problems in the way clinical reasoning is taught, assessed and applied**. Others reflect broader examples of **social stereotyping and prejudice**, including sexism, that are reflected in broader society. Examples of condition type factors and patient factors that appear to be associated with increased risk pf ErP are included in Table 1.

Table 1: Condition type and patient risk factors for ErP

| Condition type factors | Example(s) | | Patient factors |
|---|---|---|---|
| Rare condition | Porphyria | | Female |
| Rarely-diagnosed conditions (poor diagnosis rate) | Ehlers-Danlos Syndrome | | Age uncommon for actual condition |
| Neurological symptoms that mimic psychiatric disorders | Wilson's disease, anti-NMDA receptor encephalitis | | Sex/gender uncommon for condition |
| Non-neurological symptoms that mimic listed symptoms of psychiatric disorder(s) | Hypothyroidism | | Existing or historical diagnosis or suggestion (accurate or not) of mental illness, substance misuse or psychosocial problems |
| Predominantly characterised by symptoms rather than signs, or signs that are subtle or little-recognised | Post-herpatic neuralgia | | Viewed as 'difficult', 'uncooperative' or 'non-compliant' |
| Not evident on standard first-line pathology and imaging (or only evident with surgical exploration) | Endometriosis | | Experienced recent or historical stressful or traumatic event |
| Pain, fatigue or weakness are prominent symptoms | Addison's disease | | Unusual combination of conditions |
| Occur only or mostly in females | Adenomyosis | | Multiple co-morbidities |
| Feature symptoms that are severe pathological versions of experiences that, in a minor form, are common | Narcolepsy | | Has looked up own concerns or condition |

## The extent of ErP is largely hidden and unknown

The suffering, disability and death caused by ErP is likely enormous and incalculable. Yet it is an **un-examined problem**, which is widely ignored, buried, denied and minimised. While research on diagnostic error is common, particularly outside Australia, research on psychopathologisation as a specific type of diagnostic error is limited.

The great challenge of ErP is that its **impacts are likely widely underestimated** because, by its very nature, the majority of people currently experiencing it do not know that they are. Or they know or suspect that they are, but are unable to prove it. Many will never know, or will never prove it. And many will die as a result – either directly as a result of their organic condition, or as the result of desperate behaviours like self-harm and self-medication.

Sadly, the fact that ErP occurred in such cases is never documented, as their deaths by self-harm or other behavioural means only reinforce their psychiatric labels.

The degree to which cases are likely to be detected is influence by multiple factors, including duration (shorter timeframes = more detectable), degree to which psychiatric theories are honestly shared with the patient (more overt = more detectable), outcome severity (more severe = more detectable) and proximity of the correct diagnosis to the ErP event (closer proximity = more detectable).

For example, the most obvious cases are those which are **acute emergencies that end catastrophically**. For example, a woman who presents to an emergency department with breathlessness, is specifically told that her breathlessness is the result of an 'anxiety attack', is given a sedative, and subsequently dies of a pulmonary embolism. Deaths resulting from psychopathologisation in emergency situations are not uncommon. Examples include respiratory or cardiac problems mistaken for panic attacks or anxiety (especially common in women, whose heart attack symptoms are often different from men's) and pain from acute abdominal emergencies mistaken for stress, delusions, malingering or drug-seeking. There is some chance these cases **may be detected and recorded as adverse events**, as they typically occur within one health service in a compressed timeframe. However, the psychopathologising element of the error is rarely accurately reflected in the record of the event.

These errors in emergency scenarios are important, but are not the main burden of harm. **The greatest burden of harm is borne of the protracted cases** – where the misdiagnosis lasts weeks, months, years, decades, or even an entire lifetime. These are common and devastating. However, they are **rarely detected, or studied for the purposes of learning lessons and improving the system**. This is due, in part, to their drawn-out nature, involving multiple services and practitioners with little vicinity between these erroneous clinical judgements, their eventual consequences, and the discovery of the true diagnosis. Due to the passage of time and the patient journey through multiple practitioners and services, the practitioner(s) who made the original error are typically not those present in the patient's life when the true diagnosis is finally discovered. This creates diffusion of responsibility, difficulty in proving causation, and escape from accountability which reduce the impetus for health services to investigate, and the ability of patients and families to understand and expose what happened.

## The impact of ErP is often devastating, multi-faceted and life-long

ErP can have **severe repercussions** for the affected person – with the most obvious being death, reduced lifespan, disability, disfigurement and major physical harm. All of which were often preventable if the incorrect diagnosis was not made.

Like me, people subjected to ErP can find themselves in an inescapable, nightmarish and self-fulling cycle, which can result in severe psychological suffering and distress. The experience of **hopelessness and despair** during the misdiagnosis event, and the subsequent suffering and disability, can itself lead to **suicide**. For example, **up to 1 in 4 people with my genetic condition attempt suicide before the age of 25**, almost always due directly to the desperation, helplessness and unmitigated suffering while experiencing ErP, and not yet being accurately diagnosed. The proportion who die by suicide cannot be determined, as they likely almost always die by suicide without being correctly diagnosed.

The consequences of ErP can be devastating and life-long, and **touch every aspect of a person's life**. The harms caused by ErP are not limited to the period of its occurrence. They include the common impacts of disability or chronic illness more generally – such as reduced quality of life, reduced work capacity, reduced functioning, financial loses and social isolation. But the backdrop of diagnostic error, and mental illness stigma, adds additional complex layers. These include:

1. Deep psychological trauma.
2. Reduced trust in (and use of) health services.
3. Poor quality care due to stigma and loss of credibility.
4. Loss of treatment windows and opportunities.
5. Extra healthcare costs.
6. Adverse effects of unnecessary and inappropriate treatments.
7. Breakdown of relationships (including with those who doubted them).

Furthermore, getting a correct diagnosis doesn't instantly clean up the mess from the diagnostic error that came before. It is often **a burden for life**. A misdiagnosis in a clinical record, even a moment of editorial commentary as simple as 'query psychological cause?' can come back to bite patients again and again for a lifetime. As discussed below, electronic records will only make this problem worse.

Our social structures are set up to treat the magical 'diagnosis' as a golden key to support, and even basic social legitimacy. If you have an old misdiagnosis, or even a bit of diagnostic editorial, on your record, that key can become misshapen forever. For example, people who have survived ErP who apply for insurance (travel, life, income protection, disability), or who are asked to do a pre-employment medical check, are faced with questions that read 'Have you ever been diagnosed with, or received treatment for, a mental health condition'. They have to answer yes, even though the diagnosis was wrong, and face exclusions, higher premiums or outright rejection as a result.

In another example, if people who have experienced ErP later apply for illness or disability-related welfare payments or support services, or lodge worker's compensation or traffic accident claims, their experience of ErP is often used against them. **The stigmatising stain of a psychiatric diagnosis, even if false, is always there as a weapon with which to discredit** them. Even those with physical disabilities backed by iron-clad, objectively proven non-psychiatric diagnosis have had support denied due to the legacy of ErP. The grounds given are that while they have a physical health condition/disability, there is 'evidence' their belief that they require support is the result of their (psychologically-derived) failure to 'cope' with their condition.

## ErP has substantial negative impacts on the mental health system, broader health system and community

ErP takes people away from the system that should and can help them, and places them into a system that can't help them. This results in a large **waste of mental health sector resources** in the form of misguided, inappropriate and ultimately futile treatments. It also wastes physical health sector resources by **increasing the future costs to the wider health system** due to the deterioration in the person's physical condition while they languish in inappropriate mental health care.

The community and the healthcare system both bear the costs of mental health care resources being unnecessarily tied up treating people for whom they are not needed, and will not work. These resources, beds, practitioner time, places in programs etc are much better used for, and are desperately needed by, people with actual mental health concerns and conditions. Reducing ErP is not only a **moral imperative**, and a **human rights issue**, but is **economically and social responsible** – as it will free up resources for those who really need them.

The **community also bears the costs** of lost productivity, preventable need for welfare and support services (e.g. income support, disability services), increased private health insurance premiums (due to burgeoning costs of futile treatments), and the general costs associated with preventable disadvantage experienced by affected people (e.g. crime, poverty and homelessness).

## ErP is the unspoken contributing factor in some of healthcare's wicked problems

There are many examples where failure to recognise and address the impacts of ErP is a **roadblock to progress** against stubborn problems in healthcare. For example, there has been much handwringing over how 'the system' failed for so long to detect and respond to the growing crisis of harm for patients implanted with vaginal mesh. Yet, in all of public discussion, not enough has been made of the failure of individual practitioners to take women seriously, heed their concerns, and act upon them. These women were dismissed as neurotic, over-sensitive, anxious, feeble, squeamish, delusion and lacking in coping skills. In this instance and many others, the **psychopathologisation of women in physical pain** – one the most widely studied, persistent and well-documented examples of ErP – contributed to a massive and devastating personal and public health disaster. Addressing ErP is a public health necessity if we are to **improve systems for detecting and rectifying such systemic problems** in healthcare.

In another example, rates of stillbirth have remained stubbornly unchanged, and this has been the subject of much public discussion in recent times. However, a persistent factor in many stillbirths – health practitioner's **failure to**

**listen to women, take them seriously and heed their concerns** – is an under-acknowledged factor, and a sexist form of informal ErP. The role of the stereotypes of the 'hysterical woman', the 'anxious mother', and the 'over-reacting female neurotic' in these tragedies must not be underestimated. And yet it is. Public health campaigns, including Victoria's most recent 'Movement's matter' campaign, placed the burden of responsibility back on women to 'speak up' for their babies, rather than reinforcing **the duty of practitioners to listen** to women.

## Public health programs and attitude engineering have increased the risk of ErP

In the past twenty years or so, in Victoria and around Australia, mental illness and mental health narratives have become more widespread and mainstream. While the increased awareness has brought many benefits, it has also had some unintended and harmful consequences – including **increasing the risk of both overzealous and erroneous psychopathologisation**.

Increasing normalisation and mainstreaming of mental illness as a narrative in people's lives, and as an acceptable and legitimate explanation for distressing sensations, has further **emboldened practitioners towards a habit of defaulting to mental illness in the face of diagnostic uncertainty**. They often do this in the belief that such explanations are now more acceptable and relatable for patients than they may previously have been. A mental illness diagnosis – due to the impact of public health campaigns on awareness of mental illness language and concepts – can now be delivered quickly and easily, with minimal explanation or patient education required. It also allows the patient to be sent away with 'paper in hand' (e.g. a prescription, mental health plan, and mental health care referral), so they feel satisfied that something has been done. The practitioner then also has a legitimate reason to largely wash their hands of the patient, so they need not confront the discomfort of diagnostic uncertainty.

**Patients are also increasingly hesitant to question a mental illness explanation** for their symptoms, lest it be viewed as unacceptable and stigma-promoting to recoil at the notion that one has a mental illness. This also decreases their willingness to talk through their concerns about the diagnosis with family or friends. This is because **questioning the legitimacy of mental health diagnoses can provoke negative backlash** – sometimes quite vicious and uncompromising – from those who see it as 'stigma-promoting', 'ignorant' and 'unenlightened'. Therefore, public health campaigns and awareness-raising around mental illness have actually put Victorians at increased risk of experiencing ErP, with **no public acknowledgment of the extent of this risk, and no specific plan to mitigate it**.

## Electronic health records increase the risk ErP scenario will become inescapable

The rise of electronic health records, including but not limited to My Health Record, will further exacerbate the problem. The ability to escape erroneous labels and diagnoses, and adverse psychopathologising commentary on one's health records, was **one of the last remaining defences against the long shadow of ErP**. If exercised carefully, the ability to leave behind unfavourable and falsehood-riddled records and start fresh with a new service or practitioner allowed **untainted second (and subsequent) opinions**. This lifeline could help pull a person out of the ErP cycle. It also allowed people who finally received their correct diagnosis, at least to an extent, to ditch the stigmatising and prejudicial records of their past, and start fresh. This **vital and even-lifesaving right to a fresh start will soon be lost** as multi-service electronic health records ensure that the influential shadow of our health records – no matter how flawed and inaccurate their contents – will follow us for life.

Whether records are electronic or not, current legislation largely fails to provide patients with an **enforceable right to have errors and untruths in their records corrected**, where these errors are clinical in nature (as opposed, for example, to an error in their date of birth or phone number). Privacy legislation in theory affords Victorians the right to records held about them by organisation and service providers corrected in the case of errors and inaccuracies. However, these provisions either do not apply to clinical errors in medical records, or do apply, but health services insist they do not, and refuse to cooperate. There is no reason that such errors should be quarantined from correction or deletion, and **maintaining this status quo is not in the public interest**.

## ErP of people with persistent physical pain is an unfolding public health crisis

ErP is also contributing to a crisis in the management of people with persistent and chronic pain. This serves as a worthwhile detailed study in the way that **ErP can be so pervasive as to influence national policy**. As demonstrated by the **federal government's recent 'National Strategic Action Plan for Pain Management'**, the psychosocial model of chronic pain – which has its roots in ErP – is increasingly dominating approaches to chronic pain in Australia.

The federal government's plan aims to further bolster the dominance of this model – which is built around a central psychopathologising theory. Overall, the **psychosocial model of chronic pain adopts a very narrow view of persistent pain**, based on the model of injury-acquired chronic pain. This stereotypical chronic pain scenario is seen when a person who previously lived a pain-free life experiences a painful injury (such as a back injury at work). They then descend into a vicious cycle of largely psychologically-driven pain anxiety, movement hesitation, fear of further injury, inactivity and protective behaviours that cascade to cause ongoing pain sensations, long after the original injury is healed. The follow-on theory is that these patients need psychological and physical therapy interventions in order to overcome their anxieties, begin to move freely again, and return to their previously normal lives and activities. This approach will be a boon for providers of mental health services.

The effectiveness of this psychosocial approach in the narrow-scoped injury-acquired pain scenarios for which it was designed is questionable in itself, with the evidence upon which it is based being of poor quality, questionable relevance, and arising from poor methodologies (although an exploration of that issue is beyond the scope of this submission). However, it is clear that the dominance of the psychosocial model of pain management, based on the injury-acquired model of chronic pain, is **a disaster for people who have persistent pain of other types**, and from other causes. There are multiple means by which a person will end up experiencing chronic pain, only one of which is the injury-acquired version assumed by the psychosocial model. Some examples are outlined in Box 2, with type 1 corresponding to the model almost universally assumed by the psychosocial approach to pain management. The psychosocial approach is at especially high-risk of trapping people with chronic pain of types 2, 3, 4 and 5 (especially type 5) in a **cycle of ineffective, unsafe and inappropriate psychology-based treatments**. It risks denying them access to diagnosis and treatment better suited to their underlying condition.

### Box 2: Main types of chronic pain by cause type

1. **Acquired pain from healed injury** – when a previously pain-free person experiences a discreet mechanical injury, the tissue damage of the injury heals completely, but they continue to experience pain (e.g. lower back pain after a lifting injury).
2. **Acquired pain from unhealed injury** - when a previously pain-free person experiences a discreet mechanical injury, and the tissue damage of the injury does not heal completely, and they continue to experience pain (e.g. phantom pain after a limb amputation, chronic wounds).
3. **Acquired pain from transient illness** – when a previously pain-free person experiences a discreet episode of illness, and the primary disease processes of the illness resolve, but ongoing effects of the illness cause pain (e.g. postherpetic neuralgia)
4. **Acquired pain from chronic illness** – when a previously pain-free person develops a chronic pain-causing illness that cannot be cured, and the illness causes ongoing pain as a result of disease processes (e.g. rheumatoid arthritis).
5. **Innate pain from congenital causes** – when a person experiences life-long pain (i.e. has never been ongoingly pain-free) as a result of an illness, injury or physiological or anatomical difference present from birth (e.g. Ehlers-Danlos Syndrome, contractures in cerebral palsy).

A key problem with the psychosocial approach is that it lumps together chronic pain types 1-5, and treats them all as though they are the same. In turn, this has resulted in **'chronic pain' morphing away from being a symptom, to being considered a (pseudo-)diagnosis in its own right**. And once 'chronic pain' is treated as though it is a diagnosis in itself, the temptation to **skip any efforts to seek out and diagnose the underlying cause**, and instead skip straight to treating the pain only, is strong. This creates the **perfect conditions for ErP**.

The consequence of this problem are seen, for example, in the countless women with undiagnosed endometriosis being referred straight to expensive, time-consuming and ultimately ineffective chronic pain programs for their ‘diagnosis’ of ‘chronic pelvic pain’. For these women, these programs are of minimal value when proper investigation and diagnosis of the underlying cause of their pain may have seen their pain treated, and possibly eliminated, at the cause (for example through hormonal menstrual suppression). For these women, the healthcare system funnels them into a process that **tries to teach them to ‘live with’ their pain through psychological interventions, rather than just treating the pain’s true cause**.

The rise of the psychosocial model of pain, now being aggressively promoted by the federal government, risks pushing **whole generations of people into inappropriate psychiatric and psychological treatments for their physical conditions**. This is an alarming development, and needs to be mitigated with a more nuanced understanding of the breadth of causes and mechanisms of pain, and immediate action to bring the wider problem od ErP into the spotlight.

## Recommendations

1. Fund, support and carry out **research** into ErP – including its causes and contributing factors, conditions most commonly misdiagnosed, and the incorrect psychiatric diagnoses most commonly given.
2. As part of the above research, establish a **public reporting mechanism** for cases of ErP, to collect data on the true nature and extent of the phenomenon, as reported by patients and community members themselves.
3. Publish and promote the results of the above research, and use these to **inform** public health campaigns and practitioner education.
4. Using the above research, publish a **list of most commonly missed physical diagnoses** in cases of ErP, to empower patients and practitioners to critically examine and re-examine psychosomatic diagnoses and explanations for physical symptoms.
5. Develop and resource a **multi-disciplinary support program** for patients who have experienced confirmed cases of ErP, to ensure access to appropriate, stigma-free care and support to get them back on track.
6. Lobby for the creation of **diagnostic medicine as a specific, recognised medical specialty** in Australia. In the meantime, lobby for and support the creation of **training programs** in high-level diagnostics for medical practitioners with a special interest in difficult and complex diagnostic problems.
7. Fund, support and create specialised **multi-disciplinary diagnostic clinics and services** in Victoria public and private settings, specifically for those struggling to get a diagnosis for their condition, or whose proposed or current diagnosis is questionable. Allow patients to self-refer to these services, in order to maintain access for those who may be trapped in an ErP situation, and thus cannot secure a referral from a medical practitioner.
8. Mandate the opportunity for **regular physical health screening for patients diagnosed with mental illness** who are under the care of a mental health service, by practitioners with extra, intensive training in ErP, cognitive bias, and diagnostic error. Promote such screening for patients diagnosed with mental illness who are not under the care of a mental health service.
9. Clarify, strengthen and better enforce **privacy and health records legislation** to allow patients to have clinical inaccuracies and errors in their health records corrected or removed, with a certified copy of the original erroneous record provided to them in case it is needed later for legal or other purposes.
10. Advocate to the federal government for the right of patients to have selected **inaccurate health records permanently deleted** from My Health Record, rather than just ‘hidden’, to avoid their re-emergence in later legal or administrative proceedings.
11. **Critically review** the federal government’s ‘National Strategic Action Plan for Pain Management’ with a view to its sweeping adoption of psychosomatic and psychosocial theories of pain that ignore the diversity of persistent pain causes and mechanisms. Lobby for change, and alter or resist implementation of the

model where necessary to protect Victorian patients from ErP, medical neglect, and inappropriate treatment modalities.

12. Ensure that all government programs, entities and initiatives **consider existing research** on cognitive bias in medicine, diagnostic error and ErP, and require appropriate mitigation measures for health services and programs to received accreditation, funding and support from government.
13. Work with entities such as Safer Care Victoria, Victorian Agency for Health Information, Office of the Chief Psychiatrist, Australian Health Practitioner Regulation Agency, Health Complaints Commissioner and Mental Health Complaints Commissioner to ensure that **healthcare quality and safety monitoring** (for example the Sentinel Event Program) includes, tracks, analyses, and acts to prevent instances of ErP.
14. Establish a voluntary ‘diagnosis passport’ program for individuals who wish to have official, easy-to-carry proof of a medical diagnosis (for example a rare diagnosis or poorly understood diagnosis), and basic care information, where they may be at risk of ErP or other medical error.