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# **Recognising Signs of Deterioration in a Person's Mental State**

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## Preface

The Australian Commission on Safety and Quality in Health Care (the Commission) leads and coordinates national improvements in the safety and quality of health care based on best available evidence. In 2017 the Commission developed the *National Consensus Statement: Essential elements on recognising and responding to deterioration in a person's mental state* (the Consensus Statement). This is an adaptation of the successful approach to physiological deterioration outlined in the *National Consensus Statement: Essential elements for recognising and responding to clinical deterioration*. The Consensus Statement will support health service organisations in the implementation of the National Safety and Quality Health Service (NSQHS) Standards (second edition).

The Consensus Statement is built on the process of recognising the signs of deterioration in a person's mental state, being able to track these in a dynamic fashion and communicate changes in shared language, in order to initiate an effective therapeutic response. Recognition relies on combining clinical observations with the person's own self-report, corroborated by information from other key people, including families and carers. These skills form an integral part of mental health workers' current practice, but they have not been formalised into standardised processes that support consistent effective response across the health system.

Part of the success of the recognition and response approach to physiological deterioration is use of standardised observation charts for physical observations, which include agreed parameters for the escalation of care in a stepwise manner. The standardised elements of the process are designed to support, not replace clinical judgement. The signs of deterioration in a person's mental state are not measureable in a comparable manner to physical observations. Nonetheless, the Commission considers a systematic approach to monitoring change in a person's mental state will support shared decision making to prevent further deterioration and prevent adverse events.

In a 2014 study conducted for the Commission, *Recognising and responding to deterioration in mental state: A scoping review*,<sup>\*</sup> the authors identified that there was no tool currently used in clinical practice to monitor changes in a person's mental state. This finding was echoed in national consultation on the Consensus Statement in 2017.

There are existing tools that describe signs that indicate alterations in a person's mental state, and use these for different purposes. These include tools to support comprehensive assessment of a person's mental state for the purpose of diagnosis (the mental state examination), or to make triage decisions (the Mental Health Triage Tool). There are tools to support prediction of particular outcomes (HCR 20, Broset for prediction of violence). There are tools to systematically monitor changes in aspects of a person's mental state, including self-reported mood (the DI5) and agitation (agitation scales). However none of these tools is currently adapted for the purpose of monitoring deterioration in a person's overall mental state.

The Commission identified that the first step in the current process was the need to develop consensus on a set of signs specifically for the purpose of monitoring deterioration in a person's mental state. The Commission engaged Gaskin Research to undertake the project.

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<sup>\*</sup> Craze L, McGeorge P, Holmes D, Bernardi S, Taylor P, Morris-Yates A, et al. *Recognising and Responding to Deterioration in Mental State: A Scoping Review*. Sydney: ACSQHC; 2014.

They conducted the review in several phases:

- An updated literature review
- A series of interviews with stakeholders (consumers, carers and clinicians) to generate a list of signs indicating deterioration in a person's mental state
- A set of sequential surveys (Delphi process) to build consensus on the signs
- Two workshops to organise the signs into a set of provisional indicators.

The following report outlines each of these processes and findings in detail.

## Key findings

The authors report that there is consensus among consumers, carers and clinicians that effectively monitoring changes in a person's mental state requires use of multiple sources of information, monitoring of multiple signs, and the need for multiple assessments over time. It was noted that clinicians were frequently in situations where it was not possible to determine what a person's baseline mental state was, and therefore, if a particular sign indicated deterioration or not. The updated literature review confirms that there is not currently a standardised process for monitoring changes in a person's mental state. The authors identified promising developments, and identified common signs used in existing tools developed for other purposes.

The literature review and interviews generated 168 signs that can indicate deterioration in a person's mental state. These were initially grouped into 38 clusters of signs, reflecting similarities and reducing duplications. Subsequently, based on the completed Delphi process, the authors propose an approach in which 28 clusters of signs are arranged into five indicators of deterioration in a person's mental state:

- Reported change
- Distress
- Loss of touch with reality or consequence of behaviours
- Loss of function
- Elevated risk to self, others or property.

These five indicators provide an overarching framework for arranging the agreed signs for the purpose of monitoring deterioration in a person's mental state. The approach emphasises the importance of the person's self-report and input from families and carers.

## Recommendations of the report

The authors of the report recommend that the Commission undertake a national consultation on the proposed indicators of deterioration in a person's mental state to determine:

- Whether the indicators are sufficiently sensitive to enable identification of early deterioration
- The validity of the indicators for diverse populations
- How baseline information about a person's mental state can be most effectively gathered and communicated.

The authors also recommend that further work be undertaken to determine how the indicators can be translated into practice.

## Next steps for the Commission

The Commission will consider the report's recommendations in ongoing consultation with key stakeholders. The Commission will use the findings from the report to inform current and future work on recognising and responding to deterioration in a person's mental state.

The authors have used a robust method to develop consensus on the set of signs and provided a provisional structure for monitoring deterioration in a person's mental state. The Commission will seek to develop partnerships with researchers to test the validity of the proposed indicators. The Commission will also undertake work with health service partners to test the alignment of the proposed indicators with existing systems.

The aim of this work is that in the future all health sectors will have systematic processes for routinely monitoring, documenting, communicating and responding to deterioration in a person's mental state, and that clinicians, consumers and carers will feel confident in using these processes. The Commission will continue to partner with stakeholders to advance this aim.





# **Recognising Signs of Deterioration in a Person's Mental State**

## **Final Report**

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**December 2017**

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## Executive Summary

The purpose of this report is to present the findings from the project *Recognising Signs of Deterioration in a Person's Mental State*. This project involved undertaking:

- an updated review of peer-reviewed and grey literature on mental state deterioration published since the completion of *Recognising and Responding to Deterioration in Mental State: A Scoping Review*;
- a collaborative process involving clinicians and people with lived experience of mental state deterioration (consumers and carers) to build consensus on an agreed set of signs of deterioration in a person's mental state; and
- workshops with an advisory committee of clinicians and people with lived experience on the form of the set of signs and potential practice implementation issues.

Findings from the updated review and collaborative consensus-building process, as well as feedback from the workshops, contributed to the development of clusters of signs and indicators of mental state deterioration.

### Updated Literature Review

The Updated Literature Review incorporates research published from July 2013 to May 2017. The purpose of this update was to identify recently-published literature on instruments that had been developed for identifying and tracking signs of deterioration in a person's mental state. Using the same search strategy as in the Scoping Review, we identified 13 papers that met the selection criteria. In these papers, research was reported on six instruments: mental state examination scale (MSES), Five-Item Daily Symptom Index (DI-5), Dynamic Appraisal of Situational Aggression (DASA), Brøset Violence Checklist (BVC), Imminent Risk Rating Scale (IRRS), and Life-Death Implicit Association Test (IAT). Of these instruments, the MSES provides the most complete coverage of mental states, having been based on the mental state examination. The MSES is early in development, with an initial feasibility study showing that it can be used to detect change in a person's mental state when administered several days apart. The other five instruments were designed for the assessment of psychological distress (DI-5), risk of aggression and violence (DASA, BVC, and IRRS), and suicidality (IAT).

The review highlighted several themes in the literature regarding the value of:

- using individualised assessment approaches,
- measuring constructs (such as deterioration) using sets of behaviours rather than single behaviours,
- conducting multiple assessments over time versus one-off assessments, and
- obtaining information from multiple sources (for example, clinicians, consumers, and carers).

## Generation of Signs of Mental State Deterioration

In a collaborative consensus-building process, 19 clinicians and 23 people with lived experience were interviewed and participated in three rounds of surveys. The interviews, in conjunction with the findings from the review of literature, yielded 168 signs of deterioration in a person's mental state, which we synthesised into 38 clusters of signs. When rated with respect to what response may be required, 11 clusters of signs received *act* (to obtain immediate additional care) responses, 26 received *investigate* (to determine whether additional care may be required) responses, and the remaining cluster received a *monitor* (the changes) response. Clusters receiving *act* responses related to safety, psychosis, and engaging in, and responding to, care. Modest agreement between participant ratings was achieved, which may be attributable to the broad range of factors that influence whether particular behaviours represent signs of deterioration (such as the presence of other signs).

Given that a large number of clusters of signs may be challenging to use in practice, we sought ways of grouping the clusters. We found that the 38 clusters could be consolidated into five indicators of deterioration:

- (1) reported change;
- (2) distress;
- (3) loss of touch with reality or consequences of behaviours;
- (4) loss of function;
- (5) elevated risk to self, others or property.

Aside from the signs of deterioration, two themes that emerged strongly during the interviews were the need for clear baseline information for identifying change and the insufficient weight typically given to consumer and carer reports within healthcare settings. Baseline information is essential for identifying and tracking deterioration in a person's mental state, because what is typical behaviour for one person can be highly unusual for another. Clinicians and people with lived experience independently reported that the voices of consumers and (especially) carers were not being heard strongly enough in healthcare settings. Clinicians seemingly do not routinely engage with carers and may not listen to their reports of observed changes in someone's mental state.

## Review of Signs of Mental State Deterioration and Practice Implementation Issues

Two workshops were held with five clinicians and six people with lived experience who had participated in the collaborative consensus-building process, and a staff member from the Australian Commission on Safety and Quality in Health Care. The workshop participants contributed to discussions on obtaining baseline information, assessed the indicators of deterioration, and reviewed the clusters of signs.

Participants reported that baseline information can be obtained from multiple sources, including consumers, carers and next of kin, emergency service professionals, and healthcare providers. There are numerous challenges inherent in obtaining baseline information in healthcare settings, however.

Assessment of the five indicators produced an encouraging outcome. Some clusters of signs easily fitted with the proposed indicators, but many clusters could be allocated to more than one indicator. For these clusters, the relationship between cluster and indicator may depend on how a cluster manifests in any given situation. Workshop participants were able to apply the indicators to recalled examples of people experiencing deterioration. They reported that using the indicators would have enabled the detection of deterioration, especially at an advanced stage.

The review of the clusters of signs produced feedback that some of the cluster names could be modified and several clusters could be combined.

### **Proposed Clusters and Indicators**


Based on the findings from the updated review and collaborative consensus-building process, as well as the feedback received during the workshops, we propose a solution that sees the retention of the five indicators along with 28 clusters of signs. This information is presented in Figure 1.

### **Recommendations**

Recommendations are made to conduct a national consultation on the indicators and clusters of signs, and to undertake further work to determine:

- how baseline information can be obtained, communicated, and retained more effectively (including strategies and practices that support consumers and carers with reporting baseline information);
- how the five indicators can be operationalised;
- whether the indicators are sufficiently sensitive to facilitate the identification of early deterioration;
- the validity of the indicators and clusters for diverse populations; and
- how any solution for identifying and tracking deterioration may best be translated into practice.

**Figure 1:** Proposed updated definition, indicators, and clusters of signs.

<b>Mental State Deterioration</b>	
<p><b>Updated definition:</b> A change for the worse in a person's mental state, compared with the most recent information available for that person, which may indicate a need for additional care.</p>	
<p><b>Assessing Change</b></p> <p>Identifying and tracking change relies on the availability of individual baseline information to which a person's current mental state can be compared.</p> <p style="text-align: center;"> <b>Baseline information</b>  <b>Current mental state</b> </p>	
<b>Signs of Deterioration</b>	
Indicators of deterioration	Clusters of signs of deterioration
<p><b>Reported change</b></p> <p>A person, or someone who knows the person well, reports that her or his mental state is changing for the worse.</p>	<p>Self-initiated requests for assistance  Requests for treatment from healthcare professionals or those close to the person  Self-reported negative or inflated sense of self  Self-reported uncontrollable thought processes  Self-reported negative emotions</p>
<p><b>Distress</b></p> <p>A person, or someone involved in her or his care, shows signs of distress, which are evident through observation and conversation.</p>	<p>Uncharacteristic facial expressions  Physiological/medical deterioration  Negative themes in conversations  Apparent distress of self or others</p>
<p><b>Loss of touch with reality or consequence of behaviours</b></p> <p>A person is losing touch with reality or the consequences of her or his behaviour.</p>	<p>Indications of experiencing delusions  Indications of experiencing hallucinations  Unusual self-presentation  Unusual ways of behaving  Appearing confused during conversations</p>
<p><b>Loss of function</b></p> <p>A person is losing her or his ability to think clearly, communicate, or engage in regular activities.</p>	<p>Unusual movement patterns  Loss of skills  Poor daily self-care  Reduction in regular activities  Difficulty participating in conversations  Unusual speech during conversations  Seemingly impaired memory  Apparent difficulty with thinking about things in different ways</p>
<p><b>Elevated risk to self, others or property</b></p> <p>A person's actions indicate an increased risk to self, others, or property.</p>	<p>Increases in the use of restrictive practices  Reduced safety of self  Reduced safety of others  Reduced safety of property  Disengaging from treatment  Unresponsiveness to treatment</p>

# 1. Introduction

Recognising and responding to clinical deterioration is a national priority for improving the safety of the care people receive within the health system.<sup>1</sup> A national consensus statement has been developed, which outlines the essential elements for recognising and responding to acute physiological deterioration.<sup>2</sup> The Australian Commission on Safety and Quality in Health Care (the Commission) is expanding this work through a focus on deterioration in a person's mental state. In support of this work, *Recognising and Responding to Deterioration in Mental State: A Scoping Review* was prepared for the Commission.<sup>3</sup> This document provided an overview of current knowledge on recognising and responding to deterioration in mental state in emergency department and acute inpatient settings. The Scoping Review also incorporates literature on signs of deterioration and instruments developed to support the recognition of deterioration.

Vital signs and other observations that can be used to detect physiological deterioration are well-established and include, for example, respiratory rate, oxygen saturation, heart rate, blood pressure, temperature, and level of consciousness.<sup>2</sup> Equivalent signs indicative of deterioration in a person's mental state have yet to be developed, however.

In submissions to the Scoping Review, differing opinions were expressed regarding the possibility of identifying signs of deterioration in a person's mental state.<sup>3</sup> The Royal Australian and New Zealand College of Psychiatrists (RANZCP) suggested that signs of deterioration could be identified using the mental state examination. Deterioration would be observed as adverse changes in one or more features of mental state, such as affect and mood, thought (stream, form, and content), cognition (memory and orientation), perception, and behaviour. In contrast, the authors of several submissions took the position that it would be difficult to identify and to gain consensus on a set of signs of deterioration in a person's mental state. Complicating factors include the qualitative approach to identifying signs, their individualistic and idiosyncratic presentation, and their fluctuating and non-linear trajectory. One of the implications for practice is that clinicians face the challenge of gathering information to develop sufficient understanding of a person's baseline mental state, to which subsequent changes can be compared.

## Terminology Review

**Mental state** is "broadly understood to refer to a person's intellectual capacity, emotional state, and general mental health based on clinical observations and interviewing. Mental state comprises mood, behaviour, orientation, judgment, memory, problem-solving ability, and contact with reality".<sup>3</sup>

**Deterioration** refers to "changes in a person's mental state that indicate the need for closer observation, clinical review or more frequent review and for the introduction, change or 'up-scaling' of therapeutic interventions".<sup>3</sup> Mental health clinicians tend to use the terms *change* and *risk* more than *deterioration*.

**Signs** are objective findings with specific connotations (for example, loose associations are a sign of a thought disorder).<sup>4</sup>

The purpose of this project was to expand the knowledge base on identifying and tracking signs of deterioration in a person's mental state. Specifically, the aim was to produce a set of signs of deterioration that are able to be observed, reported, tracked, and communicated. The project had four phases, with each phase building upon the work of the previous phase. These phases were used to structure this report.

<b>Updated literature review</b>	A systematic search of the literature was conducted to ascertain whether any new instruments had been developed for identifying and tracking signs of deterioration in a person's mental state. This updated review focused on research published following the completion of the literature search for the Scoping Review.
<b>Generation of signs of mental state deterioration</b>	Clinicians and people with lived experience participated in a collaborative consensus-building process with the aim of generating an agreed set of signs of deterioration in a person's mental state. This process involved: <ul style="list-style-type: none"> <li>• interviews that were principally focused on identifying signs of deterioration, and</li> <li>• Delphi surveys to rate each of the signs.</li> </ul>
<b>Review of signs of mental state deterioration and practice implementation issues</b>	Workshops were held with 11 participants from the collaborative consensus-building process and a Commission staff member. The main focus of these workshops was on reviewing the signs of mental state deterioration that had been generated and reflecting upon potential practice implementation issues.
<b>Proposed signs of mental state deterioration</b>	The findings from the first three phases of the project were drawn upon to propose a set of signs of deterioration in a person's mental state that could be used for the observation, reporting, tracking and communicating of such changes.

## 2. Updated Literature Review

Deterioration in a person's mental state is not an area of concerted research effort. At the time the Scoping Review was undertaken, few studies had been published on signs of deterioration in a person's mental state and a limited number of instruments were identified that could support clinical decision-making in this area.<sup>3</sup> The evidence base was quite limited, both in detail and in scope. Major signs of deterioration identified in inpatient settings included aggression and violence, agitation and anxiety, depression, medical deterioration (including delirium), psychosis, self-harm, social withdrawal and self-neglect, and suicidality. Many of these signs would seem to be effects of deterioration, however, rather than more subtle indications that a person's mental state is deteriorating and changes in care may be required. With suicide and, to a lesser extent, self-harm and violence being the main focus of the studies reviewed, these signs represent a fairly narrow subset of indicators that a person's mental state may be deteriorating. The potential for environmental changes to contribute to deterioration has also been under-explored.

Although some promising developments for recognising deterioration in a person's mental state were noted in the Scoping Review (for example, early warning signs journaling<sup>5</sup> and the mental health thermometer<sup>6</sup>), few studies had been conducted to develop tools for recognising deterioration in a person's mental state.<sup>3</sup> A significant gap in the literature was identified with respect to the availability of valid and reliable tools that could support the tracking of a person's mental state. The purpose of the present review is to provide an update on the evidence for identifying and tracking signs of deterioration. The aim was to determine whether any tools had been developed since the Scoping Review.<sup>3</sup>

### 2.1 Method

The search strategy incorporated the same databases and search terms used for the previous review.<sup>3</sup> We identified relevant papers using the following five electronic databases: Academic Search Complete, CINAHL Complete, Health Business Elite, MEDLINE, and PsycINFO. The search terms were: *psychiatric, mental health, inpatient, mental state, deteriorat\*, risk assessment, risk management, adverse event, adverse outcome, and patient safety.\** The search was limited to peer-reviewed papers published after June 2013 (the previous review covered the period January 1995 until June 2013). The search was current as at 23 May 2017.

The search strategy for grey literature involved the Google search engine using terms such as *deterioration, mental health, and assessment*. We undertook additional searches

#### Search Strategy

01. psychiatric
02. mental health
03. inpatient
04. mental state
05. deteriorat\*
06. risk assessment
07. risk management
08. adverse event
09. adverse outcome
10. patient safety
11. 1 or 2
12. 4 or 5 or 6 or 7 or 8 or 9 or 10
13. 3 and 11 and 12

\* Asterisks are used with search terms to broaden searches. In this instance, an asterisk was used with *deteriorat\** to find words that begin with these letters.

of the following organisations' websites: American Psychiatric Association ([www.psych.org](http://www.psych.org)), National Institute for Health and Clinical Excellence ([www.nice.org.uk](http://www.nice.org.uk)), The Joint Commission ([www.jointcommission.org](http://www.jointcommission.org)), The Royal College of Psychiatrists ([www.rcpsych.ac.uk](http://www.rcpsych.ac.uk)), RANZCP ([www.ranzcp.org](http://www.ranzcp.org)), United States Department of Health and Human Services ([www.hhs.gov](http://www.hhs.gov)), UK Department of Health ([www.gov.uk](http://www.gov.uk)), and World Health Organization ([www.who.int](http://www.who.int)).

We also scanned the reference lists of included papers to identify instruments and other literature pertinent to this review.

Studies were included in the review if they were focused on tools for identifying and tracking signs of deterioration in a person's mental state. Studies were excluded if the time between assessments was more than one month (for example, studies in which a person was assessed once were excluded). Although the period of one month between assessment points is too long for tracking signs of deterioration, the intention was for the search to be over-inclusive, thereby identifying tools that may be able to be used more frequently.

## 2.2 Findings

Potentially relevant papers were identified through searches of electronic databases (n=998) and from the reference lists of included papers (n=3). After removal of duplicates (n=282), 716 papers from the electronic database search were assessed for inclusion in this review. Of these papers, 649 were excluded upon reading their titles. The abstracts of the remaining 66 papers were read, and a further 26 papers were excluded. The most common reasons why papers were excluded at this point were that the instruments were administered only once or at a frequency no greater than once per month (n=8) or the papers were commentaries or overviews (n=7). The full texts of the remaining 41 papers were read, and 30 were excluded. The most common reason why papers were excluded was that the instruments were administered only once (n=15). The remaining 11 papers were included in this review. A further three papers were identified from the reference lists of included papers. No papers were found in the grey literature search. In total, 14 papers were included in this review.<sup>7-20</sup>

The papers were focused on the following instruments: mental state examination scale (MSES)<sup>7, 8</sup>, Five-Item Daily Symptom Index (DI-5)<sup>9-11</sup>, Dynamic Appraisal of Situational Aggression (DASA)<sup>12-14</sup>, Brøset Violence Checklist (BVC)<sup>15-18</sup>, Imminent Risk Rating Scale (IRRS)<sup>19</sup>, and Life-Death Implicit Association Test (IAT).<sup>20</sup> These tests were designed to measure mental state (MSES), psychological distress (DI-5), risk of aggression and violence (DASA, BVC, IRRS), and suicidality (IAT). In the studies included in this review, instruments were administered daily or twice-daily (DI-5, DASA, and BVC) or twice weekly (MSES, IRRS, and IAT).



## 2.2.1 Mental State Examination Scale

Based on the mental state examination, which is central to psychiatric assessment, the MSES was designed to be used in clinical practice for the measurement of mental state across diagnostic groups.<sup>7, 8</sup> The MSES contains a set of 35 commonly observed mental state features (see Table 1), which clinicians rate on a scale that ranges from 0.0 (the feature is absent) to 0.9 (the feature is present in its full severity). A software tool is used to calculate global and subscale scores from the clinician ratings. Work on the feasibility of the scale showed that the MSES can be used for assessing the initial mental state of a person exhibiting psychosis and mania, tracking the process of recovery, and facilitating timely treatment decisions.<sup>8</sup>

**Table 1:** Features included in the mental state examination scale.

Mental State Features		
Poor self-care	Reduced volume in speech	Persecutory thoughts/delusions
Poor eye contact	Reduced flow of speech	Bizarre delusions
Over familiarity	Increased flow of speech	Non-bizarre delusions
Slowing of motor activity	Tangential thought form	Auditory hallucinations
Distractibility	Lack of coherence in speech	Mood congruency of psychotic symptoms
Agitation	Grandiosity	Visual hallucinations
Irritability	Guilt and self-blame	Lack of insight
Lack of reactivity of affect	Low self-esteem and confidence	Impaired concentration
Lability of affect	Increased self-esteem	Impaired registration
Level of anxiety in affect	Worrying thoughts	Impaired recall
Level of depression in affect	Pessimistic thoughts	Disorientation
Lack of prosody in speech	Self-harm thoughts	

Source: Fernando & Henskens.<sup>7</sup>

## 2.2.2 Five-Item Daily Symptom Index

The DI-5 is a self-report measure of affective psychological distress designed for daily administration with people who are depressed or anxious.<sup>9</sup> The DI-5 was designed as a companion instrument for the five-item World Health Organization Wellbeing Index, which measures subjective wellbeing.<sup>21</sup> Completion of the DI-5 requires people to respond to items about feeling that they are not coping, anxious, depressed, worthless, and suicidal. Initial work on the instrument showed that it was valid, reliable, and responsive to change over time.<sup>9</sup>

Subsequent research with people receiving inpatient care showed a modest relationship between psychological distress (DI-5) scores on Day One and deliberate self-harm (odds ratio (OR) = 1.2).<sup>10</sup> Better predictive outcomes were achieved, however, when people were classified based on their responses to the DI-5 over seven consecutive days. Four trajectories of scores were able to be identified in the data

### Terminology Review

**Odds ratios** describe, for example, the odds of an event happening (for example, self-harm) given the presence versus absence of a potentially causative factor (for example, psychological distress).

and were labelled *Responders Low Start* (19.5% of people; low symptom severity with consistent improvement over seven days), *Responders Medium Start* (29.6%; medium to high symptom severity with early improvement), *Responders High Start* (28.7%; high symptom severity with less improvement), and *Non-Responders* (22.2%; high symptom severity with no improvement over seven days). People classified as Non-Responders had substantially increased likelihood of deliberate self-harm compared with others receiving care (OR=6.7). That is, there was a six-fold increase in the predictive utility of this instrument when assessments made over several days were used to classify people. Similar findings were evident in a study focusing on the suicidality item within the DI-5, "I have had thoughts about killing myself".<sup>11</sup> People with elevated scores on this item for two days had a four-fold increase in the risk of self-injury over the expected base rate.

### 2.2.3 Dynamic Appraisal of Situational Aggression

The DASA is an instrument designed to assess the risk of imminent aggression in people receiving psychiatric inpatient care.<sup>22</sup> The DASA contains seven items: irritability, impulsivity, unwillingness to follow directions, sensitivity to perceived provocation, easily angered when requests denied, negative attitudes, and verbal threats. The initial evidence from the instrument's developers showed that the chances of someone being physically aggressive during the subsequent 24-hour period was associated with the presence or absence of these seven items. Specifically, those with higher scores (that is, more of the seven behaviours were observed) were more aggressive.

Three papers on the DASA met the selection criteria for this review.<sup>12-14</sup> The findings from these studies were supportive of the predictive validity of this instrument. When used within one acute and one secure non-forensic extended-stay mental health unit in Victoria, the DASA significantly outperformed unstructured clinical judgements (UCJ) in predicting aggression, both over the next eight-hour shift and the following 24 hours.<sup>13</sup> The DASA was superior to UCJ both on its own or part of structured professional judgements (that is, assessments incorporating DASA scores and any other factors the assessors deemed relevant). Whereas the accuracy of predictions using UCJ was barely above chance

for both the next shift (area under curve [AUC]=.52) and following 24 hours (AUC=.54), the predictive validity of the DASA over the next shift (AUC=.69) and 24 hours (AUC=.70) was much higher (confidence intervals [CI] have not been provided for these AUC, because they appear to have been misreported in the original paper).

Slightly more impressive results were reported from three southern Finnish mental health inpatient units.<sup>14</sup> Over the 24 hours following assessment, the

#### Terminology Review

**Area under curve** is a measure of the accuracy of a test. Values can range from 0 to 1. A test with perfect accuracy would have an AUC value of 1, whereas a value of .5 indicates the test has no better accuracy than chance.

**Confidence intervals** describe the range of values within which a given population parameter (for example, AUC values) would be expected to fall. At the 95% level, it would be expected that 95% of confidence intervals would contain the population parameter.

DASA proved to be a reasonably strong predictor of physical aggression against others (AUC=.92, 95% CI=.87-.97) and verbal aggression against others (AUC=.86, CI=.62-1.00). Given the small size of this study, some caution when interpreting these results seems warranted. Only 12 of 72 people receiving care agreed to participate in this study and few acts of aggression against others (physical, n=3; verbal, n=5) were recorded. There were no acts of physical aggression against objects.

With multiple assessments over time, several methods can be used to determine risk, including the mean risk state (the average score from the recent past), peak risk state (the highest score from the recent past), and current state (the most recent score).<sup>12</sup> Initial evidence from acute units at a high-security mental health hospital showed that both mean and peak risk scores (calculated from the daily assessments of the previous seven days) were more strongly associated with interpersonal violence, verbal threats, and any impatient aggression in the following 24 hour period than the most recent risk scores.<sup>12</sup> These findings suggest that clinicians should not only consider the most recent risk assessments, but also the occurrence of heightened risk over several days and assessments of higher risk over that time.

## 2.2.4 Brøset Violence Checklist

With the BVC, clinicians assess the presence (scoring one) or absence (scoring zero) of six behaviours: attacks on objects, boisterousness, confusion, irritability, physical threats, and verbal threats.<sup>23</sup> For people who are well known to clinicians, a score of zero represents habitual, non-violent behaviour, whereas a score of one represents an increase in the behaviour described. The scores for each behaviour are summed, with higher scores interpreted as there being greater risk of violent acts. This initial work was supportive of the instrument's predictive ability during the 24 hours after assessment (AUC=.82, CI=.75-.89), with scores of two or more predictive of a violent act during the next 24 hours. The BVC also had strong predictive ability for the next shift.

Four papers on the BVC met the selection criteria for this review.<sup>15-17</sup> Three of these papers included reports of the predictive validity of Chinese<sup>15, 18</sup> and extended German<sup>16</sup> versions of the BVC. Like in the initial testing of the BVC<sup>23</sup>, the Chinese version had strong predictive validity for the next shift (AUC=.85, CI=.80-.91).<sup>15</sup> The German version was extended through the use of a visual analogue scale with which risk is rated on a sliding scale (from *no risk* to *very high risk*).<sup>16</sup> Using this extended German version, risk scores are derived from the presence or absence of the six behaviours and the rating on the visual analogue scale. This version, too, had strong predictive power (AUC=.93, CI=.88-.98).

Performing assessments every shift may contribute to a reduction in the incidence of aggressive behaviour.<sup>17</sup> In a study involving 15 psychiatric wards in Denmark, the implementation of BVC assessments on seven wards was associated with a marked, but statistically non-significant, decrease in aggressive incidents. Although promising, these findings need replicating with larger samples (that is, involving more wards, more people receiving care, longer follow up periods, or a combination of these factors).

## 2.2.5 Imminent Risk Rating Scale

The IRRS is a clinical measure of a person's imminent risk of violence against others.<sup>19</sup> The instrument has seven items: history of violence, diagnostic subtype, overt expression of hostility, impaired expression/communication, level of stress, impaired social functioning, and contextual/environmental factors. Clinicians rate each of these items as *absent*, *partially present*, or *fully present*. In the development of the instrument, information was obtained twice weekly via chart reviews. The findings suggest that the IRRS was better than chance alone of predicting physical aggression (AUC=.69, CI=.50-.88 to AUC=.74, CI=.60-.88) and verbal aggression (AUC=.63, CI=.50-.75 to AUC=.76, CI=.66-.88) over a period of approximately half a week.

## 2.2.6 Life-Death Implicit Association Test

The IAT represents a novel approach to the assessment of suicide risk. The application of implicit association testing to suicide prevention bypasses the issue of people being unable or unwilling to disclose suicidal intentions.<sup>24</sup> With this brief, computer-based test, reaction times are recorded as people respond to stimuli representing the ideas *life* and *death*, and the attributes *me* and *not me*.<sup>24</sup> Faster responses on the death/me blocks relative to the life/me blocks indicate a stronger association between death and self. Findings from the initial study involving people seeking treatment at a psychiatric emergency department showed that those with an implicit association with death/suicide had an approximately six-fold increase in the odds of attempting suicide in the following six months.<sup>24</sup> The predictive accuracy of implicit association testing was superior to that of known risk factors (for example, suicide attempt history) and the predictions of both clinicians and people receiving care. The IAT has also been shown to have potential for predicting self-harm.<sup>25</sup>

In this review, one paper on the IAT met the selection criteria.<sup>20</sup> Administered twice weekly to people with complex, treatment resistant disorders receiving care in a private psychiatric hospital, IAT scores changed in a positive direction between admission and discharge, and predicted discharge suicidal ideation after adjustment for scores on hopelessness, depression, and suicide severity rating scales.

## 2.3 Discussion

The purpose of this review was to identify any tools that have been developed since the completion of the literature search for the Scoping Review<sup>3</sup> for identifying and tracking signs of deterioration in a person's mental state. Six tools were identified, three of which were developed during the window of this updated review (MSES, DI-5, IRRS). Of the six tools, the MSES provides the most comprehensive coverage of possible signs of deterioration, having been based on the mental state examination.<sup>8</sup> Although the initial work on the feasibility of the MSES is promising and the scale appears sensitive to change (at least, over a few days), more developmental work needs to occur before this instrument could be used with confidence for identifying and tracking signs of deterioration in a person's mental state. The DI-5 has shown promise in detecting changes in psychological distress over time, which can be used to

determine who may be at greater risk of self-harm. The value of the DI-5 beyond people with affective disorders is unclear, however. The remaining four tools were designed to facilitate more accurate predications with respect to aggression and violence (DASA, BVC, and IRRS) and suicidality (IAT). To varying degrees, these instruments seem useful in identifying risks of particular events. Their potential for identifying and tracking signs of deterioration in a person's mental state, however, would appear limited.

In addition to identifying these six tools, several themes in the literature became apparent during this update. These themes were:

- individualised assessment approaches,
- measurement using multiple behaviours,
- prediction with one-off versus multiple assessments over time, and
- multiple possible sources of information.

These themes are addressed below.

### 2.3.1 Individualised Assessment Approaches

There has been growing recognition that assessment needs to be individualised.<sup>26-28</sup> In their submission to the Scoping Review, the RANZCP reflected that the movement in contemporary mental health care is towards personalisation and recovery.<sup>3</sup> This expectation for individualised approaches is emphasised in best practice guidelines and standards, both in Australia<sup>27</sup> and overseas.<sup>28</sup> The shift towards individualised assessment is reflected in some instruments, such as the DI-5, the BVC, and one widely-used instrument excluded from this review,<sup>\*</sup> the Historical-Clinical-Risk Management-20 (HCR-20).<sup>29</sup>

**“Mental health treatment, care and support should be tailored to meet the specific needs of the individual consumer.”**

Key principle within the National Standards for Mental Health Services<sup>27</sup>

In addition to having utility for the assessment of risk of self-harm<sup>10, 11</sup>, evidence suggests that the DI-5 can enhance treatment outcomes through aiding the daily monitoring of treatment progress and the provision of feedback to therapists and people receiving care.<sup>30, 31</sup> Daily use of the instrument can also enable the identification of clinically significant improvement in symptoms, which could be useful for informing decisions about discharge readiness.<sup>32</sup>

BVC assessments are conducted differently for people who are well known to clinicians.<sup>23</sup> That is, instead of determining the presence or absence of six behaviours, clinicians are required to determine whether the behaviours observed are habitual and non-violent or whether there has been an increase in one or more of the six behaviours. This approach accentuates the importance of clinicians developing baseline knowledge of each person's behaviours, which may be equally relevant to detecting deterioration in a person's mental state.

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\* Several papers on the HCR-20 were excluded from the review, predominantly due to the instrument being administered once or infrequently (once every 6 months or less often) in the reported studies.

With respect to the HCR-20, Version 3 of this instrument (HCR-20<sup>V3</sup>) includes features that facilitate individualised approaches to assessment.<sup>29</sup> In developing HCR-20<sup>V3</sup>, changes were made to the administration procedure and risk factors. For Version 3, a seven-step process is introduced:

- gather information on risk factors from multiple sources;
- determine the presence of each of a specified set of risk factors;
- assess the relevance of each risk factor to the person, including the extent to which relevant risk factors act as a motivator (increasing the perceived benefit of violence), disinhibitor (decreasing the perceived cost of violence), or destabiliser (impairing decision making);
- undertake risk formulation to develop theories on why the person was violent in the past and may be again in the future;
- generate risk scenarios of what could reasonably happen in the future;
- develop management strategies to address important or relevant risk factors;
- draw conclusions about the person's risk level and the prioritisation of services;

The potential relevance of the HCR-20<sup>V3</sup> to the recognition and response to deterioration in a person's mental state lies not so much in the risk factors (which are focused on violence; see Table 2), but in the person-centred approach that clinicians are required to take. The process requires clinicians to get to know the people whom they are assessing. Emphasis is placed on appreciating differences between individuals and on responding in ways that are appropriate for their particular needs. In practice, evidence confirms that the HCR-20<sup>V3</sup> produces more individualised assessments than the previous version of this instrument.<sup>33</sup>

**Table 2:** Risk factors for violence within the HCR-20<sup>V3</sup>.

Historical Scale	Clinical Scale	Risk Management Scale
History of problems with: <ul style="list-style-type: none"> <li>• violence</li> <li>• other antisocial behaviour</li> <li>• relationships</li> <li>• employment</li> <li>• substance use</li> <li>• major mental disorder</li> <li>• personality disorder</li> <li>• traumatic experiences</li> <li>• violent attitudes</li> <li>• treatment or supervision response</li> </ul>	Recent problems with: <ul style="list-style-type: none"> <li>• insight</li> <li>• violent ideation or intent</li> <li>• symptoms of major mental disorder</li> <li>• instability</li> <li>• treatment or supervision response</li> </ul>	Future problems with: <ul style="list-style-type: none"> <li>• professional services and plans</li> <li>• living situation</li> <li>• personal support</li> <li>• treatment or supervision response</li> <li>• stress or coping</li> </ul>

Source: Douglas et al.<sup>29</sup>

### **2.3.2 Measurement using Multiple Behaviours**

Constructs are abstract summaries of aspects of reality, which are related to observable entities or events.<sup>34</sup> Deterioration in a person's mental state is an example of a construct. Whereas deterioration in a person's mental state cannot be observed directly, it is possible to witness behaviours that may be indicative of deterioration, such as apparent confusion, crying, or aggressive acts. The measurement of psychological constructs typically involves assessing sets of behaviours rather than single behaviours. A broad number of behaviours are generally required to properly describe an underlying construct. From an empirical perspective, sets of behaviours have found to be more predictive of, for example, aggression and violence than single behaviours.<sup>23</sup> The observance of a single behaviour, however, may provide reason for increased observation or other interventions (for example, engaging with people receiving care). In identifying deterioration in a person's mental state, it may be likely that clusters of behaviours – potentially unique to individuals, time, and environment – are stronger indicators of the need for additional care than single behaviours alone.

### **2.3.3 Prediction with One-Off versus Multiple Assessments over Time**

Research on several instruments (MSES, DASA, DI-5) has highlighted the value of assessing risk regularly over time. Research with the DI-5, for example, showed that the instrument was substantially more accurate for assessing risk of self-harm when it was administered daily over seven consecutive days than when only Day One scores were used for prediction.<sup>10</sup> To be able to perform regular assessments, instruments must be well suited for that purpose. Some instruments used once every several days or less often may not be easily used on a daily basis.

### **2.3.4 Multiple Sources of Information**

Focusing on signs of deterioration elevates the importance of clinical observation. Indeed, most of the instruments included in this updated review rely on clinician observations. A theme among submissions to the Scoping Review, however, was that, wherever possible, assessments should be conducted in partnership with people receiving care.<sup>3</sup> Assessments would ideally draw on information from them, as well as from family and friends. The evidence available for this review update suggests that useful information can be obtained from people receiving care, either through self-report<sup>9-11</sup> or implicit association testing.<sup>20, 24, 25</sup> In recognising and responding to deterioration in a person's mental state, there would seem to be value in drawing more heavily on information from those experiencing deterioration, as well as seeking information from carers. Doing so would give people providing care a deeper understanding of the person experiencing deterioration and place them in a better position to respond.

## 2.4 Conclusion

Currently, the MSES may have the most potential for identifying and tracking signs of deterioration in a person's mental state. The MSES offers the broadest coverage of mental states of the instruments included in this review. The MSES appears to be early in development, however, and there is no published information on how it might perform when administered more frequently than once every few days. The other instruments reviewed were not designed to measure mental state and, therefore, do not include items that would be fully representative of the features of mental state. Further work would seem necessary to develop an instrument for the identification and tracking of deterioration in a person's mental state. Such an instrument would ideally facilitate individualised assessments, incorporate a broad set of behaviours, enable repeated assessments over time, and draw upon multiple sources of information (including clinical observations and the reports of people experiencing deterioration and those who know them well).



### 3. Generation of Signs of Mental State Deterioration

One of the findings from the Updated Literature Review is that no tool has been developed for the purpose of comprehensively identifying and tracking signs of deterioration in a person's mental state. Given the unavailability of such a tool, we used a collaborative consensus-building process to identify signs of deterioration. The main aim of this investigation was to generate signs of deterioration in a person's mental state that clinicians can observe and signs, symptoms, and experiences of deterioration that people with lived experience can report. As part of this process, we also explored how changes in mental state are recognised and what care options are used in response to such changes.

#### 3.1 Method

##### 3.1.1 Design

We used the Delphi method with experts to build consensus on signs of deterioration in a person's mental state. Items (representing clusters of signs of deterioration in a person's mental state) were generated from findings of the Updated Literature Review and through interviews with clinicians and people with lived experience.<sup>35, 36</sup> Subsequently, these items were rated over three rounds using online surveys.

The interviews were also used to elicit information on recognising change and additional care options in response to change (including urgent care options), as well as to invite comments with respect to recognising and responding to deterioration in a person's mental state.

##### 3.1.2 Participants

The participants were 19 clinicians (8 prescribing and 11 non-prescribing clinicians) and 23 people with lived experience (9 consumers and 14 carers). Clinicians were recruited with the intention of gaining representation from a broad range of settings (for example, tertiary mental health services, emergency departments, perinatal services, general practice, and academia), and professions (for example, psychiatry, nursing, emergency medicine, and pharmacy). People with lived experience were principally recruited through established representative bodies (for example, National Mental Health Consumer and Carer Forum, and Private Mental Health Consumer and Carer Network). The participants who were involved in this project are listed in Appendix A.

#### Delphi Method

The Delphi method is commonly used in mental health research, and involves a structured process whereby the opinions of experts are refined with the aim of reaching consensus of opinion, judgement, or choice.<sup>35, 36</sup> The method involves a process of generating items and then rating them over several rounds. Using this method, participants provide their responses anonymously, which mitigates or removes the biasing effects of personality, experience, seniority, and group dynamics that are often present when alternative methods, such as focus groups, are used. This method is an effective and reliable way of collecting data that is particularly useful when there is uncertainty or minimal knowledge in the area of interest.

### 3.1.3 Interview Schedule

Participants were asked to recall a time when they noticed deterioration in their own or another person's (for example, a patient or a family member) mental state. With these experiences in mind, participants were asked the following questions:

1. What did you notice that made you aware of the change?
2. How did you know that this sign represented a change?
3. How would you communicate this change?
4. What are the current additional care options available to respond to the changes you have listed?
5. What changes would cause you to believe there was a need for urgent additional care?
6. What are the current additional care options to respond to such changes?
7. What other comments or thoughts do you have that need to be included in this study?

During initial interviews, the fourth question was: How much weight or importance did you attribute to this sign? Participants experienced difficulties with responding to this question, however. *Importance* was considered too vague and was re-conceptualised in terms of the need for additional care. This question was replaced with questions four through to six.

### 3.1.4 Online Survey

Three online surveys were administered, with approximately two weeks between each survey. In each survey, participants were asked to rate each cluster of signs in terms of the need for additional care using the following rating scale options: *act*, *investigate*, *monitor*, and *do nothing* (see Table 3). The definition of deterioration presented in the Scoping Review<sup>3</sup> (that is, "changes in a person's mental state that indicate the need for closer observation, clinical review or more frequent review and for the introduction, change or 'up-scaling' of therapeutic interventions") influenced the development of this scale. The emphasis within this definition on clinical responses suggests that the severity of changes could be judged in terms of the response required. The progression from *do nothing* to *monitor* to *investigate* to *act* was considered to be an escalation of care options that could be relevant to a range of community and healthcare settings. The scale was developed at the same time as the interviews, which afforded the opportunity to seek feedback on the scale from some of the participants prior to the commencement of the surveys. Feedback was invited from six participants (one prescribing and three non-prescribing clinicians, and two carers) who were interviewed consecutively at the time we were developing the scale. All of these participants provided positive comments on the useability of the proposed scale. Given the consistency of these comments, no further feedback was sort.

Participants also had the option of providing general comments at the end of each survey. For the second and third survey, each participant was provided with her or his ratings from the previous round, as well as summaries of how clinicians and people with lived experience rated each cluster. During the second survey, participants were also invited to provide explanations for their ratings of

clusters for which consensus had not been achieved. These explanations were summarised and fed back to participants for the third survey.

**Table 3:** Response options for the online surveys and descriptions of these options.

Response Option	Description
Act to obtain immediate additional care	Additional care needs to be sought, or provided, immediately. Examples of additional care include a carer providing more practical or emotional support, care in the community (for example, from a general practitioner), attending a hospital emergency department, admission to a psychiatric inpatient unit, and closer observation while in psychiatric inpatient care. Note that obtaining further information does not constitute additional care.
Investigate to see if additional care may be required	Prompt seeking of further information is needed to help to decide if additional care might be required (for example, asking the person questions, speaking with carers, consulting with the person in relation to pre-planned responses, and assessing mental state). Information is urgently required rather than adopting a “wait and watch” observational approach.
Monitor the changes	Observations are worthy of communicating to others, but would not warrant further action at this time. Communications could be in the form of, for example, entries in clinical notes, clinicians discussing the observations during handover, and carers or a person experiencing a changed mental state mentioning their observations/experiences to each other or to clinicians when they next see them.
Do nothing	The observation is not important enough to warrant communication as part of continued monitoring or the seeking of further information to help to decide if additional care is needed (that is, ignore the observation).

### 3.1.5 Procedures

To enhance the generalisability of the findings from this project, we used purposive sampling to recruit participants from diverse settings and backgrounds. Informing the recruitment strategy was an awareness that outcomes from this project would need to be relevant to a broad range of healthcare settings, including:

- specialist mental health settings,
- medical and surgical wards,
- maternity and paediatric units,
- emergency departments,
- multipurpose services and remote clinics,
- justice health,
- ambulance services, and
- community-managed organisations.

In addition, several populations that have specific mental health needs<sup>37</sup> were identified, including:

- children and adolescents,
- people with intellectual disability,
- people with chronic physical conditions,
- people from culturally and linguistically diverse (CALD) backgrounds,
- Aboriginal and Torres Strait Islanders, and
- people who identify as lesbian, gay, bisexual, transgender, and intersex.

We recruited participants through organisations and groups representing the interests of healthcare professionals, consumers, carers, and specific populations (e.g., people with disability), as well as from referrals from some of the people contacted. To assist with recruitment, the Commission provided introductory emails to several organisations and potential participants.

To help potential participants understand the project and the roles of clinicians, consumers, and carers, we provided them with written information, which included an overview of the project, questions and answers about the project, and information on remuneration and travel allowances. Participation was voluntary and participants could withdraw from the project at any time. Prior to each interview, participants were given the opportunity to ask questions about the project, the participant information provided, and their involvement in the project. Their questions were answered. At this time, they provided informed consent to participate in the interviews and surveys. Participants were eligible to receive remuneration for their time if they were: (a) unfunded or non-salaried representatives of peak agencies or non-government organisations, or (b) individuals who would be earning income if they were not engaged in this project.

One of us (Dr Gavin Dagley) conducted the interviews with each participant via telephone. Participants' responses to the interview questions were manually recorded. As a check of the accuracy of the notes taken, they were read back to participants at the end of interviews and participants were given the opportunity to make corrections. Participants were also sent an electronic copy of their notes and asked to make any necessary corrections. The corrected versions of the notes were the material used for the interview analysis.

The analysis of interview material informed the development of the survey. Participants were asked to complete the survey on three occasions, and were provided with copies of their previous responses and the summarised responses of other participants prior to the second and third surveys. The data from the three rounds of surveys were used for the analysis.

### **3.1.6 Analysis**

#### **3.1.6.1 Interview material**

We conducted a thematic analysis of the interview material using a multi-phase process: (a) familiarisation with the data, (b) generating initial codes, (c) searching for themes, (d) reviewing themes, (e) defining and naming themes, and (f) producing the report.<sup>38</sup> Independent of each other, we

familiarised ourselves with the data, generated initial codes, and searched for themes, before coming together to review our findings. Differences in our analyses were resolved through discussion. With regard to the signs of deterioration in a person's mental state, signs identified from the review of literature were introduced to the analysis and incorporated with the signs identified in the interview material from clinicians and people with lived experience.

### 3.1.6.2 Survey data

The presentation of findings from the analysis of Delphi survey data focuses predominantly on the third survey, because this survey was the final opportunity for participants to rate the items. When analysing Delphi survey data, attention is typically paid to ratings of importance (that is, the response required in terms of the need for additional care: *act*, *investigate*, *monitor*, or *do nothing*) and consensus (the extent to which participants agree on the ratings).<sup>35</sup> With respect to ratings of importance, the main focus was on the median responses for each item. Determining consensus is more challenging, with researchers applying thresholds of between 50% and 100% agreement in their analyses. Recognising that any threshold selected is somewhat arbitrary, items are highlighted where there was at least 75% agreement.

## 3.2 Findings

In this section, we first present the findings on signs of deterioration in a person's mental state. The findings from the interview material are provided, followed with the results from the survey data. We then return to the interview material, and provide findings on recognising change, additional care options in response to change, and participants' general comments.

### 3.2.1 Signs of Deterioration

In total, 168 signs of deterioration in a person's mental state were identified. From the interviews with clinicians and people with lived experience, 93 and 120 signs were identified, respectively. These signs were analysed together with the 53 signs originating from the literature search. Many of the signs were common to multiple sources (that is, some signs were evident in the literature and also arose in the interviews with clinicians and people with lived experience), with 27 signs coming from all three sources, 44 from two sources, and 97 from single sources.

Further analysis was undertaken to cluster similar signs. The decision to cluster the signs was made based on: (a) the strong similarity of some signs to others, (b) the probable respondent fatigue if 168 signs were presented as items to rate in a Delphi survey, and (c) the likely impracticality of

#### Terminology Review

Different terms have been used in this project to describe varying degrees of abstraction of the signs of deterioration:

**Signs of deterioration** are the many signs that were identified from the literature and interviews.

**Clusters of signs** are groups of signs that are similar.

**Indicators of deterioration** are groups of clusters of signs that are similar.

using large numbers of signs in practice. The 168 signs were grouped into 38 clusters. The origins of the signs in each cluster are as follows: 25 clusters contain signs from all three sources (literature, clinicians, and people with lived experience), 6 clusters have signs from people with lived experience only, 3 clusters contain signs from clinicians only, 3 clusters have signs from clinicians and people with lived experience, and the remaining cluster contains signs from the literature and clinicians. In summary, the majority of clusters had signs originating from all three sources (see Table 4).

**Table 4:** Clusters of signs and the sources of signs within each cluster.

Sign Cluster	Source			Sign Cluster	Source		
	LR	C	LE		LR	C	LE
Unusual self-presentation				Appearing to hear or see things that are not real			
Unusual ways of behaving				Appearing challenging during conversations			
Unusual movement patterns				Appearing disconnected during conversations			
Loss of skills				Appearing distracted during conversation			
Withdrawing from social situations				Speech during conversations			
Self-initiated care-seeking behaviours				Difficulty following conversations			
Care-seeking initiated by carers and others				Facial expressions			
Disengaging from care				Appearing confused during conversations			
Increases in the use of restrictive practices				Seemingly impaired memory			
Unresponsiveness to care				Apparently inflexible thought processes			
Constantly changing symptoms of a mental health condition				Reduced safety of self			
Physiological/medical				Reduced safety of others			
Poor daily self-care				Reduced safety of property			
Reduction in regular activities				Self-reported sadness			
Low energy behaviours				Self-reported fear			
High energy behaviours				Self-reported anger			
Reduced self-restraint				Self-reported sense of self			
Pessimistic talk during conversations				Self-reported uncontrollable thought processes			
Expressing strong beliefs that are contradicted by reality or rational argument				Social circumstances and environment			

Note: Shading indicates the sources of signs within each cluster. LR=literature review, C=clinicians, LE=lived experience

### 3.2.2 Ratings of the Clusters of Signs

Attrition was reasonably low during the project, with 86% of participants completing the interviews and the three surveys. Almost all participants engaged with the first survey (n=40; 17 clinicians and 23 people with lived experience), with slightly fewer completing the second (n=37; 15 clinicians and 22 people with lived experience) and third (n=36; 14 clinicians and 22 people with lived experience) surveys. All participants involved in the surveys rated 100% of the clusters of signs (that is, no surveys were left partially completed).

#### 3.2.2.1 Importance

Importance was conceptualised as the need for additional care, with participants provided with four options for responding to each cluster of signs: *act*, *investigate*, *monitor*, or *do nothing*. For 11 of the 38 clusters of signs, the median ratings among clinicians, people with lived experience, or all participants was *act* (see Appendix B). These 11 clusters predominately relate to safety, psychosis, and engaging in, and responding to, care. The median ratings for 26 clusters was *investigate*. These clusters mainly related to interactions, daily patterns, self-reported feelings, appearances, and disinhibition. The median rating for the remaining cluster (relating to inflexible thought processes) was *monitor*.

#### Terminology Review

Means and medians are two types of averages.

The **mean** is calculated by summing a set of values and dividing the total by the number of values.

The **median** is the middle value when values are listed in numerical order.

On average, people with lived experience tended to prefer the *act* option more than clinicians (36% and 29%, respectively) and clinicians selected the *investigate* option more often than people with lived experience (58% and 50%, respectively). There were minimal differences between clinicians and people with lived experience in their use of the *monitor* (12% and 13%, respectively) and *do nothing* (0% and 1%, respectively) options.

The ratings of clinicians and people with lived experience were very similar. Inspection of the participant responses (see Appendix B), however, revealed marked differences for several clusters. People with lived experience tended towards *act* responses slightly more than clinicians for clusters relating to care (disengaging from care, unresponsiveness to care, and self-initiated care-seeking behaviours), psychosis (expressing strong beliefs that are contradicted by reality or rational argument, and appearing to hear or see things that are not real), and functioning (loss of skills, and unusual movement patterns). Clinicians tended towards *act* responses slightly more than people with lived experience for clusters relating to participating in conversations (appearing distracted during conversation), cognition (appearing confused during conversations, apparently inflexible thought processes, and self-reported uncontrollable thought processes), and appearance (unusual self-presentation).

No inferential statistics were performed to investigate the differences between clinicians and people with lived experience. The Delphi method is designed to reduce the variance in participant responses, thereby increasing the potential for

larger effect sizes and statistically significant results when differences between groups of participants are assessed.<sup>35</sup> That is, differences that are small and not practically significant have a much greater chance of being statistically significant after three rounds of Delphi surveys.

### 3.2.2.2 Consensus

The levels of agreement improved slightly over the three surveys. For all participants, mean agreement increased between the first (60%), second (65%), and third (69%) surveys. Among clinicians, the mean agreement increased from the first survey (69%) to the second (76%), and fell for the third survey (71%). For people with lived experience, mean agreement increased between the first (57%), second (61%), and third (69%) surveys.

Using a 75% consensus threshold, more clusters achieved consensus among clinicians (n=15) than among people with lived experience (n=9). Only 9 clusters achieved consensus among all participants. Half the clusters (n=19) achieved consensus among people with lived experience, clinicians, or both.

### 3.2.2.3 Participant comments

Some participants chose to provide comments after rating clusters in the first (n=17), second (n=16), and third (n=13) surveys. Comments could be grouped into several themes: dependent factors, assessment issues, clusters of signs, responding to the survey, and differences between clinicians and people with lived experience. Within each theme, there were no frequently occurring comments, with each comment being made by one participant or a small number of participants. The reporting back of comments to participants following the first and second surveys may have discouraged other participants from repeating the same points that others had made.

On dependent factors, comments were made that how people would respond to clusters of signs would be dependent on a broad range of factors, including:

- the setting,
- the skills and experiences of clinicians,
- the frequency and timeframe during which signs were observed,
- the presence of other signs, and
- the gender, age, ability, and background of the person showing the signs.

With regard to assessment issues, comments were made that:

- tracking signs may be more of an art than a science,
- most signs are insufficient on their own for recognising deterioration,
- there is a need to consider the whole person and their circumstances in making assessments,
- any tool developed should be integrated into current assessment protocols rather than used as a separate list, and
- there is a need for cultural responsiveness in the assessment of Aboriginal people.



On the clusters of signs, comments were received that:

- they represent a good range of indicators,
- there was incongruence between several of the cluster descriptors and the examples of signs provided,
- not all the examples within some of the clusters required the same response,
- examples relevant to people with intellectual disability need to be added,
- some of the terms used in the examples need to be rewritten in plain English, and
- the signs don't necessarily pertain to everyone's lived experience.

With respect to responding to the survey some participants mentioned that:

- they were using the same response for nearly every sign (either *act* or *investigate*),
- they had used a particular frame of reference when providing responses (for example, one participant reported responding with reference to her own situation of caring for someone with mental health issues and another participant provided conservative, generalist responses),
- more response options would have been helpful,
- what counts as a severe crisis differs between people,
- the explanations for ratings provided in the second survey affected third survey responses, and
- they disagreed with other participants' ratings.

One person noted that there were differences between clinicians and people with lived experience. This person raised the question as to whether such differences are one of the big issues in mental health care.

### 3.2.3 Grouping the Clusters of Signs

The outcomes of the analyses (38 clusters of signs, 37 of which had median ratings of *act* or *investigate*) prompted questions about how usable such a large number of signs would be for identifying and tracking deterioration in a person's mental state. A potential solution to this issue is to group the clusters of signs in ways which focus attention on the key indicators of deterioration that clinicians can observe and people with lived experience can report. One way of grouping these clusters is as follows:

- **Reported change** – A person, or someone who knows the person well, reports that her or his mental state is changing for the worse.
- **Distress** – A person shows signs of distress, which are evident through observation and conversation.
- **Loss of touch with reality or consequence of behaviours** – A person is losing touch with reality or the consequences of her or his behaviour.
- **Loss of function** – A person is losing her or his ability to think clearly, communicate, or engage in regular activities.
- **Elevated risk to self, others or property** – A person's actions indicate an increased risk to self, others, or property.

Table 5 shows how each cluster of signs may be assigned to each of these indicators.

**Table 5:** Initial assignment of the clusters of signs to the indicators.

Reported Change	Distress	Loss of Touch with Reality or Consequence of Behaviours	Loss of Function	Elevated Risk to Self, Others or Property
Self-initiated care-seeking behaviours Care-seeking initiated by carers and others Self-reported sadness Self-reported fear Self-reported anger Self-reported sense of self Self-reported uncontrollable thought processes	Pessimistic talk during conversations Appearing challenging during conversations Facial expressions Social circumstances and environment	Unusual self-presentation Unusual ways of behaving High energy behaviours Expressing strong beliefs that are contradicted by reality or rational argument Appearing to hear or see things that are not real	Unusual movement patterns Loss of skills Poor daily self-care Reduction in regular activities Low energy behaviours Appearing disconnected during conversations Appearing distracted during conversation Speech during conversations Difficulty following conversations Appearing confused during conversations Seemingly impaired memory Apparently inflexible thought processes	Withdrawing from social situations Disengaging from care Increases in the use of restrictive practices Unresponsiveness to care Constantly changing symptoms of a mental health condition Physiological/medical Reduced self-restraint Reduced safety of self Reduced safety of others Reduced safety of property

### 3.2.4 Recognising Change

The need for a clear baseline to which current signs could be compared was a consistently strong theme throughout the interviews. Participants considered that having a baseline was necessary to distinguish deterioration from other possible explanations for what has been observed or experienced. For example, an observed behaviour may be typical for that person, even if it may be unusual for others. From the interviews, several sources of information about what is typical for a person emerged:

- knowing the person over an extended period of time,
- familiarity with the person's history,
- witnessing a change in a person's behaviour,
- seeking information from the person as to what has changed, and
- obtaining information from carers and family members.

The first three of these sources highlight the importance of multiple time points for recognising change. The final two sources point to the need for multiple perspectives (that is, the experiences of a person experiencing deterioration, as well as those of people who know this person well).

Participants also identified a broad range of issues that may influence the interpretation of signs in the community and in healthcare settings. Small numbers of participants mentioned each of these issues: information availability and interpretation, insufficient time, differentiating deterioration from natural variation, appearance of signs, psychiatric diagnosis, alternative explanations, communication difficulties, observer sensitivity, potential or actual risk, and context (see Table 6).

**Table 6:** Issues that may influence the interpretation of signs in the community and in healthcare settings.

Issue	Explanation
Information availability and interpretation	Difficulties with knowing what to do with single observations (including first-time experiences of a particular change), inaccurate data, and the unavailability of a tool to assist in measuring change.
Insufficient time	Clinicians not having sufficient time to know the person, the speed of the changes, potential acceleration of cycles of deterioration over time, and timeframes of the changes (for example, a few days versus weeks).
Differentiating deterioration from natural variation	Distinguishing observations and experiences from those that are typical and routine (for example, changes in mood or eating patterns), especially early in an episode of deterioration.
Appearance of signs	Whether a sign appears on its own or as one of several observed signs.
Psychiatric diagnosis	A person's psychiatric diagnosis may affect how signs may be interpreted.
Alternative explanations	The availability of explanations for signs other than a deterioration in a person's mental state (for example, medication changes).
Communication difficulties	When people have difficulty communicating what they are experiencing or others have difficulty understanding what is being communicated.
Observer sensitivity	Not having sufficient knowledge and experience to recognise early signs of potential deterioration, including the training of the person exercising professional judgement.
Potential or actual risk	The level of urgency, danger, or risk associated with signs.
Context	The context in which a sign appears.

Note: The issues in this table were drawn from the interview material.

### 3.2.5 Additional Care Options in Response to Changes

Participants were asked what additional care options were available to them in response to deterioration in a person's mental state. The most commonly mentioned additional care option was hospital/emergency department/crisis team support (see Table 7).

**Table 7:** Additional care options in response to deterioration in a person's mental state.

Commonly-mentioned options	Less-commonly mentioned options	
<ul style="list-style-type: none"> <li>• hospital/emergency department/crisis team</li> <li>• medications or electroconvulsive therapy</li> <li>• assistance from family and friends</li> <li>• general support</li> <li>• assistance from community and non-government organisations</li> <li>• consumer and carer plans</li> <li>• general practitioners</li> <li>• mental health clinicians</li> <li>• self-care</li> </ul>	<ul style="list-style-type: none"> <li>• telephone support services</li> <li>• police involvement</li> <li>• speaking with the person/de-escalation</li> <li>• treating team consultation</li> <li>• psychological therapies</li> <li>• knowledge of what works for the person</li> <li>• modify basic health interventions currently being used</li> <li>• Internet resources</li> </ul>	<ul style="list-style-type: none"> <li>• treating physiological/medical issues</li> <li>• modifying the hospital environment</li> <li>• create/update clinical plan</li> <li>• monitoring/"specialling"</li> <li>• restrictive practices (for example, seclusion and chemical restraint)</li> <li>• security personnel involvement</li> <li>• voluntary or involuntary inpatient admission</li> <li>• emergency call activation</li> </ul>

Participants also cited several factors that they took into consideration when deciding upon the need for additional care. Foremost among the considerations were the support a person is able to access through private insurance or the National Disability Insurance Scheme, carer burden (for example, one carer spoke of the toll it takes being constantly vigilant), and the potential consequences of obtaining or not obtaining support (for example, loss of employment). Other considerations, each of which one or two people mentioned, included the need to avoid getting to crisis point, whether the issue is acute (the person's safety becomes the priority) or chronic (engagement of ongoing supports becomes necessary), the preference for least restrictive environments (remaining at home if possible), the involvement of people who can support them, and shared decision-making between consumers and carers.

#### 3.2.5.1 Urgent care options

Participants indicated that urgent care may be required when risk is elevating. When a person has become unmanageable at home, the most commonly mentioned additional care option was hospital/emergency department attendance/ambulance call out. Other common options included police involvement, inpatient admission (voluntary or involuntary), and medication review. When a person is manageable at home, the most common urgent care options included existing clinical contacts, general practitioners, family and friends, community-based services, support to settle, and telephone support lines.

For many participants, a strong consideration was the desire to avoid hospitals and the mental health system. Some participants also suggested that using the least restrictive responses was a consideration.

### 3.2.6 Participants' General Comments

Several themes emerged from participants' general comments on the topic of recognising and responding to deterioration in a person's mental state. These themes were: voices of people with lived experience, useful practices, tools, diverse backgrounds and specific populations, and suggestions for practice.

#### 3.2.6.1 Voices of people with lived experience

This theme was particularly strong in the interview material. Many people with lived experience and several clinicians commented that carers' voices were not being heard in healthcare settings. They commented that clinicians routinely did not engage with carers and did not listen when carers reported changes in a person's mental state. Participants suggested that ignoring carers can lead to poor outcomes. Consumers and carers also stated that consumer voices commonly were not being heard and respected.

#### 3.2.6.2 Useful practices

Participants suggested many practices that may be helpful in recognising and responding to deterioration in a person's mental state. Carers suggested documenting observed behaviours, using a Wellness Recovery Action Plan® (WRAP®)<sup>39</sup> or another form of individualised plan, attending courses (such as South East Sydney Local Health District's *Staying Connected When Emotions Run High*), employing *Open Dialogue*, entering *Step Up and Step Down* programs, gaining support from assertive outreach teams, using dialectical behaviour therapy, working with the *Haven Project*, and being involved with carer support groups. Clinicians highlighted the potential usefulness of advanced care directives.

#### 3.2.6.3 Tools

Several clinicians mentioned various tools, such as a pro re nata (PRN\*) scale and the Mental Health Triage Scale. In recognition of the importance of baselines, one clinician reported being involved in developing a tool for carers to help record this information. Some participants reiterated the importance of asking the right questions.

#### 3.2.6.4 Diverse backgrounds and specific populations

A small number of participants raised concerns about people with diverse backgrounds and those from specific populations, including young people, women receiving maternity services, those living in rural areas, people with intellectual disability, people from CALD backgrounds, and indigenous people. The main concerns regarded their access to care.

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\* PRN is an abbreviation for the Latin term *pro re nata* meaning "as required". The term is often used with reference to medication.

### 3.2.6.5 Suggestions for practice

A small number of participants offered several suggestions for practice. The main suggestions focused on the need for additional training for mental health clinicians, nurses, and carers. Participants also stated that there was a need for greater awareness of the environments to which consumers will be going upon discharge, as well as a need a holistic approach to care (that is, attending to both mental and physical health).

## 3.3 Discussion

The collaborative consensus-building process produced several key findings:

- (1) baseline information is essential to determining whether deterioration has occurred;
- (2) there are many signs of potential deterioration in a person's mental state;
- (3) when synthesised into clusters of signs, the majority of clusters contained signs from the literature and interviews with clinicians and people with lived experience;
- (4) the ratings indicated that all clusters of signs may be relevant to identifying deterioration in a person's mental state;
- (5) there was only modest agreement between participants in their ratings of many clusters, which seems to be attributable to the broad range of factors influencing participants' responses;
- (6) clinicians and people with lived experience were broadly similar in their ratings except for several clusters relating to care, psychosis, functioning, participating in conversations, cognition, and, appearance;
- (7) the highest rated clusters relate to safety, psychosis, and engaging in, and responding to, care;
- (8) clusters can be sorted into five indicators that might have practical utility; and
- (9) there is a need for clinicians to listen to people with lived experience.

These findings echo some of the main themes from the Updated Literature Review, namely: individualised assessment approaches, measurement using multiple behaviours, prediction with one-off versus multiple assessments over time, and multiple sources of information.

### 3.3.1 Individualised Assessment Approaches

As in the Updated Literature Review, the need for individualised assessment approaches was a theme that emerged strongly in the collaborative consensus-building process. Evidence from participants was clear that baseline information is essential for recognising deterioration. In addition, when asked if particular signs were indicative of mental state deterioration, participants' responses were often qualified (that is, whether or not individual signs represent deterioration is



frequently dependent on other factors, such as baseline information and the presence or absence of other signs).

### 3.3.1.1 Baseline Information Essential for Identifying Deterioration

The Scoping Review touched on the importance of baseline information to identifying deterioration.<sup>3</sup> The findings of the present project reinforce the need to obtain individualised baseline information to enable assessment of deterioration. Baseline information is essential, because what is typical behaviour for one person may be highly unusual for another. Identifying and tracking mental state deterioration, therefore, differs from assessing acute physiological deterioration. When assessing a person's vital signs, clinicians can document the normal physiological range for that person (that is, develop a baseline), but also draw upon established thresholds for each physiological parameter (or combination of parameters) that are indicative of abnormality.<sup>2</sup> By contrast, norms for measures of psychological attributes are far less robust (for example, norms often apply only to narrowly-defined populations and can quickly become dated).<sup>34</sup> These learnings prompted us to adapt the definition of deterioration in the Scoping Review to reinforce the point that determining change is entirely individualised, relying on the availability of previous information about a person. In our updated definition, deterioration is:

*A change for the worse in a person's mental state, compared with the most recent information available for that person, which may indicate a need for additional care.*

In adapting the definition, we also took the opportunity to broaden the definition through removing the reference to clinical options that may be used following the recognition of deterioration, and replacing these terms with "a need for additional care". This change expands the definition to include the potential for interventions from carers and the use of self-care strategies.

### 3.3.1.2 Responses to Signs Highly Dependent on Other Factors

The high proportion of clusters rated as *investigate* and modest levels of consensus for many clusters can probably be attributed to the large number of factors affecting participant decision-making. The survey required participants to consider each cluster of signs in isolation, which contrasts with the reality that additional information (for example, the presence of other signs) will typically influence decision-making. A strong theme running through the interview material and the participants' comments at the end of the surveys was that decisions were dependent on a multitude of factors, rather than one observed cluster of signs. Such factors include those relating to the person who is possibly experiencing deterioration (for example, gender, age, ability, cultural background, and psychiatric diagnosis), the signs and their assessment (for example, differentiating deterioration from natural variation, the availability of accurate baseline information, the frequency and timeframe during which signs were observed, the presence of other signs, the time available for diagnosis, and communication difficulties), and the setting (for example, the context in which signs are observed and the skills and experiences of clinicians).

There were also aspects of the survey and patterns of responding that contributed to variations in responses. Such aspects included the tendency for some participants to prefer an *act* response and others *investigate*, the breadth of signs within some of the clusters, and the differing frames of reference that participants used (for example, responding with reference to own experiences of signs rather than more generally).

Although there was more variation in responses than may be expected at the conclusion of a Delphi process, the findings seem to deliver a clear message. That is, (1) almost all of the clusters of signs warrant further investigation or immediate action, and (2) most clusters are insufficient indications of deterioration on their own, but contribute to an overall assessment of whether deterioration has occurred.

### 3.3.2 Measurement using Multiple Behaviours

Whereas recognising clinical deterioration relies on the regular monitoring of vital signs and other physiological parameters,<sup>2</sup> assessing deterioration in a person's mental state (a psychological construct) calls for the identification of behaviours that relate to this construct.<sup>34</sup> Through the collaborative consensus-building process, we identified a broad number of signs that are relevant to the deterioration in a person's mental state. We have also concluded that the highest rating clusters of signs may represent deterioration that has already occurred, and shown how the clusters can be sorted into five indicators.

#### 3.3.2.1 Broad Number of Relevant Signs of Deterioration in a Person's Mental State

This project has highlighted the significant breadth of signs that could be indicative of deterioration in a person's mental state. The identification of 168 signs underscores one of the difficulties inherent in recognising deterioration. That is, there are many signs that have the potential to be indicators of deterioration and each of these signs could have explanations other than deterioration.

To facilitate their use in this project (as well as in practice), these signs were synthesised into clusters, with each cluster containing signs that are similar. Even with this thematic analysis, 38 clusters of signs emerged, all of which were rated as requiring some type of response (either *act*, *investigate*, or, for one cluster, *monitor*). These ratings suggest that all clusters could be relevant to identifying deterioration in a person's mental state.

Although clustering signs may be necessary for enhancing their useability, one issue created is that some signs in a cluster may be more closely related than others. Five participants commented that some of the clusters were challenging to rate, because they would have provided different ratings for the signs within each of these clusters. Such comments illustrate the trade-off between parsimony and precision. Generating tighter clusters of signs (in which the signs are strongly similar) would necessitate the inclusion of more clusters.

### 3.3.2.2 Highest Rated Clusters May Signify that Deterioration has already Occurred

One of the purposes of using the Delphi method was to facilitate differentiation between the clusters in terms of importance. The findings suggest that many of the most highly rated clusters may represent signs of deterioration that has already occurred. Reductions in safety (of self, others, and property) represented three of the four highest-rated clusters. Along with increases in the use of restrictive practices (rated fifth), these clusters signify (seemingly with a high degree of certainty) that deterioration has occurred. Although deterioration would seem to be fairly advanced if these clusters of signs are present, their inclusion in any protocol could serve to remind clinicians to consider mental state deterioration as an explanation for these signs.

The high rating of the physiological/medical cluster of signs serves as a reminder of the need to attend to the physical health needs of consumers. There is a strong body of evidence that people with serious mental illness have higher rates of medical conditions and earlier mortality than the general population, as well as experiencing inequalities in healthcare.<sup>40, 41</sup> There were also several comments and stories from the interviews about people receiving inadequate medical care on the basis that their primary presenting issues pertained to their mental health. The high rating of this cluster attests to the need to take a holistic approach to care, rather than considering physical health separately from mental health.

Clusters focusing on signs of psychosis (expressing strong beliefs that are contradicted by reality or rational argument, and appearing to hear or see things that are not real) rated highly, mainly due to the particularly high ratings that people with lived experience gave to these signs. One explanation for the differences in ratings could be that psychosis can be a deeply distressing experience for people with lived experience,<sup>42</sup> whereas caring for people with psychosis is routine practice for many clinicians.

Several clusters relating to care (unresponsiveness to care, disengaging from care, and self-initiated care-seeking behaviours) were also rated highly. The majority of people with lived experience rated these clusters as *act*, whereas clinicians typically preferred the *investigate* option. This finding seems somewhat counter-intuitive, with a possible explanation being that clinicians may have more experience with these clusters of signs and consider there to be multiple possible pathways from each (some more serious than others). An unexpected finding was that people with lived experience rated one of the clusters relating to care (care-seeking initiated by carers and others) meaningfully lower than the aforementioned care-related clusters. The majority of people with lived experience responded with *investigate*, rather than *act*. This finding seems to conflict with other evidence that the voices of carers need to be heard more strongly in healthcare settings. An alternative explanation is that the finding could be an artefact of the scale used as a proxy for importance.

### 3.3.2.3 Clusters can be Sorted into Five Indicators that Might have Practical Utility

The outcomes from the Delphi survey (that is, almost all clusters receiving median ratings of *act* or *investigate*) raised concerns as to the practicalities of using 38 clusters of signs in practice. Our attention was drawn to how these clusters could be meaningfully grouped to enhance their potential utility for practice. Several ways of sorting the clusters (for example, into the themes of appearance, care, biomedical, thoughts, conversations, behaviours, and feelings) led to unsatisfactory outcomes. Such generic themes did not provide information on what behaviours indicate deterioration; clinicians would still need to refer to the clusters of signs, largely eliminating the value of grouping the clusters. For example, knowing that a person's *thoughts* or *behaviours* may indicate deterioration, provides no clues as to what content in expressed thoughts and what behaviours clinicians should be identifying as possible signs of deterioration. Our proposed solution overcomes the limitations of such groupings of clusters through providing indicators of deterioration that are informative without the underlying clusters of signs. These indicators are:

- reported change;
- distress;
- loss of touch with reality or consequence of behaviours;
- loss of function; and
- elevated risk to self, others or property.

There are several appealing aspects of this solution. First, the indicators would seem to have the potential to be used independently of the clusters of signs. Although the clusters contain valuable information for identifying and tracking deterioration, the set of five indicators would seem to have practical utility for facilitating the recognition and response to deterioration. Second, the indicators can be described in ways that may be readily accessible to consumers, carers, and clinicians without backgrounds nor extensive training in mental health. Third, the importance of the voices of consumers and carers is made clear through the *reported change* indicator. With evidence from the interviews suggesting that clinicians, in general, commonly do not listen to consumer and, in particular, carer reports, this indicator may serve as a salient reminder that people with lived experience are invaluable sources of information about a person's mental state. The inclusion of this indicator is also consistent with the RANZCP Code of Ethics, which encourages the active participation of family and other non-professional carers in a person's clinical care.<sup>43</sup> Fourth, the indicators are positioned well with respect to ethical guidelines that call for psychological assessments to be based on data from a range of sources.<sup>44</sup> Evidence strongly suggests that distinct assessment methods provide unique information.<sup>45</sup> The indicators invite the use of multiple sources in determining whether deterioration has occurred.

### 3.3.3 Prediction with One-Off versus Multiple Assessments over Time

The purpose, design, and conduct of this project has led to the generation of clusters of signs and indicators that appear to be responsive to change. That is, these clusters and indicators appear to lend themselves to repeated use over time to monitor changes in mental state. Establishing how these clusters and indicators could be used in practice and a pilot evaluation of their utility, however, was beyond the scope of this project. Further research is warranted in these areas.

### 3.3.4 Multiple Sources of Information

Evidence from the Scoping Review,<sup>3</sup> research literature,<sup>45</sup> and practice documents<sup>43, 44</sup> all points to the necessity of including information from multiple sources when conducting assessments. The inherent value in drawing upon multiple sources of information was also apparent in the material collected during the collaborative consensus-building process. Participants spoke of the need for clinicians to pay greater attention to the voices of people with lived experience. Differences between clinicians and people with lived experience in the rating of some clusters also suggests that different perspectives may yield valuable and complementary information about changes in a person's mental state.

#### 3.3.4.1 Listening to People with Lived Experience

Baseline information can come from many sources, including from knowing the person over an extended period of time, being familiar with the person's history, observing changes in the person's behaviour, and seeking information from the person, carers, and family members. Evidence from workshop participants\*, however, suggests that obtaining this information is not done well. In particular, people with lived experience described how carers' voices were often not heard in healthcare settings. The consumers and carers commented that it was common practice for clinicians not to engage with carers and not to listen when carers attempted to report changes in a person's mental state. This finding echoes the research literature, in which the disempowerment, exclusion, and invisibility of families in relation to mental health service delivery has been reported.<sup>46</sup>

The findings stand in contrast to the position of the RANZCP in its submission to the Scoping Review.<sup>3</sup> The RANZCP noted that families and close friends have a central role in identifying early stages of deterioration in a person's mental state. Thus, there would seem to be a gap between what is considered best practice and what some consumers and carers are experiencing.

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\* Workshop participants were presented with the preliminary findings from the collaborative consensus-building process. Where appropriate, their insights have been integrated into the discussion of this stage of the project.

### 3.3.4.2 Differences between the Ratings of Clinicians and People with Lived Experience

Overall, clinicians and people with lived experience were similar in their ratings of clusters. Caution needs to be exercised when interpreting differences in ratings due to the sample size (14 clinicians and 22 people with lived experience completed the final survey). For clinicians, a change in one participant's ratings results in a 7% shift in percentages. For people with lived experience, one person shifts the outcome almost 5%.

The clusters for which sizable differences are present seem to have common overarching themes. Differences on clusters relating to care and psychosis have been mentioned already. In addition, some clusters relating to functioning (unusual movement patterns, and loss of skills) received markedly higher ratings from people with lived experience. Perhaps the signs within these clusters are less familiar (and potentially particularly concerning) to people with lived experience (compared with, for example, self-reported sadness, fear, and anger) and so may have been more likely to elicit higher ratings. In contrast, clinicians provided higher ratings for clusters relating to participating in conversations, cognition, and appearance. Perhaps clinicians identified these clusters of signs as having potentially serious connotations.

### 3.3.5 Research Considerations

A strength of the collaborative consensus-building process was the engagement of clinicians and people with lived experience with diverse backgrounds. Even so, additional consultation with people from CALD backgrounds, Aboriginal and Torres Strait Islander peoples, and people with disability would be highly desirable. Although we approached organisations representing the interests of specific populations, engaging potential participants was not always possible. The timeframe of this project meant that some people were unavailable to participate at the times required. The timelines also limited our ability to engage further with these organisations to identify other potential participants.

In response to feedback received from someone with a CALD background completing the first survey, two words were clarified to improve understanding; that is, "boisterousness" was changed to "boisterousness (being overexcited/rowdy)" and "trajectory" was changed to "pathway/trajectory". Defining terms only goes part way to ensuring the clusters of signs are appropriate for use with people from CALD backgrounds.

Broad consultation with Aboriginal and Torres Strait Islander peoples was not achieved in this project. As such, the meaning of deterioration in a person's mental state to Aboriginal and Torres Strait Islander people remains underexplored. Furthermore, participants noted the need for cultural responsiveness in the assessment of Aboriginal people. Additional engagement with Aboriginal and Torres Strait Islander peoples is needed.

Input from people with disability into the collaborative consensus-building process was also limited. The point was made that many of the clusters of signs rely on complex behaviour or verbal communication, which is challenging for some people (for example, people with intellectual disability). More work is

required to identify equivalent behaviours for signs that are typically expressed verbally. In this regard, one participant recommended drawing on the resources of the Department of Developmental Disability Neuropsychiatry at the University of New South Wales.\*

### 3.4 Conclusion

There were many signs of possible deterioration in a person's mental state identified in this study. These signs form 38 clusters, which, themselves, can be synthesised into five indicators. The clusters are all important, with almost all requiring *act* or *investigate* responses. Although the ratings seem to provide evidence on what clusters require the most urgent responses (that is, clusters with a median rating of *act*), these clusters may also signify that deterioration has already occurred. Identifying deterioration early in its trajectory probably involves working with the many clusters for which an interpretation of “this person’s mental state is deteriorating” is much more uncertain (that is, those clusters rated as *investigate* or *monitor*). The development of the five indicators has salience, because they may represent a solution that is more workable in practice than 38 clusters. The indicators also have the advantage of promoting the importance of consumer and carer voices in healthcare settings (due to explicit inclusion of their input through the *reported change* indicator), which both clinicians and people with lived experience suggest are limited at present.

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\* <http://www.idhealtheducation.edu.au>

## 4. Review of Signs of Mental State Deterioration and Practice Implementation Issues

Workshops were held to review the findings from the literature review and collaborative consensus-building process. Including clinicians and people with lived experience at this point afforded us the opportunity to discuss the findings of the project and our interpretations of these findings, conduct further validation work in relation to these findings, and to explore potential practice implementation issues. The involvement of consumers and carers in the research process, other than as research participants (in this instance, in the interpretation of findings), is consistent with international trends towards involving people with lived experience in health research.<sup>47</sup> Drawing on the expertise of clinicians and people with lived experience at this stage was designed to strengthen the outcomes from this project. The central focus of the workshops was on:

- obtaining baseline information;
- assessing the indicators; and
- reviewing the clusters of signs.

### 4.1 General Approach

Twelve participants from the collaborative consensus-building process (six clinicians and six people with lived experience) and staff from Commission were invited to attend two full-day workshops. One clinician was absent from both workshops due to personal circumstances and another clinician was unable to attend the first workshop due to major flight disruptions. Selection of participants to invite to the workshops was based on:

- the extent to which people participated in the interviews and three surveys,
- an aim to achieve a balance between clinicians (including clinicians with different backgrounds) and people with lived experience (including consumers and carers),
- an intention to recruit participants across Australian states and territories,
- an aim to include representatives of people from diverse backgrounds, and
- the availability of participants for both workshops.

Those attending the workshops received a briefing on the project's findings (on which they were encouraged to provide feedback) and engaged in several exercises designed to stimulate thought on obtaining baseline information, the indicators, and the clusters of signs. Material generated through these exercises was recorded (using feedback sheets, whiteboards, and digital photography) and used to inform the finalisation of proposed clusters of signs and indicators.



## 4.2 Obtaining Baseline Information

One of the main findings from the interviews was that having baseline information is necessary for the assessment of deterioration in a person's mental state. Given this finding, some attention needs to be paid to how baseline information can be obtained in healthcare settings.

We asked workshop participants to focus on the communication of baseline information. To stimulate their thinking, we invited them to reflect on times when the communication of baseline information had gone well. Participants worked individually, were involved in small group discussions, and then reported back to the whole group. Ideas from the group were recorded on a whiteboard, transcribed, and used for subsequent analysis.

What follows is a summary of the ideas that participants put forward. Participants spoke about information content; sources of information; resource implications of obtaining baseline information; timing of information availability; obtaining information from consumers, carers, and next of kin; obtaining information from other clinicians; communication of information; shared responsibility; and tools.

### 4.2.1 Information Content

Baseline information is necessary on consumers' histories with respect to mental health, social issues, and functioning. Recency and primacy of information are both important. Participants acknowledged that the clinical value of separate pieces of information may vary depending on the sources of that information and the perceptions of people involved in its collection.

### 4.2.2 Sources of Information

Several sources of information were mentioned during the discussions: consumers, carers and next of kin, emergency service professionals, and healthcare providers.

#### 4.2.2.1 Consumers

Participants suggested that consumers were often the most important sources of baseline information. Consumers can assist those providing care through being good historians and bringing with them written information about their health and contact details for carers and next of kin. Consumers may also make use of advance care plans or WRAP®. Clinicians should acknowledge and use this information. The point was also made that this information should be traceable (that is, there should be evidence of the sources of information).

#### 4.2.2.2 Carers and Next of Kin

Carers and next of kin can be valuable sources of baseline information. Concerns were expressed, however, that some clinicians may not be listening to carers due to perceived privacy and confidentiality issues. Although consumer consent should be obtained when required, the rights of carers to report information to clinicians should also be recognised and respected.

#### 4.2.2.3 Emergency Service Professionals

Emergency service professionals (for example, ambulance personnel and police) involved in handovers to clinicians can be sources of baseline information. This information can be in written or verbal form. If baseline information is not obtained during handover, it is highly likely that this information will not be recoverable at a later point in time. Information provided in written form must be acknowledged and read.

#### 4.2.2.4 Healthcare Providers

Baseline information can exist in hospital records, and records from other hospitals, general practitioners, and other health providers. Workshop participants drew attention to the need for the health information system to have the capacity to record, retain, and make accessible historical information (that is, baseline information) that could be used for the assessment of deterioration in a person's mental state. The current system has weaknesses in this respect. One of the key advantages of having such information available is that consumers would be spared the possible re-traumatisation of having to retell their stories with each episode of care or to multiple clinicians during single admissions.

### 4.2.3 Resource Implications of Obtaining Baseline Information

Obtaining baseline information has resource implications (for example, staff time involved in obtaining records from other service providers). Clinicians practice within resource constraints and are required to make decisions on how to use these resources most effectively. The value of obtaining additional baseline information needs to be weighed against competing priorities for resources.

#### 4.2.4 Timing of Information Availability

Comprehensive baseline information may not be initially available. Typically, information becomes available progressively over time. Given that decisions need to be made without comprehensive baseline information, priority needs to be given to obtaining as much information as possible to inform the next clinical decisions.

### 4.2.5 Obtaining Information from Consumers, Carers, and Next of Kin

The manner in which clinicians approach the task of obtaining information from consumers, carers, and next of kin can significantly influence what information is disclosed. More and better quality information is likely to be disclosed when clinicians show care and respect, and have the patience to allow people to divulge information in their own time. The availability of cultural supports (for example, interpreters and clinicians showing cultural awareness) can assist this process.

Obtaining baseline information from consumers, carers, and next of kin is a skilful task. Central to interactions is the rapport between clinicians and those

providing baseline information. Clinicians are likely to be more effective when they take the time to hear people's stories, ask many objective questions, refrain from being dismissive of aspects of people's stories or their concerns, remain calm and empathic when working in emotional situations, use language that is consistent with the language of those with whom they are conversing (for example, less technical, more experiential language), and display positive body language. Care is needed to avoid making assumptions or drawing conclusions based on experiences with similar people or issues.

There is a power differential inherent in relationships between clinicians and consumers, carers, and next of kin. When obtaining baseline information, the differences in power of those involved need to be recognised and made transparent.

Recording information facilitates the communication of information to others involved in care. Such communication can reduce the likelihood that consumers, carers, and next of kin will need to repeat their stories to many clinicians.

#### **4.2.6 Obtaining Information from Other Clinicians**

Obtaining baseline information from other healthcare professionals necessitates the identification of the right person within the healthcare system. Attempts should be made to speak with the clinician who knows the person well.

#### **4.2.7 Communication of Information**

Baseline information needs to be transferred directly to the person making clinical decisions, rather than that person receiving information second-hand.

#### **4.2.8 Shared Responsibility**

The responsibility for having baseline information available is one that can be shared between consumers, carers, and clinicians. Acknowledgement that this responsibility is shared would assist in tracking changes and in treatment. This shared responsibility extends to the consideration of what consumers, carers, and clinicians could do to improve the process of understanding and communicating baseline information.

#### **4.2.9 Tools**

The use of a checklist is one way of facilitating the recording of baseline information. The design of such a checklist should enable information to be recorded objectively, capture information that is meaningful, be appropriately sensitive to the circumstances, and accommodate the skills of the end users. A tool designed for non-mental health clinicians might be particularly useful.

## 4.3 Assessment of the Indicators

One of the outputs from the analysis of interview data was the five indicators: reported change, distress, loss of touch with reality or consequence of behaviours, loss of function, and elevated safety concerns. We presented these indicators to participants and invited them to engage in activities to assess the validity of the indicators and to gauge their potential usefulness to practice.

### 4.3.1 Sorting of Clusters into Groups

As an initial test of the validity of the indicators, we asked workshop participants to sort the clusters of signs into the indicators we described. For this exercise, we asked participants to organise themselves into three groups: carers, consumers, and clinicians (that is, participants chose which group they joined). We gave each group a set of five cards with the names and descriptions of the potential indicators and another set of 38 cards with the clusters. They were asked to attempt to sort the clusters into the indicators.

For 15 of the 38 clusters, workshop participants in all three groups (carers, consumers, and clinicians) agreed on the groupings (see Table 8). For 21 clusters, two of the three groups (consumers and carers,  $n=7$ ; consumers and clinicians,  $n=13$ ; carers and clinicians,  $n=1$ ) agreed on the groupings. There was no agreement between groups for the remaining two clusters.

The notes to Table 8 provide details of where each group sorted the clusters. There were two main areas of difference: (a) consumers and carers sorted clusters about self-initiated care-seeking behaviours and self-reported emotions to *reported change* whereas clinicians assigned them to *distress*, and (b) consumers and clinicians sorted clusters about observations during conversations (for example, appearing distracted during conversations) to *loss of function*, whereas carers allocated these clusters to *loss of touch with reality or the consequences of behaviours*.

The sorting of clusters to indicators of the workshop participants compare favourably with those that we initially developed (compare Table 5 with Table 8). For the 15 clusters where there was agreement between the three groups, our assignments of clusters to the indicators matched those of workshop participants. For the 21 clusters for which two of the three groups agreed, our analysis matched theirs for 18 of these clusters. The areas of difference were: (a) we had allocated the *physiological/medical* cluster to *elevated risk to self, others or property* (as did carers), whereas consumers and clinicians sorted this cluster to *distress*; (b) we had sorted *appearing confused during conversations* to *loss of function* (as did consumers), whereas carers and clinicians considered this cluster fitted best with *loss of touch with reality or the consequences of behaviours*; and (c) we placed *withdrawing from social situations* with *elevated risk to self, others or property* (as did carers), whereas consumers and clinicians sorted this cluster to *loss of function*.

**Table 8:** Workshop participants' groupings of the clusters of signs.

Reported Change	Distress	Loss of Touch with Reality or Consequence of Behaviours	Loss of Function	Elevated Risk to Self, Others or Property
Clusters that consumers, carers, and clinicians assigned to the same indicators				
Care-seeking initiated by carers and others Self-reported sense of self Self-reported uncontrollable thought processes	Appearing challenging during conversations Facial expressions	Expressing strong beliefs that are contradicted by reality or rational argument Appearing to hear or see things that are not real	Unusual movement patterns Loss of skills Poor daily self-care	Increases in the use of restrictive practices Reduced self-restraint Reduced safety of self Reduced safety of others Reduced safety of property
Clusters for which two of three groups of participants agreed on the indicators				
Self-initiated care-seeking behaviours <sup>a</sup> Self-reported sadness <sup>a</sup> Self-reported fear <sup>a</sup> Self-reported anger <sup>a</sup>	Physiological/medical <sup>b</sup> Pessimistic talk during conversations <sup>b</sup>	Unusual self-presentation <sup>c</sup> Unusual ways of behaving <sup>d</sup> High energy behaviours <sup>e</sup> Appearing confused during conversations <sup>f</sup>	Withdrawing from social situations <sup>g</sup> Reduction in regular activities <sup>e</sup> Low energy behaviours <sup>e</sup> Appearing disconnected during conversations <sup>h</sup> Appearing distracted during conversation <sup>h</sup> Speech during conversations <sup>e</sup> Difficulty following conversations <sup>h</sup> Seemingly impaired memory <sup>h</sup> Apparently inflexible thought processes <sup>h</sup>	Disengaging from care <sup>i</sup> Unresponsiveness to care <sup>d</sup>
Clusters for which there was no agreement between consumers, carers, and clinicians				
Constantly changing symptoms of a mental health condition <sup>j</sup>		Social circumstances and environment <sup>k</sup>		

Note: Agreement between participants are provided in superscripts.

<sup>a</sup>Agreement between consumers and carers. Clinicians allocated cluster to *distress*.

<sup>b</sup>Agreement between consumers and clinicians. Carers allocated cluster to *elevated risk to self, others or property*.

<sup>c</sup>Agreement between consumers and clinicians. Carers allocated cluster to *loss of function*.

<sup>d</sup>Agreement between consumers and carers. Clinicians allocated cluster to *loss of function*.

<sup>e</sup>Agreement between consumers and clinicians. Carers allocated cluster to *distress*.

<sup>f</sup>Agreement between carers and clinicians. Consumers allocated cluster to *loss of function*.

<sup>g</sup>Agreement between consumers and clinicians. Carers allocated cluster to *elevated risk to self, others or property*.

<sup>h</sup>Agreement between consumers and clinicians. Carers allocated cluster to *loss of touch with reality or the consequences of behaviours*.

<sup>i</sup>Agreement between consumers and carers. Clinicians allocated cluster to *loss of touch with reality or the consequences of behaviours*.

<sup>j</sup>No agreement. Consumers allocated cluster to *elevated risk to self, others or property*. Carers allocated cluster to *distress*. Clinicians allocated cluster to *reported change*.

<sup>k</sup>No agreement. Consumers did not allocate cluster to any group. Carers allocated cluster to *distress*. Clinicians allocated cluster to *loss of function*.

### 4.3.2 Reflections on the Cluster Sorting Exercise

In addition to sorting the clusters, we asked workshop participants for their reflections on this exercise. They commented that:

- The five indicators are not discrete; several of the clusters could be sorted to more than one indicator. The clinicians reported that clusters relating to judgement and communication were initially left out of their solution. They suggested that these clusters could form separate indicators. With further thought and discussion, however, they were able to fit the clusters into the five-indicator solution. The group of participants identifying as consumers reported that clusters relating to external judgements of change (deterioration) were initially difficult to sort to the five indicators.
- They could see how observations relating to any of these indicators may be sufficient to prompt escalation of care.
- There is a need to use measures that are as objective as possible.
- It is likely that multiple observations will be used to make judgements. There may be potential for these clusters and indicators to be used to build a score, and it could be this score that is communicated.
- There remains a need to focus on a person's overall wellbeing, not only the clusters and indicators (that is, both physical and psychosocial functioning should be considered).

### 4.3.3 Using the Indicators

As an assessment of the potential utility of the indicators, we conducted an exercise in which workshop participants were invited to apply the indicators to examples of deterioration in a person's mental state from their own experiences. Participants were asked to recall an example of when they, or someone for whom they were caring, experienced deterioration in mental state, and to record the signs of change.

We asked participants to imagine that the person experienced this deterioration while in the care of someone who was clinically competent, but who was not that person's primary carer or a mental health specialist. We asked them to consider whether the clinician, using these five indicators, would have a reasonable chance of (a) detecting the deterioration, (b) making sense of the deterioration, and (c) being able to do these things relatively early in the deterioration. The feedback from participants was that:

- The indicators would work in clinical settings.
- Many, if not all, of the five indicators were apparent in the examples recalled. That is, the indicators could be used to identify deterioration. In examples of psychosis, all five indicators were apparent. Participants suggested that advanced deterioration could be fairly easily identified using the five indicators, but that the indicators would probably have worked several days prior to the person presenting to healthcare professionals.

- The inclusion of *reported change* elevates the importance of subjective experiences (for example, reports from consumers and carers) versus objective indicators.
- In some of the examples recalled, it was clinicians and carers who were distressed (for example, due to noticing unusual behaviours, receiving angry responses, and worrying about risk) rather than (or as well as) the person experiencing deterioration. For example, clinicians visiting a person's home may observe carer distress. There may be a need to broaden the definition of the distress indicator to include the distress of clinicians and carers.
- Doubt was expressed about whether these indicators could be used at home to detect early deterioration. WRAP® may be of more use to people with lived experience in home settings. Clinicians and other healthcare professionals undertaking home visits, however, would be able to use these indicators to identify deterioration, especially when there is regular contact with people who may experience deterioration.
- We also asked participants how the indicators could be made more usable for clinicians. They suggested that:
  - There needs to be recognition throughout the healthcare sector that identifying and tracking deterioration in a person's mental state should be aspects of routine care.
  - There are inherent problems with medicine being separated into "silos". Identifying and tracking deterioration in a person's mental state would require integrated screening processes and, when mental health issues are identified, appropriate services need to be easily accessible.
  - The indicators would need to be integrated into referral criteria to facilitate access to appropriate services.
  - There is a need for decision-support tools to assist clinicians to identify and track deterioration.
  - Providing training to clinicians is necessary (for example, through in-service training and team meetings). Such training should be a priority for entry-level healthcare practitioners and locums. Thought also needs to be given to the training of police, ambulance officers, and general practitioners in the use of these indicators. There was an acknowledgement, however, that training alone is an ineffective strategy for changing healthcare practises.
- The potential exists for the clusters and indicators to be made accessible as an app (application software) for a phone or tablet.
- Local customisation of the clusters within each indicator may be possible.



## 4.4 Review of the Clusters of Signs

Feedback received during the administration of the surveys suggested that the wording of some of the clusters of signs could be improved. We requested that workshop participants identify clusters that may need revising and to suggest what changes could be made.

Participants provided feedback on 25 of the 38 clusters of signs (see Appendix C). Most of these 25 clusters received feedback from one (n=9) or two (n=10) participants. The clusters that received feedback from the most numbers of participants were *self-initiated care-seeking behaviours*, *care-seeking initiated by carers and others*, and *pessimistic talk during conversations*. The central issue with the first two of these clusters was that the term *care-seeking* has negative connotations for many people. For example, care-seeking can sometimes be interpreted as attention-seeking. Also, the examples provided for these clusters relate to treatment, rather than care, more generally. In respect to the third cluster, the term *pessimistic talk* was considered too narrow for the examples provided. The participants suggested that the name of the cluster could be broadened to reflect the negative themes evident in the examples.

## 4.5 Discussion

The conversations with workshop participants served to highlight many of the complexities in obtaining baseline information. In the context of busy healthcare settings, clinicians have the challenge of obtaining clear and reliable information from several potential sources. New innovations – such as the use of mobile apps to track and share information on mood, behaviour, and activities<sup>48</sup> – may be helpful in this regard. Given that there are different sources of baseline information, however, a range of solutions to enhance the timely communication of this information seem necessary. In addition, workshop participants identified several practice issues, such as the need for integrated screening processes across the “silos” in healthcare, which need to be addressed. Further work is required to develop a suite of measures that may be effective for enhancing the timely availability of baseline information.

The feedback from workshop participants on the potential utility of the indicators was particularly encouraging. Before the indicators may be ready to be implemented into practice, there are key questions that will need addressing. Foremost among these questions are:

- How should the five indicators be operationalised to enable both the identification and tracking of signs of deterioration? Although some of the indicators may be sufficient in themselves to enable the identification of deterioration, tracking deterioration will necessitate some form of collecting and collating evidence in a systematic manner. Part of the answer may lie in the use of instruments such as the DI-5<sup>9-11</sup> (a measure of psychological distress identified in the Updated Literature Review), as well as determining what assessment tools are already in use, with a view to preventing duplication. Any introduction of new instruments may increase administrative burden, which must be weighed against the practical outcomes associated with such changes to practice.

- Do the five indicators allow the identification of deterioration at a sufficiently early stage to prevent significant further deterioration in a person's mental state? The potential value in the five indicators is in their use to identify deterioration at a sufficiently early stage to enable intervention to prevent further worsening of a person's mental state. Evidence is required of the five indicators being fit for this purpose.
- How can any solution best be implemented into practice to ensure meaningful outcomes for people experiencing deterioration in their mental states? The complexity of translating evidence into practice is well-recognised.<sup>49</sup> Generating change typically requires action at multiple levels (clinician, healthcare team, organisation, broader environment) that is tailored to specific settings and the professionals involved. The discussion with workshop participants only provided initial insights into what may be required. The training of healthcare professionals was identified as an essential, but insufficient, component of practice change. Thought needs to be given to how a potential solution to identifying and tracking deterioration could be implemented across many healthcare settings and types of healthcare professionals.

Although there may have been merit in revising the clusters prior to the Delphi surveys, we have doubts whether a review of clusters at that time would have produced feedback similar to that which was received during the second workshop. The workshop participants performed this review with the benefit of already having engaged in an interview, three surveys, and the first workshop, in which the findings of the interviews and surveys were discussed. Had a workshop been held prior to the surveys, only the 168 signs and 38 clusters were known. A review at this point may have resulted in an increased number of clusters, rather than feedback to merge clusters. Indeed, feedback received during the surveys suggested that several participants wanted some clusters to be split into additional clusters. Furthermore, one of the central outcomes from the surveys was that all clusters were important to identifying and tracking deterioration. The findings from the collaborative consensus-building process in association with the feedback suggest the need to retain the content of all clusters, albeit in a slightly tighter solution (that is, fewer clusters).

## 4.6 Conclusion

Consumers can be the most valuable source of baseline information. There are many other sources of baseline information, including carers and next of kin, emergency service professionals, and healthcare providers. Inherent challenges with obtaining baseline information include circumstances when:

- consumers are not good historians of their own health and healthcare information;
- clinicians do not display care and respect in their interactions with consumers, carers, and next of kin;
- information must be obtained in a timely manner to prevent it from becoming lost;
- information is not available, or cannot be easily accessed, from the information systems of healthcare providers; and

- the collation of information places significant additional demands on stretched healthcare resources.

Workshop participants were generally positive about the potential utility of the indicators. Participants suggested that the indicators would work well in clinical environments and that observations relating to any of the five indicators may be sufficient to prompt an escalation of care.

Many of the clusters of signs each appear to be related to more than one indicator. How a cluster manifests in any given situation may dictate the indicator to which it best relates.

Alternative names were provided for some of the clusters of signs. There were also suggestions that some clusters covered similar territory and could be merged.

## 5. Proposed Clusters and Indicators

Workshop participants were generally supportive of the clusters, the indicators, and their potential for use in healthcare settings. Nevertheless, their feedback invited reflection on the clusters and indicators. Here, we present proposed changes to the clusters and indicators.

### 5.1 Proposed Clusters

Workshop participant feedback was principally directed towards merging clusters considered similar and changes to the names of some clusters. Based on this feedback and discussions with participants, we propose (commonly minor) changes to the clusters (see Table 9 and Appendix C). A full list of the clusters with examples of the signs that contribute to each cluster is available in Appendix D.

#### 5.1.1 Cluster Merging

The content of 10 clusters was merged with other clusters. These changes resulted in the elimination of clusters that were too similar in content to other clusters. For example, several clusters relating to a person's functioning in conversations have been merged into one cluster. The specificity evident in the original 38 clusters may be unnecessary for clinicians to identify and track signs of deterioration in a person's mental state.

#### 5.1.2 Cluster Renaming

The names of 14 clusters were modified to reflect their underlying signs better (for example, *pessimistic talk during conversations* was changed to *negative themes in conversations*) (see Appendix C). Many of the changes were relatively minor, and served to strengthen the clarity of the clusters.

#### 5.1.3 Cluster Removal

One cluster (*social circumstances and environment*) was removed, because social circumstances and environments are risk factors rather than behaviours that may be indicative of deterioration.

#### 5.1.4 Cluster Addition

An issue inherent in the proposed indicators was that the clusters allocated to the *distress* grouping provided a rather weak representation of the concept of distress. This weak representation seemed inconsistent with feedback from workshop participants that *distress* was a relevant indicator of mental state deterioration. In addition, evidence from the workshop participants' sorting of clusters to indicators suggested that there may be some degree of overlap between *reported change* and *distress* (clinicians sorted clusters pertaining to self-initiated requests for assistance and self-reported negative emotions to *distress*). These findings prompted us to investigate the extent to which distress was evident in the data on signs of deterioration that emerged from the literature review and the interviews. We found that distress was mentioned in

the literature and during interviews with consumers, carers, and clinicians. These data were coded to various other clusters. During the interviews, participants made reference to experiencing, self-reporting, and observing distress, as well as to the distress of others (carers and clinicians). On the strength of this evidence, we propose the introduction of an additional cluster (*apparent distress of self or others*).

## 5.2 Proposed Indicators

On the basis of the evidence and feedback from the workshops, the five indicators would appear to have potential utility for identifying and tracking signs of deterioration in a person's mental state. We propose that the description of the *distress* indicator be extended to reflect the feedback that it is the people involved in a person's care (e.g., carers, clinicians, emergency service professionals) who may be showing signs of distress (that is, they are distressed about the person's mental state) (see Table 9). No other changes are proposed.

## 5.3 Conclusion

The findings from the collaborative consensus-building process and the feedback received during the workshops support the proposal of five indicators of deterioration in a person's mental state and 28 clusters of signs. The initial support for these indicators and clusters is encouraging, and we suggest that they are suitable to be taken forward to a national consultation. To enhance the practical utility of the indicators and clusters, work is needed on how baseline information can be more effectively obtained, communicated, and retained in healthcare settings. Further work is also necessary to determine how the indicators and clusters can be operationalised, whether they are sufficiently sensitive to identify deterioration (especially in its early stages), their validity for diverse populations, and what strategies work best to implement them into practice.

**Table 9:** Proposed clusters of signs and indicators of deterioration in a person's mental state.

Reported Change	Distress	Loss of Touch with Reality or Consequence of Behaviours	Loss of Function	Elevated Risk to Self, Others or Property
<b>Descriptions</b>				
A person, or someone who knows the person well, reports that her or his mental state is changing for the worse.	A person, or someone involved in her or his care, shows signs of distress, which are evident through observation and conversation.	A person is losing touch with reality or the consequences of her or his behaviour.	A person is losing her or his ability to think clearly, communicate, or engage in regular activities.	A person's actions indicate an increased risk to self, others, or property.
<b>Clusters of Signs</b>				
Self-initiated requests for assistance <sup>a</sup> Requests for treatment from healthcare professionals or those close to the person <sup>a</sup> Self-reported negative or inflated sense of self <sup>a</sup> Self-reported uncontrollable thought processes Self-reported negative emotions <sup>a b</sup>	Uncharacteristic facial expressions <sup>a</sup> Physiological/medical deterioration <sup>a</sup> Negative themes in conversations <sup>a</sup> Apparent distress of self or others	Indications of experiencing delusions <sup>a</sup> Indications of experiencing hallucinations <sup>a</sup> Unusual self-presentation Unusual ways of behaving <sup>b</sup> Appearing confused during conversations	Unusual movement patterns Loss of skills Poor daily self-care Reduction in regular activities <sup>b</sup> Difficulty participating in conversations <sup>a b</sup> Unusual speech during conversations <sup>a</sup> Seemingly impaired memory Apparent difficulty with thinking about things in different ways <sup>a</sup>	Increases in the use of restrictive practices Reduced safety of self Reduced safety of others Reduced safety of property Disengaging from treatment <sup>a</sup> Unresponsiveness to treatment <sup>a</sup>

Note: Changes to clusters are provided in superscripts (refer to Appendix B for details).

<sup>a</sup>The name of the cluster has been modified.

<sup>b</sup>The cluster has been combined with other clusters.

## 6. Conclusions

### Updated Literature Review

- 6.1 Since the completion of the Scoping Review, papers have been published on three new instruments (MSES, DI-5, and IRRS) and three existing instruments (DASA, BVC, and IAT) that have varying potential for identifying and tracking some of the signs of deterioration in a person's mental state.
- 6.2 Based on the mental state examination, the MSES may have the most potential for identifying and tracking possible signs of deterioration. This instrument is early in development, however.
- 6.3 The DI-5 has shown promise in tracking psychological distress.
- 6.4 Three of the instruments (DASA, BVC, and IRRS) were designed for predicting aggression and violence.
- 6.5 The IAT has shown considerable potential for the assessment of suicidality and risk of self-harm.
- 6.6 Several themes were apparent in the literature, including:
  - 6.6.1 the need for individualised assessment approaches (that is, knowing people and their behaviors and needs),
  - 6.6.2 the importance of measuring constructs with sets of behaviors rather than single behaviours,
  - 6.6.3 the increased predictive validity of multiple assessments over time versus one-off assessments, and
  - 6.6.4 the value in obtaining information from multiple sources.

### Generation of Signs of Mental State Deterioration

- 6.7 The review of literature and interviews with 19 clinicians and 23 people with lived experience enabled the identification of 168 signs of deterioration in a person's mental state.
- 6.8 These 168 signs could be summarised as 38 clusters of signs.
- 6.9 Following three rounds of Delphi surveys with clinicians and people with lived experience, 11 clusters were rated as requiring *act* responses, 26 clusters as needing *investigate* responses, and the remaining cluster as requiring a *monitor* response.
- 6.10 The highest-rated clusters relate to safety, psychosis, and (engaging in and responding to) care, and may signify that deterioration has already happened.

- 6.11 There were modest levels of agreement between participants' ratings, which may be attributable to a range of factors that affect judgements of whether particular behaviours represent deterioration (for example, the frequency with which signs were observed, and the presence of other signs).
- 6.12 The 38 clusters could be summarised into five indicators: reported change; distress; loss of touch with reality or consequences of behaviours; loss of function; and elevated risk to self, others, or property.
- 6.13 Clear baseline information is required for identifying changes in a person's mental state.
- 6.14 Several common sources of baseline information are: (a) knowing the person over an extended period of time, (b) familiarity with the person's history, (c) witnessing a change in a person's behaviour, (d) seeking information from the person as to what has changed, and (e) obtaining information from carers and family members.
- 6.15 When someone is experiencing mental state deterioration, the most commonly mentioned additional care option was hospital/emergency department/crisis team support.
- 6.16 The voices of people with lived experience are not consistently being heard in healthcare settings.
- 6.17 Although people with diverse backgrounds were involved in the project, some populations remained under-represented, including people from CALD backgrounds, Aboriginal and Torres Strait Islander peoples, and people with disability.

## **Review of Signs of Mental State Deterioration and Practice Implementation Issues**

- 6.18 Key sources of baseline information include consumers (most importantly), carers and next of kin, emergency service professionals, and healthcare providers.
- 6.19 There are many challenges inherent in obtaining baseline information.
- 6.20 The five indicators may have potential utility in healthcare settings.
- 6.21 Observations relating to any of the five indicators may be sufficient for prompting an escalation of care.
- 6.22 The five indicators were able to be applied to recalled examples of people experiencing deterioration, and would have enabled the detection of the deterioration, especially in advanced stages.
- 6.23 The description of the *distress* indicator could be expanded to include the distress of carers and clinicians, rather than only the distress of consumers.



- 6.24 To make the five indicators accessible for clinicians, attention may need to be paid to the level of recognition within the healthcare sector of the need to identify and track deterioration in mental state, the need for integrated screening processes across the “silos” within healthcare, referral pathways that are easily accessible when mental health issues are identified, the availability of decision-support tools to assist clinicians, and the training of healthcare and emergency service professionals in identifying and tracking deterioration.
- 6.25 Several of the clusters could be reviewed for language and some could be combined.

### **Proposed Clusters and Indicators**

- 6.26 Based on feedback and discussions with workshop participants, we propose merging 10 clusters of signs with other clusters, renaming 14 clusters, removing one cluster, and adding one cluster.
- 6.27 Based on the evidence from workshop participants, the five indicators can be retained and the description of the *distress* indicator can be expanded to incorporate the distress of people caring for a person experiencing deterioration in their mental state.

## 7. Recommendations

- 7.1 The five indicators of deterioration in a person's mental state and 28 clusters of signs should be taken forward to a national consultation.
- 7.2 Further work is necessary to determine:
  - 7.2.1 how baseline information can be more effectively obtained, communicated, and retained in healthcare settings (including strategies and practices that support consumers and carers with reporting baseline information);
  - 7.2.2 how the five indicators can be operationalised to enable the identification and tracking of signs of deterioration in a person's mental state;
  - 7.2.3 whether the five indicators facilitate the identification of deterioration at a sufficiently early stage to prevent significant further deterioration;
  - 7.2.4 the validity of the indicators and clusters of signs for diverse populations, such as people from CALD backgrounds, Aboriginal and Torres Strait Islander peoples, and people who may communicate differently to others due to disability (for example, people with intellectual disability); and
  - 7.2.5 how any solution for identifying and tracking deterioration in a person's mental state may best be translated into practice.

## Appendix A: Project Participants

The people with lived experience and clinicians who participated in the interviews and Delphi surveys are listed below. Those who also attended the workshops are identified with asterisks.

### Consumer and Carer Representatives

Mrs De Backman-Hoyle, QLD

Ms Alina Beverley, NSW

Ms Satu Beverley, NSW

Ms Emma Donaldson\*, National Mental Health Consumer and Carer Forum

Ms Marilyn Gotlieb, NSW

Ms Monica Hastings\*, Consumer Peer Worker, Tasmania

Mr Peter Heggie, National Mental Health Consumer and Carer Forum

Ms Elizabeth Hennessey, NSW

Ms S Lewis, NSW

Ms Eileen McDonald\*, National Mental Health Consumer and Carer Forum (Deputy Carer Co-Chair), Safety and Quality Partnership Standing Committee, Australian Commission on Safety and Quality in Health Care (Mental Health Advisory Group), National Register of Mental Health Consumers and Carer Representatives, and Mental Health Carers NSW (Co-Chair, Carer Peak Advisory Committee)

Ms Janne McMahon OAM, Private Mental Health Consumer Carer Network

Ms Janet Milford, National Mental Health Consumer and Carer Forum

Mr Noel P Muller\*, QLD

Mrs Mag Eli, NSW

Mr Lei Ning, Independent Mental Health Advocate, Victoria

Mrs Heather Nowak, Mental Health Consumer Advocate, SA

Ms Kathryn Pritchard\*, NSW

Ms Hayley Purdon, ACT

Ms Yvonne Quadros, NSW

Ms Debra Sobott, National Mental Health Consumer and Carer Forum

Ms Arahni Sont, NSW

Ms Jan West, National Mental Health Consumer and Carer Forum

Ms Qin Yi Lily Wu\*, Peer Support Worker, South Western Sydney Local Health District Mental Health Service (Liverpool Hospital) and Mental Health Services, Sydney Local Health District (Croydon Core Team), NSW

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Dr Nathan Gibson, Office of the Chief Psychiatrist, WA

Mr Malcolm Green, Clinical Excellence Commission, NSW

Dr Peter Jenkins, Eastern Health and the Royal Australian and New Zealand College of Psychiatrists, Victoria

Ms Maureen Lewis, National Mental Health Commission

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Ms Vicki Wade, Senior Cultural Advisor, Rheumatic Heart Disease Australia

Dr Murray Wright, NSW Ministry of Health

## Appendix B: Participants' responses for each cluster in Survey 3

Cluster of Signs	Clinicians					People with Lived Experience					All Participants			
	Act	Investigate	Monitor	Do nothing		Act	Investigate	Monitor	Do nothing		Act	Investigate	Monitor	Do nothing
Clusters for which the median rating was to <i>act</i> for clinicians, people with lived experience, or all participants														
Reduced safety of self	93%	7%	0%	0%		100%	0%	0%	0%		97%	3%	0%	0%
Reduced safety of others	100%	0%	0%	0%		95%	5%	0%	0%		97%	3%	0%	0%
Physiological/medical	93%	7%	0%	0%		86%	14%	0%	0%		89%	11%	0%	0%
Reduced safety of property	93%	7%	0%	0%		86%	14%	0%	0%		89%	11%	0%	0%
Increases in the use of restrictive practices	71%	29%	0%	0%		82%	18%	0%	0%		78%	22%	0%	0%
Expressing strong beliefs that are contradicted by reality or rational argument	57%	36%	7%	0%		91%	9%	0%	0%		78%	19%	3%	0%
Appearing to hear or see things that are not real	57%	43%	0%	0%		77%	23%	0%	0%		69%	31%	0%	0%
Unusual ways of behaving	71%	21%	7%	0%		73%	27%	0%	0%		72%	25%	3%	0%
Unresponsiveness to care	43%	57%	0%	0%		73%	27%	0%	0%		61%	39%	0%	0%
Disengaging from care	21%	79%	0%	0%		64%	36%	0%	0%		47%	53%	0%	0%
Self-initiated care-seeking behaviours	21%	79%	0%	0%		55%	32%	14%	0%		42%	50%	8%	0%

Cluster of Signs	Clinicians				People with Lived Experience				All Participants			
	Act	Investigate	Monitor	Do nothing	Act	Investigate	Monitor	Do nothing	Act	Investigate	Monitor	Do nothing
Clusters for which the median rating was to <i>investigate</i> for clinicians, people with lived experience, or all participants												
Reduced self-restraint	50%	43%	7%	0%	41%	55%	5%	0%	44%	50%	6%	0%
Unusual movement patterns	21%	79%	0%	0%	41%	55%	5%	0%	33%	64%	3%	0%
Care-seeking initiated by carers and others	21%	71%	7%	0%	32%	68%	0%	0%	28%	69%	3%	0%
Social circumstances and environment	29%	57%	14%	0%	41%	45%	14%	0%	36%	50%	14%	0%
Self-reported fear	14%	71%	14%	0%	27%	68%	5%	0%	22%	69%	8%	0%
Constantly changing symptoms of a mental health condition	7%	79%	14%	0%	27%	68%	5%	0%	19%	72%	8%	0%
Appearing confused during conversations	36%	57%	7%	0%	9%	77%	14%	0%	19%	69%	11%	0%
Seemingly impaired memory	14%	79%	7%	0%	23%	64%	14%	0%	19%	69%	11%	0%
Self-reported sadness	21%	64%	14%	0%	18%	73%	9%	0%	19%	69%	11%	0%
Loss of skills	0%	93%	7%	0%	27%	64%	5%	5%	17%	75%	6%	3%
Self-reported uncontrollable thought processes	7%	93%	0%	0%	23%	59%	18%	0%	17%	72%	11%	0%
Withdrawing from social situations	7%	79%	14%	0%	14%	82%	5%	0%	11%	81%	8%	0%
Difficulty following conversations	14%	71%	14%	0%	18%	64%	18%	0%	17%	67%	17%	0%

Cluster of Signs	Clinicians				People with Lived Experience				All Participants			
	Act	Investigate	Monitor	Do nothing	Act	Investigate	Monitor	Do nothing	Act	Investigate	Monitor	Do nothing
Appearing distracted during conversation	36%	50%	14%	0%	14%	59%	27%	0%	22%	56%	22%	0%
Appearing challenging during conversations	29%	43%	29%	0%	18%	59%	23%	0%	22%	53%	25%	0%
Self-reported sense of self	14%	71%	7%	7%	14%	68%	18%	0%	14%	69%	14%	3%
Speech during conversations	7%	71%	21%	0%	14%	64%	23%	0%	11%	67%	22%	0%
High energy behaviours	7%	79%	14%	0%	9%	73%	9%	9%	8%	75%	11%	6%
Reduction in regular activities	7%	71%	21%	0%	9%	73%	14%	5%	8%	72%	17%	3%
Self-reported anger	7%	64%	21%	7%	14%	68%	18%	0%	11%	67%	19%	3%
Facial expressions	7%	71%	21%	0%	5%	73%	23%	0%	6%	72%	22%	0%
Appearing disconnected during conversations	7%	64%	29%	0%	14%	55%	32%	0%	11%	58%	31%	0%
Poor daily self-care	7%	79%	14%	0%	5%	68%	23%	5%	6%	72%	19%	3%
Unusual self-presentation	0%	79%	21%	0%	14%	45%	41%	0%	8%	58%	33%	0%
Pessimistic talk during conversations	7%	64%	29%	0%	5%	64%	23%	9%	6%	64%	25%	6%
Low energy behaviours	0%	64%	36%	0%	5%	64%	27%	5%	3%	64%	31%	3%

	Act	Investigate	Monitor	Do nothing		Act	Investigate	Monitor	Do nothing		Act	Investigate	Monitor	Do nothing
Clusters for which the median rating was to <i>Monitor</i> for clinicians, people with lived experience, or all participants														
Apparently inflexible thought processes	0%	50%	50%	0%		5%	27%	59%	9%		3%	36%	56%	6%

Note: Values represent the percentages of participants who selected each response option. Shading signifies 75% or more agreement with a single response option.



## Appendix C: Responses to Feedback on the Clusters of Signs

Cluster	Feedback Provided	Responses to Feedback
<b>1. Unusual self-presentation.</b> Examples: unusual appearance, unusual clothing, unusual wearing of make-up	No feedback provided.	No change.
<b>2. Unusual ways of behaving.</b> Examples: shopping without paying, overspending, being over-generous, asking inappropriate questions, inability to self-regulate, unusual rituals, unusual requests, erratic behaviour, disorientated behaviour, bizarre behaviour	<ul style="list-style-type: none"> <li>• Could be combined with <b>low energy behaviours</b> (Cluster #15), <b>high energy behaviours</b> (#16), and <b>reduced self-restraint</b> (#17).</li> <li>• <i>Shopping without paying</i> seems too vague (Did they forget or was it intentional?); perhaps it can be contextualised.</li> </ul>	<ul style="list-style-type: none"> <li>• Cluster changed to incorporate <b>low energy behaviours</b> (Cluster #15), <b>high energy behaviours</b> (#16), <b>reduced self-restraint</b> (#17), and <b>constantly changing symptoms of a mental health condition</b> (see feedback on #11).</li> <li>• <i>Shopping without paying</i> removed.</li> </ul> <p><b>2. Unusual ways of behaving.</b> Examples: overspending, being over-generous, asking inappropriate questions, unusual requests, inability to self-regulate, unusual rituals, erratic behaviour, disorientated behaviour, bizarre behaviour, being uncharacteristically loud or quiet, less careful with possessions, increased substance use (tobacco smoking, alcohol, drugs), reckless driving, risky sexual behaviours</p>
<b>3. Unusual movement patterns.</b> Examples: fidgeting, restlessness, slowed (or increased) motor activity, dyskinesia/uncontrolled jerky movements	No feedback provided.	No change.
<b>4. Loss of skills.</b> Examples: planning/decision making difficulties, loss of mastered skills, impaired judgement	No feedback provided.	No change.
<b>5. Withdrawing from social situations.</b> Examples: withdrawal, isolating self from contact, becoming closed to loved ones, becoming uncommunicative	No feedback provided.	<ul style="list-style-type: none"> <li>• Cluster deleted. Content incorporated into <b>reduction in regular activities</b> (#14).</li> </ul>

Cluster	Feedback Provided	Responses to Feedback
<b>6. Self-initiated care-seeking behaviours.</b> Examples: direct requests for help, indirect care-seeking (for example, confirming appointments), seeking to be physically close to others, self-reported worsening of mental health	<ul style="list-style-type: none"> <li>• The term <i>care seeking</i> has negative connotations for some people. For example, care seeking might be seen as attention seeking.</li> <li>• Alternative names for the cluster include "Report from ...", "Seeking to be close to others" (or the opposite), "Change in care-seeking behaviour" (change in frequency, care setting, and care providers), "Increased input", "Exploring further resources", "Increased self-initiated requests for assistance", "Self-reporting help seeking", "Actively seeking care", and "Change in patterns of healthcare attendances".</li> <li>• Seeking to be physically close to others is really important.</li> <li>• Indirect care – dislike for the example <i>confirming of appointments</i>, because this behaviour could indicate wellness</li> <li>• The examples relate to <i>treatment</i> rather than <i>care</i> more generally.</li> </ul>	<ul style="list-style-type: none"> <li>• The term <i>care seeking</i> has been removed.</li> <li>• <i>Confirming of appointments</i> has been removed as an example.</li> <li>• This cluster has examples that are broader than treatment specifically (for example, <i>seeking to be close to others</i> extends to gaining assistance from carers).</li> </ul> <p><b>6. Self-initiated requests for assistance.</b> Examples: direct requests for help, indirect indications of need for support, seeking to be physically close to others, self-reported worsening of mental health</p>
<b>7. Care-seeking initiated by carers and others.</b> Examples: information/concern from family carers, information/concern from emergency workers	<p>This cluster received similar feedback to <b>self-initiated care-seeking behaviours</b> (#6).</p> <ul style="list-style-type: none"> <li>• The term <i>care seeking</i> has negative connotations for some people.</li> <li>• Alternative names for the cluster include "Report from ...", "Change in care-seeking behaviour" (change in frequency, care setting, and care providers), "Requests for help and assistance from carers or other healthcare workers", "Increased concern reported by third parties", and "Increased concern from family/carers".</li> <li>• The examples relate to <i>treatment</i> rather than <i>care</i> more generally.</li> </ul>	<ul style="list-style-type: none"> <li>• The term <i>care seeking</i> has been removed.</li> <li>• The cluster relates to treatment, as suggested.</li> </ul> <p><b>7. Requests for treatment from healthcare professionals or those close to the person.</b> Examples: information/concern from family carers, information/concern from emergency service workers</p>

Cluster	Feedback Provided	Responses to Feedback
<b>8. Disengaging from care.</b> Examples: inability to wait safely, ambivalence about treatment, refusal of medication, stopping taking medication, expressed dissatisfaction with care, missing appointments	<ul style="list-style-type: none"> <li>• Use <i>treatment</i> instead of care, because the examples are about treatment.</li> <li>• Disengaging from treatment should be a person's choice – exceptions would be when there is reduced safety of self and others (#30 and #31).</li> </ul>	<ul style="list-style-type: none"> <li>• The examples are about treatment.</li> <li>• Disengaging from treatment is sometimes an informed choice, but not always.</li> </ul> <p><b>8. Disengaging from treatment.</b> Examples: inability to wait safely, ambivalence about treatment, refusal of medication, stopping taking medication, expressed dissatisfaction with treatment, missing appointments</p>
<b>9. Increases in the use of restrictive practices.</b> Examples: use of seclusion, use of physical or mechanical restraint, increased use of medications administered/taken as needed (known as PRN medications), increased level of observation	<ul style="list-style-type: none"> <li>• Split in two – physical and mechanical restraint versus PRN medications.</li> </ul>	<ul style="list-style-type: none"> <li>• The distinctions between these practices are recognised. Splitting them, however, would seem to create a level of specificity/precision not afforded to other signs of deterioration. This reasoning may be sufficient to keep them together.</li> </ul>
<b>10. Unresponsiveness to care.</b> Examples: unexpected re-admission/return seeking care, unresponsiveness to de-escalation attempts, self-medication, not following expected improvement pathway/trajectory	<ul style="list-style-type: none"> <li>• Cluster name needs changing to reflect the signs better.</li> <li>• The examples relate to <i>treatment</i> rather than <i>care</i> more generally.</li> </ul>	<ul style="list-style-type: none"> <li>• The examples are about treatment.</li> </ul> <p><b>10. Unresponsiveness to treatment.</b> Examples: unexpected re-admission/return seeking treatment, unresponsiveness to de-escalation attempts, self-medication, not following expected improvement pathway/trajectory</p>
<b>11. Constantly changing symptoms of a mental health condition.</b> Example: changing from loud and demanding to withdrawn and quiet	<ul style="list-style-type: none"> <li>• Cluster name needs changing to focus on behaviour.</li> <li>• This cluster could probably be combined with <b>unusual ways of behaving</b> (#2).</li> </ul>	<ul style="list-style-type: none"> <li>• Cluster deleted. Content incorporated into <b>unusual ways of behaving</b> (#2).</li> </ul>

Cluster	Feedback Provided	Responses to Feedback
<b>12. Physiological/medical.</b> Examples: medical deterioration (including delirium), autonomic arousal (for example, sweating, increased pulse), adverse effects of medication, unplanned weight loss	<ul style="list-style-type: none"> <li>• <i>Unexpected weight gain</i> needs to be added to the examples.</li> </ul>	<ul style="list-style-type: none"> <li>• <i>Unexpected weight gain</i> added to the examples.</li> <li>• Cluster name changed.</li> </ul> <p><b>12. Physiological/medical deterioration.</b> Examples: medical deterioration (including delirium), autonomic arousal (for example, sweating, increased pulse), adverse effects of medication, unplanned weight loss/gain</p>
<b>13. Poor daily self-care.</b> Examples: poor self-care and hygiene, disturbed sleep patterns (for example, increased or decreased sleep time), staying in bed longer, eating/appetite changes	<ul style="list-style-type: none"> <li>• Add <i>staying in one position for numerous hours</i> to the examples – although this example may be too specific.</li> </ul>	<ul style="list-style-type: none"> <li>• Example considered too specific for inclusion.</li> </ul>
<b>14. Reduction in regular activities.</b> Examples: inability to work, reducing or stopping normally enjoyed activities, changes in daily routines, difficulty with performing daily living activities	<ul style="list-style-type: none"> <li>• Add <b>withdrawing from social situations</b> (#5) to this cluster.</li> </ul>	<ul style="list-style-type: none"> <li>• Content from <b>withdrawing from social situations</b> (#5) added to this cluster.</li> </ul> <p><b>14. Reduction in regular activities.</b> Examples: inability to work, reducing or stopping normally enjoyed activities, changes in daily routines, difficulty with performing daily living activities, withdrawal, isolating self from contact with others</p>
<b>15. Low energy behaviours.</b> Examples: less care taken with possessions, reduced ability to deal with change, lowered libido	<ul style="list-style-type: none"> <li>• <i>Lowered libido</i> is a subjective report, not a behaviour.</li> </ul>	<ul style="list-style-type: none"> <li>• Cluster deleted. Content incorporated into <b>unusual ways of behaving</b> (#2).</li> </ul>
<b>16. High energy behaviours.</b> Examples: boisterousness (being overexcited/rowdy), loudness, listening to loud music, energy outbursts, talkativeness, taking on too much	No feedback provided.	<ul style="list-style-type: none"> <li>• Cluster deleted. Content incorporated in <b>unusual ways of behaving</b> (#2).</li> </ul>
<b>17. Reduced self-restraint.</b> Examples: increased tobacco smoking, increased alcohol use, increased substance abuse, reckless driving, risky sexual behaviours, impulsivity	<ul style="list-style-type: none"> <li>• Could be combined with <b>self-initiated care-seeking behaviours</b> (#6).</li> </ul>	<ul style="list-style-type: none"> <li>• Cluster deleted. Content incorporated into <b>unusual ways of behaving</b> (#2).</li> </ul>

Cluster	Feedback Provided	Responses to Feedback
<b>18. Pessimistic talk during conversations.</b> Examples: negativity in attitudes/responses, guilt and self-blaming, expressed pessimism	<ul style="list-style-type: none"> <li>Cluster name could be revised to "Increased negative themes in conversation".</li> <li>Additional examples include suicidal ideation, despair, hopelessness, and increasing negativity.</li> <li>Negativity and pessimism could be cultural.</li> <li>May be difficult to interpret in practice.</li> </ul>	<ul style="list-style-type: none"> <li>Cluster name changed to reflect examples better.</li> <li>Suicidal ideation already included in <b>reduced safety of self</b>, so not required here.</li> <li><i>Despair</i> and <i>hopelessness</i> included as examples.</li> </ul> <p><b>18. Negative themes in conversations</b> Examples: negativity in attitudes/responses, despair, hopelessness, guilt and self-blaming, expressed pessimism</p>
<b>19. Expressing strong beliefs that are contradicted by reality or rational argument.</b> Examples: bizarre delusions (for example, the belief that others are reading one's mind), non-bizarre delusions (for example, the mistaken belief that one is under police surveillance), paranoia, suspicion, distrustfulness, mentioning persecutory thoughts, grandiosity (for example, the mistaken belief that one is powerful or has a special relationship with a famous person), mood-incongruent delusions (for example, others are inserting thoughts into one's mind)	<ul style="list-style-type: none"> <li>Could be combined with <b>appearing to hear or see things that are not real</b> (#20) – "Delusions and hallucinations".</li> <li>The cluster is too long as a descriptor.</li> </ul>	<ul style="list-style-type: none"> <li>The two clusters are considered sufficiently different to justify keeping them separated.</li> <li>The cluster name has been shortened and the former name used in the examples.</li> </ul> <p><b>19. Indications of experiencing delusions.</b> Examples: expressing strong beliefs that are contradicted by reality or rational argument (for example, the belief that others are reading one's mind, the mistaken belief that one is under surveillance, mentioning persecutory thoughts, the mistaken belief that one is powerful or has a special relationship with a famous person)</p>
<b>20. Appearing to hear or see things that are not real.</b> Examples: auditory hallucinations (for example, reporting hearing voices or appearing to respond to voices in one's mind), visual hallucinations (for example, reporting seeing things that do not exist or appearing to respond to such images)	No feedback provided.	<ul style="list-style-type: none"> <li>The cluster name has been shortened and the former name used in the examples.</li> </ul> <p><b>20. Indications of experiencing hallucinations.</b> Examples: appearing to hear or see things that are not real (for example, reporting hearing voices or appearing to respond to voices in one's mind, reporting seeing things that do not exist or appearing to respond to such images)</p>

Cluster	Feedback Provided	Responses to Feedback
<b>21. Appearing challenging during conversations.</b> Examples: conflictual, accusatory, argumentative, dominating, intrusive, demanding, irritated, volatile/reactive, sensitivity to perceived provocation, low tolerance of others	<ul style="list-style-type: none"> <li>• These behaviours may be appropriate in certain situations.</li> <li>• Inter-rater reliability might be poor for this cluster.</li> <li>• Along with <b>appearing disconnected during conversations</b> (#22), <b>appearing distracted during conversation</b> (#23), and <b>difficulty following conversations</b> (#25), this cluster relates to the single issue of participating in conversation.</li> </ul>	<ul style="list-style-type: none"> <li>• Clusters #21, #22, #23, and #25 have been combined.</li> </ul> <b>21. Difficulty participating in conversations.</b> Examples: appearing distracted, disconnected, or challenging during conversations; having difficulty following conversations
<b>22. Appearing disconnected during conversations.</b> Examples: disinterested, passive, unaware of others, secretive, not hearing others	<ul style="list-style-type: none"> <li>• Along with <b>appearing challenging during conversations</b> (#21), <b>appearing distracted during conversation</b> (#23), and <b>difficulty following conversations</b> (#25), this cluster relates to the single issue of participating in conversation.</li> </ul>	<ul style="list-style-type: none"> <li>• Cluster deleted. Content incorporated in <b>appearing challenging during conversations</b> (#21).</li> </ul>
<b>23. Appearing distracted during conversation.</b> Examples: tangential thinking (going off topic, never returning to the original topic), distractibility (changing topic during mid-speech due to something in the environment), inability to complete ideas (stopping in the middle of a train of thought), impaired concentration	<ul style="list-style-type: none"> <li>• Along with <b>appearing challenging during conversations</b> (#21), <b>appearing disconnected during conversations</b> (#22), and <b>difficulty following conversations</b> (#25), this cluster relates to the single issue of participating in conversation.</li> </ul>	<ul style="list-style-type: none"> <li>• Cluster deleted. Content incorporated in <b>appearing challenging during conversations</b> (#21).</li> </ul>
<b>24. Speech during conversations.</b> Examples: unusual intonation, stress, or rhythm; reduced (or increased) loudness/volume; reduced (or increased) flow of words; inability to speak	<ul style="list-style-type: none"> <li>• Cluster may have poor specificity.</li> </ul>	<ul style="list-style-type: none"> <li>• Cluster name changed.</li> </ul> <b>24. Unusual speech during conversations.</b> Examples: unusual intonation, stress, or rhythm; reduced (or increased) loudness/volume; reduced (or increased) flow of words; inability to speak

Cluster	Feedback Provided	Responses to Feedback
<b>25. Difficulty following conversations.</b> Examples: slow responding, limited understanding of conversation, inability to respond to questions	<ul style="list-style-type: none"> <li>Along with <b>appearing challenging during conversations</b> (#21), <b>appearing disconnected during conversations</b> (#22), and <b>appearing distracted during conversation</b> (#23), this cluster relates to the single issue of participating in conversation.</li> </ul>	<ul style="list-style-type: none"> <li>Cluster deleted. Content incorporated in <b>appearing challenging during conversations</b> (#21).</li> </ul>
<b>26. Facial expressions.</b> Examples: poor eye contact, uncharacteristic facial expression, crying/signs of upset	<ul style="list-style-type: none"> <li>Culturally, avoiding eye contact may be appropriate – adjust to “uncharacteristic eye contact” or “changes in eye contact”.</li> </ul>	<ul style="list-style-type: none"> <li>Adjustment made to <i>eye contact</i> example.</li> <li>Cluster name changed.</li> </ul> <p><b>26. Uncharacteristic facial expressions.</b> Examples: uncharacteristic eye contact/facial expressions, crying/signs of upset</p>
<b>27. Appearing confused during conversations.</b> Examples: lack of coherence, irrational responding, inability to have a sensible conversation, impaired thought clarity, confusion	No feedback provided.	No change.
<b>28. Seemingly impaired memory.</b> Examples: impaired recall (for example, inability to recall the contents of a short paragraph), impaired registration (for example, inability to repeat a set of words that has just been read)	No feedback provided.	No change.
<b>29. Apparently inflexible thought processes.</b> Examples: black-and-white thinking, rigid thinking	<ul style="list-style-type: none"> <li>Inflexible thought processes can be the norm for an individual – change to “Changes in thought processes - increasingly rigid in thinking”.</li> <li>This cluster may be challenging for those with poor English.</li> </ul>	<ul style="list-style-type: none"> <li>Although inflexible thought processes can be the norm, clusters of signs are interpreted with reference to a person’s own baseline.</li> </ul> <p><b>29. Apparent difficulty with thinking about things in different ways.</b> Examples: rigid thinking, black-and-white thinking</p>
<b>30. Reduced safety of self.</b> Examples: suicidal ideation/attempts, self-harm or attempted self-harm	No feedback provided.	No change.

Cluster	Feedback Provided	Responses to Feedback
<b>31. Reduced safety of others.</b> Examples: verbal threats, verbal aggression, physical threats, physical aggression, expressed homicidal thoughts	No feedback provided.	No change.
<b>32. Reduced safety of property.</b> Examples: attacks on objects, burning of objects	No feedback provided.	No change.
<b>33. Self-reported sadness.</b> Examples: feeling low, feeling teary, feeling fragile, feeling depressed, feeling despair, feeling flat	<ul style="list-style-type: none"> <li>• Could be combined with <b>self-reported fear</b> (#34), <b>self-reported anger</b> (#35), <b>self-reported sense of self</b> (#36), and <b>self-reported uncontrollable thought processes</b> (#37).</li> </ul>	<ul style="list-style-type: none"> <li>• Clusters #33, #34, and #35 have been combined because they all relate to negative emotions.</li> <li>• Clusters #36 and #37 focus on sufficiently distinct concepts to justify separation.</li> </ul> <p><b>33. Self-reported negative emotions.</b> Examples: feelings of sadness (despair, weeping, depression), fear (anxiety, worry, stress, terror), or anger (frustration, rage)</p>
<b>34. Self-reported fear.</b> Examples: feeling anxious, having worrying thoughts, feeling agitated, feeling stressed/not coping, feeling fearful	<ul style="list-style-type: none"> <li>• Low specificity, so concerned about clinical yield.</li> <li>• This cluster may be redundant, because it is affected by other domains.</li> <li>• Remove agitated, because it is irrelevant.</li> </ul>	<ul style="list-style-type: none"> <li>• Cluster deleted. Content incorporated in <b>self-reported sadness</b> (#33).</li> </ul>
<b>35. Self-reported anger.</b> Examples: feeling frustrated, feeling angry	No feedback provided.	<ul style="list-style-type: none"> <li>• Cluster deleted. Content incorporated in <b>self-reported sadness</b> (#33).</li> </ul>
<b>36. Self-reported sense of self.</b> Examples: feeling worthless, feeling hopeless, feeling low (or high) self-esteem, feeling low (or high) in confidence	<ul style="list-style-type: none"> <li>• A low-yield indicator for high-risk outcomes – perhaps replace with a mood score.</li> </ul>	<ul style="list-style-type: none"> <li>• Cluster name could be improved.</li> </ul> <p><b>36. Self-reported negative or inflated perceptions of self.</b> Examples: feeling worthless, feeling hopeless, feeling low (or high) self-esteem, feeling low (or high) in confidence</p>
<b>37. Self-reported uncontrollable thought processes.</b> Examples: racing thoughts, rumination (overthinking issues), obsessive thinking	No feedback provided.	No change.



Cluster	Feedback Provided	Responses to Feedback
<b>38. Social circumstances and environment.</b> Examples: situational crisis/significant change in social circumstances (for example, having to move house), inability to cope in a different environment (for example, hospital emergency department), inability to cope with environmental stimuli (for example, too much noise)	<ul style="list-style-type: none"> <li>• Need to use Trauma Informed Care language.</li> <li>• Social circumstances cannot be defined as a behaviour, and many variables would be dichotomous, not allowing for tracking</li> </ul>	<ul style="list-style-type: none"> <li>• Cluster deleted. Social circumstances and environments are risk factors rather than behaviours. Examples are not behaviours, so they have not been merged into other clusters.</li> </ul>

## Appendix D: Proposed Clusters of Signs with their Examples

Cluster of Signs	Examples
Reported Change	
Self-initiated requests for assistance	direct requests for help, indirect indications of need for support, seeking to be physically close to others, self-reported worsening of mental health
Requests for treatment from healthcare professionals or those close to the person	information/concern from family carers, information/concern from emergency service workers
Self-reported negative or inflated sense of self	feeling worthless, feeling hopeless, feeling low (or high) self-esteem, feeling low (or high) in confidence
Self-reported uncontrollable thought processes	racing thoughts, rumination (overthinking issues), obsessive thinking
Self-reported negative emotions	feelings of sadness (despair, weeping, depression), fear (anxiety, worry, stress, terror), or anger (frustration, rage)
Distress	
Uncharacteristic facial expressions	uncharacteristic eye contact/facial expressions, crying/signs of upset
Physiological/medical deterioration	medical deterioration (including delirium), autonomic arousal (for example, sweating, increased pulse), adverse effects of medication, unplanned weight loss/gain
Negative themes in conversations	negativity in attitudes/responses, despair, hopelessness, guilt and self-blaming, expressed pessimism
Apparent distress of self or others	observed distress, self-reported distress, distress of others (including carers and clinicians)
Loss of touch with reality or consequence of behaviours	
Indications of experiencing delusions	expressing strong beliefs that are contradicted by reality or rational argument (for example, the belief that others are reading one's mind, the mistaken belief that one is under surveillance, mentioning persecutory thoughts, the mistaken belief that one is powerful or has a special relationship with a famous person)
Indications of experiencing hallucinations	appearing to hear or see things that are not real (for example, reporting hearing voices or appearing to respond to voices in one's mind, reporting seeing things that do not exist or appearing to respond to such images)
Unusual self-presentation	unusual appearance, unusual clothing, unusual wearing of make-up
Unusual ways of behaving	overspending, being over-generous, asking inappropriate questions, unusual requests, inability to self-regulate, unusual rituals, erratic behaviour, disorientated behaviour, bizarre behaviour, being uncharacteristically loud or quiet, less careful with possessions, increased substance use (tobacco smoking, alcohol, drugs), reckless driving, risky sexual behaviours
Appearing confused during conversations	lack of coherence, irrational responding, inability to have a sensible conversation, impaired thought clarity, confusion
Loss of function	
Unusual movement patterns	fidgeting, restlessness, slowed (or increased) motor activity, dyskinesia/uncontrolled jerky movements
Loss of skills	planning/decision making difficulties, loss of mastered skills, impaired judgement

Cluster of Signs	Examples
Poor daily self-care	poor self-care and hygiene, disturbed sleep patterns (for example, increased or decreased sleep time), staying in bed longer, eating/appetite changes
Reduction in regular activities	inability to work, reducing or stopping normally enjoyed activities, changes in daily routines, difficulty with performing daily living activities, withdrawal, isolating self from contact with others
Difficulty participating in conversations	appearing distracted, disconnected, or challenging during conversations; having difficulty following conversations
Unusual speech during conversations	unusual intonation, stress, or rhythm; reduced (or increased) loudness/volume; reduced (or increased) flow of words; inability to speak
Seemingly impaired memory	impaired recall (for example, inability to recall the contents of a short paragraph), impaired registration (for example, inability to repeat a set of words that has just been read)
Apparent difficulty with thinking about things in different ways	rigid thinking, black-and-white thinking
Elevated risk to self, others or property	
Increases in the use of restrictive practices	use of seclusion, use of physical or mechanical restraint, increased use of medications administered/taken as needed (known as PRN medications), increased level of observation
Reduced safety of self	suicidal ideation/attempts, self-harm or attempted self-harm
Reduced safety of others	verbal threats, verbal aggression, physical threats, physical aggression, expressed homicidal thoughts
Reduced safety of property	attacks on objects, burning of objects
Disengaging from treatment	inability to wait safely, ambivalence about treatment, refusal of medication, stopping taking medication, expressed dissatisfaction with treatment, missing appointments
Unresponsiveness to treatment	unexpected re-admission/return seeking treatment, unresponsiveness to de-escalation attempts, self-medication, not following expected improvement pathway/trajectory

## Acronyms

<b>AUC</b>	area under curve
<b>BVC</b>	Brøset Violence Checklist
<b>CALD</b>	culturally and linguistically diverse
<b>CI</b>	confidence interval
<b>DASA</b>	Dynamic Appraisal of Situational Aggression
<b>DI-5</b>	Five-Item Daily Symptom Index
<b>HCR-20<sup>V3</sup></b>	Historical-Clinical-Risk Management-20, Version 3
<b>IAT</b>	Life-Death Implicit Association Test
<b>IRRS</b>	Imminent Risk Rating Scale
<b>MSES</b>	mental state examination scale
<b>OR</b>	odds ratio
<b>PRN</b>	pro re nata
<b>RANZCP</b>	Royal Australian and New Zealand College of Psychiatrists
<b>UCJ</b>	unstructured clinical judgement
<b>WRAP®</b>	Wellness Recovery Action Plan

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