

# Partnering in Healthcare: Strengthening opportunities for patients, carers and family members to escalate care in Victorian health services

A RAPID REVIEW OF RESEARCH AND PRACTICE EVIDENCE

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All links up to date at 30 April 2019. Finalised 30 May 2019.

# 1 Glossary and acronyms

|                                  |  |
|----------------------------------|--|
| ATSI                             | Aboriginal and Torres Strait Islander  |
| CALD                             | Culturally and Linguistically Diverse  |
| CEC                              | Clinical Excellence Commission   |
| CEO                              | Chief Executive Officer  |
| Condition 'H'                    | Condition Help (An American based carer-initiated escalation program)  |
| Consumer                         | A broad collective term used mostly to refer to patients and carers.   |
| CRM                              | Customer Relationship Management   |
| ERG                              | Expert Reference Group   |
| Escalation                       | Action or steps taken to elevate the level of attention or care provided to an in-patient. This can include a request for a review of care, a change to treatment, change to communication protocols, Medical Emergency Team activation or transfer to provide acute care.       |
| ICU                              | Intensive Care Unit  |
| LGBTIQ+                          | Lesbian, Gay, Bisexual, Transgender, Intersex, Queer and any/all other identity terms that are not heterosexual/cis gender.  |
| MET                              | Medical Emergency Team   |
| NIC                              | Nurse In Charge  |
| NSQHS                            | National Safety and Quality in Health Care Standards   |
| NSW                              | New South Wales  |
| Patient, carer and family member | A more specific phrase used to refer when necessary to patients, carers or family members who have insight into the health issues relevant to the in-patient stay. The emphasis is on "knowledge of the patient" and the insight this brings, not the label of the relationship. |
| QLD                              | Queensland   |
| REACH                            | Rapid Escalation for Acute Care in Hospitals   |
| RR                               | Rapid Review   |
| RR                               | Ryan's Rule  |
| RRS                              | Rapid Response System  |
| RRT                              | Rapid Response Team  |
| SCV                              | Safer Care Victoria  |
| SA                               | South Australia  |
| USA                              | United States of America   |
| VAHI                             | Victorian Agency for Health Information  |
| VHES                             | Victorian Health Experience Survey   |

## 2 Executive Summary

In 2019 Safer Care Victoria launched the [Partnering in Health Care Framework](#) to support Victorian health services strengthen how they approach patient centred care and continue to empower patients, carers and family members to participate in health care. One important contributor to establishing health care partnerships is ensuring people know they will be heard if they have a concern about the medical status and care for themselves or a patient.

The [National Safety and Quality Health Service Standards](#) demonstrate a clear priority to strengthen consumer partnerships with health services. This is also reflected in the actions proposed to engage consumers in detection and response to deterioration under Standard 8 - Recognising and Responding to Acute Deterioration. This Standard is now a requirement for Australian health service accreditation.

For the purposes of this report, consumer-initiated escalation is understood as a consumer's ability to raise any medical concerns they may have with a medically trained person, either within their immediate medical team, or with a third party. Emphasis is primarily on building strong, trusting relationships between consumers and health services, with promotion of additional, last-resort opportunities (an escalation phone number) to escalate their concerns, request a medical review or an escalation of care if needed.

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### CONSUMER-INITIATED ESCALATION IN VICTORIA

For a number of years, Victorian hospitals have been adapting, designing and implementing their individual approaches to patient, carer or family member (i.e. consumer)-initiated escalation processes to meet National Standard 8. This individual approach has resulted in high degree of inconsistency in messaging, degrees or understanding of effectiveness and steps involved in consumer-initiated escalation services in Victoria. The lack of consistency was highlighted clearly in a 2018 Safer Care Victoria survey of 64 Metropolitan and Regional public hospitals (SCV 2017).

To ensure that health services, patients and carers have access to a state-wide recognisable safety net for when, or if, things go wrong, Victoria is establishing a central consumer-initiated escalation telephone service called HEAR ME. This will be supported by a principles-based implementation framework that Victorian health services can draw on when establishing their own consumer-initiated escalation processes. The principles for consumer-initiated escalation of care in Victoria are directly aligned with and complement the SCV [Partnering for Healthcare Framework](#) as any successful consumer-initiated escalation process needs to be embedded in existing efforts to strengthen consumer health care partnerships within all Victorian health services.

## HEAR ME PRINCIPLES – CONSUMER-INITIATED ESCALATION IN VICTORIA

### **Principle 1: Consumers feel empowered through HEAR ME**

Patients, carers and family members are empowered and supported to raise and directly escalate concerns about care and treatment.

### **Principle 2: Clinicians and health service managers feel ready and enabled to participate in HEAR ME**

Health service clinicians are supported by health services to learn about and engage with consumer-initiated escalation at all levels of the process.

### **Principle 3: Patients and carers are confident in the quality and safety of the Victorian healthcare system**

HEAR ME contributes to ongoing system learning and assurance of the quality and safety of patient care, experience and outcomes.

### **Principle 4: HEAR ME has strong and transparent governance, coordination and management processes**

HEAR ME provides true value for consumers, health services and the community.

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The HEAR ME central 1300 phone number does not replace existing escalation phone numbers used by some Victorian health services – but it does provide a common infrastructure throughout Victoria for those health services without their own working, efficient and effective escalation phone numbers. The HEAR ME phone service and supporting implementation framework will complement existing efforts of individual health services to implement their own consumer-initiated escalation processes for consumers, and help strengthen consistency in approach and messaging throughout the state.

Ultimately, the SCV principles-based implementation framework for consumer-initiated escalation needs to be a tool for health services to support their existing efforts in strengthening relationships and communication between consumers and health services, an area that is also a Partnering in Healthcare Framework priority.

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## RAPID REVIEW

The Centre for Health Communication and Participation (CHCP), La Trobe University, was requested to conduct a rapid review of evidence and experience of patient, carer or family member-initiated escalation processes and systems. The review findings are intended to inform these plans for both a central support phone number and developing a recommended best practice framework for consumer-initiated escalation in Victoria.

The rapid review included research on consumer-initiated escalation and how these findings link to experiences of consumer participation in care. It also included a review of existing consumer-initiated escalation services in Australia to identify learning and experiences that can inform best practice recommendations for Victoria. Interviews with stakeholders were used to explore common themes that emerged from the evidence, and an Advisory Committee was formed to review and critique the report and its recommendations.

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## THEMES AND RECOMMENDATIONS

The recommendations have been structured according to the four principles of the SCV HEAR ME implementation framework and by priority:

- Highly recommended considerations
- Critical recommendations

The recommendations outlined in Section 8 reflect key themes that emerged from the evidence review and experiences of existing consumer-initiated escalation systems. These themes have directly informed the recommendations for consideration in the Victorian principles-based implementation framework and include:

- Consumers have considerable value to add to their care or to the overall care of a patient.
- Communication is a critical area to be addressed. Communication is understood to be not just the delivery of information, but the establishment and management of relationships between consumers and health services. Recommendations in this area focus on recognition of the skills required to have effective, positive, partnership-based relationships.
- Efforts to strengthen consumer partnerships in healthcare and maintain strong consumer/health service relationships are the foundation for consumer-initiated escalation of care processes and systems.
- Consumer-initiated escalation services provide a clear opportunity to help measure efforts to strengthen partnerships in healthcare.
- There needs to be broad awareness of the steps and expectations of consumer-initiated escalation systems or processes among consumers and health services. Having a consistent three step approach in Victoria that emphasises strong relationships between consumers and their medical teams will be key.

Implementing consumer-initiated escalation should be treated like any form of change management. Key stakeholders need to be prepared and understand the change to support its successful implementation. This includes providing guidance to support health services to be ready to respond to consumer-initiated escalation requests and strengthen links between consumer escalation processes and health service's overarching efforts to build consumer partnerships in healthcare.

- Health services are encouraged to recognise the importance of strong comprehensive communication skills in existing training modules/programs for staff. Staff training and education requirements should also incorporate modules that build recognition of the Victorian consumer-initiated escalation implementation framework principles, three step structure and expectations.
- A critical balance is needed between 1) the need for a central phone number for escalation with consistent messaging of a principles-based implementation framework and 2) the importance of respecting independence of health services to innovate, adapt and establish services tailored to their needs.
- Victoria is in a strong position to integrate research, evaluation and learning within the consumer-initiated escalation program that will help address research and evidence gaps and position the state as a leader in supporting partnerships in health.

## 3 Introduction

In 2019, it is mandatory for all Australian hospitals to have a mechanism for patients and their family members or carers (i.e. consumers) to independently initiate escalation for clinical deterioration under National Standard 8, 'Recognising and Responding to Acute Deterioration' Standard. In Australia, there are lessons to be learned from the different approaches adopted (including the centralised approach of *Ryan's Rule* in Queensland and the localised implementation of *R.E.A.C.H.* in New South Wales). This report presents the key themes identified through a rapid review of evidence (Section 2) and key Australian experiences of designing, implementing and evaluating consumer-initiated escalation processes.

For a number of years, Victorian hospitals have been adapting, designing and implementing different approaches to consumer-initiated escalation processes. This individualised approach has resulted in a broad range of different messages, degrees of effectiveness and names for the program dependent on the particular service. A 2018 Safer Care Victoria (SCV) survey of 64 Metropolitan and Regional public hospitals helps to highlight that there is very little consistency in approach in Victoria (SCV 2018).

To ensure that health services and consumers have access to a state-wide recognisable safety net for when things go wrong, Victoria is establishing HEAR ME. HEAR ME is a central phone number for consumers to call if, and when, they have concerns for themselves or for an in-patient and need to be heard, and a supporting principles-based implementation framework to support Victorian health services.

At the core of HEAR ME is the need to invest time, resources and attention to strengthening communication and relationships between consumers and health services. SCV is promoting that all health services adopt a three-step process for consumers to escalate their medical concerns, with the first two steps focused on the communication and relationship between consumer and health service. Partnering in healthcare is a priority for Victoria and is central to empowering consumers to raise their concerns in a confident and timely way that can support the care being provided.

The HEAR ME phone number represents a third step in an escalation process if and when needed. The HEAR ME phone number doesn't replace the consumer escalation processes health services have implemented to date. However, it does create consistent awareness and opportunity for consumers to raise medical concerns, request a review or request an escalation of care no matter which service a patient is attending in Victoria.

This report aims to inform the implementation of this state-wide program and is in line with SCV's recently published *Partnering in Healthcare Framework*. From an analysis of the evidence and hospital experiences, barriers and enablers are outlined, forming the basis of a set of recommendations directed to consumers, health service staff, health service executives, and SCV.



## 4 Evidence of patient, carer and family member participation in escalation

### SECTION SUMMARY

- Patient, carer and family member participation, i.e., consumer-initiated escalation processes are embedded in steps to adopt stronger consumer partnerships in health care.
- Escalation programs may lead to improved health outcomes for patients, including reductions in mortality or serious morbidity, and are typically associated with high satisfaction for those using the programs.
- Communication issues have been identified as a frequent reason for consumer-initiated escalation processes.
- Providing appropriate training and education for health services staff and potential users of the escalation service is critical.
- Ensuring access to adequate, high quality data to inform learning, systems strengthening, and promotion efforts is critical.
- Escalation programs do not result in over burdening of health services, large numbers of calls, or large numbers of 'inappropriate' calls.
- Additional work needs to be done to tailor and pilot messages to different consumers' cultural and linguistic needs.
- Education and training for health services staff is an important component of establishing a consumer-initiated escalation system. Core competencies for staff need to emphasise high level awareness, ability to respond to an escalation notification and the development of strong, comprehensive communication skills to support implementation.
- Multi-channel promotion is required to support broad consumer awareness of escalation opportunities and steps.
- Consumer-initiated escalation processes should be tailored to local health services' needs and contexts, but also need to reflect a commonly held set of principles to provide consumers with some consistency in opportunity and service.

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## 4.1 EVIDENCE REVIEW METHODS: INTRODUCTION

To understand the experience of Australian efforts to empower consumers to support and initiate escalation, a range of stakeholders were consulted. Those consulted include representatives of Carers Victoria, people responsible for consumer participation and engagement in health services, health services with experience in working with CALD communities and representatives from SCV.

An Advisory Committee was established to review the report and framework recommendations and involved a range of stakeholders including consumer representatives, health services, SCV. The Committee members provided either written or verbal comments on an original draft and these were presented and discussed during a teleconference/video conference consultation. (See Appendix 3.2.)

A systematic overview was undertaken of reviews of evidence and experiences on escalation (See Section 4.2) and an in-depth analysis was undertaken of qualitative studies of carers' experiences of patient safety issues in Victorian hospitals (See Section 4.3). We undertook a review of existing consumer-initiated escalation services in Australia to identify learning and experiences that can inform recommendations for Victoria. Interviews with stakeholders were used to explore common themes that emerged from the evidence (See Section 4.4)

In addition, information was sourced about the systems and approaches used to engage patients, carers and family members in escalation. Information brochures, flyers, posters and non-academic articles related to escalation education or evaluation and publicly available Coronial reports linked to escalation were identified through direct sourcing (provided by authors or organizations participating in consultations) or internet searches. Databases accessed to source resources included the Victorian Government's [Health Translations website](#) for translated materials about escalation.

In an attempt to rapidly map and identify efforts undertaken by Victorian health services to develop, implement and evaluate consumer-initiated escalation processes, a review of all 2017/18 Quality Accounts was undertaken. Using the list of health services provided by SCV the documents were reviewed manually, and then word searches were undertaken to ensure relevant content was not missed. All documents were searched using the terms "escalation", 'deterioration', 'worry/worried', 'concern', and 'consumer'. (See Appendix 5).

Other sources of information sought included reviewing publicly available Victorian Coroner's reports. Unfortunately, the online search limitations for Coroner's reports meant a more time-consuming manual approach would be required to thoroughly identify all reports that mention or are related to consumer involvement in care or consumer engagement (or lack thereof) in escalation. It is recommended that a more thorough compilation of Coroner's reports and findings is undertaken but it was outside the scope of this rapid review. (See Sections 2 and 8).

## 4.2 SYSTEMATIC OVERVIEW

### 4.2.1 RATIONALE

This summary of quantitative evidence on consumer-initiated escalation of care is based on a pragmatic approach to summarising the evidence available. Systematic reviews identify, appraise and synthesise the evidence from primary research studies, allowing identification of relevant evidence, and gaps, in an efficient manner. The decision was made to focus on this higher-level evidence in preference to primary studies, in order to quickly and efficiently develop an evidence base as one component of the evidence. This decision means that there is likely to be additional relevant primary studies which might also have contributed to the evidence base summarised in this section, but which are not yet reflected in the findings of the included systematic reviews. This is a limitation of the approach used.

### 4.2.2 SYSTEMATIC OVERVIEW DESIGN

A systematic overview was undertaken to address the following objectives:

- To summarise high-level (review-level) evidence of the effects of consumer-initiated escalation of care services in hospital.
- To identify main features of such escalation care services, including major barriers and facilitators to implementation, and if possible, differences between localised and centralised services, with a focus on outcomes for consumers.

One reviewer applied the selection criteria to citations identified from search activities. Screening was done in the first instance based on title and abstract. For studies identified as potentially relevant, full text copies were assessed against the selection criteria.

### INCLUSION AND EXCLUSION CRITERIA

The selection criteria in Table 1 were applied to identify relevant high-level evidence for this rapid review.

**Table 1: Selection criteria**

|   | Included  | Excluded  |
|---|---|---|
| <b>Type(s) of study</b>                       | Systematic review, narrative review, qualitative evidence review (synthesis)                              | Primary studies   |
| <b>Types of primary study</b>                 | Quantitative studies, qualitative studies   |   |
| <b>Population</b>                             | Patients and carers (family members, friends, others with an interest in and/or knowledge of the patient) | Health professionals  |
| <b>Setting</b>                                | Hospital  | Community, primary care                                       |
| <b>Intervention or phenomenon of interest</b> | Consumer escalation of care<br>Factors affecting consumer escalation of care                              | Clinical RRS/T activation with no consumer-initiation present |
| <b>Date range</b>                             | Searches run 2017-2018<br>Additional searching not restricted by date                                     |   |

#### 4.2.3 SCREENING SEARCH OUTPUTS

704 citations were identified from major search activities. Of these, 689 were excluded based on title and/or abstract, 12 were assessed in full text but excluded (see Appendix 1b for reasons for exclusion) and 3 reviews were included.

Additional searches of review-level databases (PDQ, Health Systems Evidence), and cross-searching of government and agency websites yielded several possibly-relevant documents (see Appendix 1a), with a further 2 reviews identified for inclusion from these searches.

In total, 5 reviews were included in this summary (Albutt et al 2017, Berger et al 2014, Gill et al 2016a, Van Voorhis et al 2009, Vorwerk & King 2015) (see Appendix 1b). In four reviews there was a focus on patient and carer or family-initiated escalation of care; one review took a broader focus on consumer engagement in hospital patient safety, of which some findings related more specifically to escalation of care by consumers (Berger et al 2014).

Numbers of relevant studies included in the reviews ranged from an unspecified number (Van Voorhis et al 2009) to 11 (Vorwerk & King 2015). However, it is important to note that there was a great deal of duplication of included studies, and across all 5 reviews only 13 unique empirical studies were identified (See Appendix 1b). This relatively sparse evidence base resulting from extensive searches reflects the conclusions of several of the included reviews themselves (i.e. that further high-quality research is needed in this area to build a more convincing evidence base on effectiveness and impacts).

None of the included primary studies were of rigorous design for assessing effectiveness, and methodological limitations of the studies may limit confidence in the certainty of the findings.

#### 4.2.4 FEATURES OF POPULATIONS (PATIENTS)

Studies examined patient/ family escalation of services for both paediatric and adult patient populations. One review (Albutt et al 2017) noted that earlier studies tended to focus on escalation of care for paediatric patients, possibly as children may tend to deteriorate more rapidly than adults. One review (Van Voorhis et al 2009) presented two case study sites involving paediatric hospitals; the remaining reviews included studies of adult and paediatric populations.

#### 4.2.5 SETTINGS OR UNITS

Most studies involved patient/ family escalation occurring across units or wards within a hospital; one studied patients discharged from ICU to a hospital ward.

Almost all studies described patient/ family escalation systems that were provided as 'add-ons' to existing clinician-activated Rapid Response Team (RRT<sup>1</sup>) mechanisms. A single study (in Albutt et al 2017) reported a comparison between separate patient/ family-activated and clinician-activated systems.

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<sup>1</sup> Different health services, reviews and researchers use slightly different terms to describe the responding team. A Rapid Review (RR) is most often used to describe a secondary clinical review of a patient that has been requested as part of what is commonly describes a Rapid Response System (RRS). A Rapid Review Team (RRT) is often used to describe the team that conducts a RR.

A RR is not an activation of a Medical Emergency Team (MET) but it could result in this action if the RR indicates it is required.

## 4.2.6 MAIN FINDINGS FROM INCLUDED REVIEWS

### 4.2.7 FEATURES OF ESCALATION SERVICES IMPLEMENTED

#### 4.2.7.1 DIRECT OR INDIRECT ACTIVATION

Included reviews described consumer-initiated escalation processes that were both direct (i.e. patients and/or family members could directly activate the RRT) and indirect (i.e. patients' and/or family members' concerns were triaged through staff or a dedicated system (e.g. Condition Help) to determine whether a RRT was required).

One review (Van Voorhis et al 2009) described a paediatric system piloted initially as an indirect escalation mechanism, but later expanded to enable direct family activation of RRT. In the initial phases, family members were asked to immediately raise any concerns about their child with staff. Subsequent evaluation (1 year) showed that family concern was a reason for RRT activation in 8% of cases, with over half requiring ICU transfer; the system was subsequently expanded to allow direct family RRT activation through the same mechanism as staff.

One review (Albutt et al 2017) reported that indirect activation systems were used more often than RRT systems requiring direct patient/ family member activation.

#### 4.2.7.2 CRITERIA FOR ESCALATION OF CARE

One review (Gill et al 2016a) discussed criteria in place to help patients/ family members to decide whether or not to escalate care. Studies identified up to four separate criteria for consumers to consider when making the decision to escalate patient care, these being: clinical deterioration or a noticeable change in the patient's condition, breakdown of communication with clinicians/ staff, perceived error, and concerns about the planning, delivery or management of care.

Another review noted that consumers responded favourably and appreciated increased knowledge about changes in physical signs to watch for taught to them by clinical staff (Vorwerk & King 2015) – yet only a very small number of studies educated patients/ family members on specific signs.

Several reviews noted that clear criteria for consumers are needed, for instance, clarity about whether consumer-initiated escalation is based on clinical deterioration or concerns about care (Gill et al 2016a, Vorwerk & King 2015). Further, consumers' ability or confidence to detect clinical deterioration in order to activate care escalation has been little studied (Albutt et al 2017, Gill et al 2016a, Vorwerk & King 2015), despite its centrality to the system of escalation of care.

### 4.2.8 USAGE AND OUTCOMES OF ESCALATION SERVICES AND REASONS FOR USE

#### 4.2.8.1 NUMBERS OF CALLS (ACTIVATION)

Numbers of calls were reported in variable ways across reviews. These have been consolidated in this summary but are presented as indicative estimates of call numbers, rather than definitive numbers.

Typically, numbers of calls were recorded in order to monitor for over use of patient/ family activation of care escalation (Albutt et al 2017). Reported rates were generally low, a pattern reflected by estimates captured in the grey literature (ie from institutional websites; Albutt et al 2017).

Overall, consumer-initiated RRT activation rates were low but increased after introduction of the escalation function. One review (Albutt et al 2017) reported a mean of 15.33 calls per year across studies: findings from primary studies showed increases post-implementation of the consumer escalation function, such as an increase

from 3 to 5 calls to Condition H, and an increase from 16 to 24 calls per 1000 discharges. Another review (Vorwerk & King 2015) reported a small increase from 0.08 to 2.46 calls per month following implementation in 10/11 included studies, with a higher rate of 11.5 calls/ month reported in one study.

Numbers of calls made by staff also increased (Gill et al 2016a, Vorwerk & King 2015) with introduction of patient/ family-initiated RRT systems. Numbers were variable, ranging from a small increase of 2.34 calls per month to 193 calls per month, with a small proportion (25/193, 13%) reflecting calls made by patients or family members (Gill et al 2016a).

#### 4.2.8.2 CLINICAL OUTCOMES OF CALLS (ACTIVATION OF ESCALATION)

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Clinical outcomes were reported in some studies. Single studies reported decreased mortality (from 31 per 1000 discharges with RRS programme to 22.9/1000 discharges for RRS programme with consumer activation), reduced non-ICU adverse events (codes), and increased survival following codes (Vorwerk & King 2015, Gill et al 2016a), compared with the pre-implementation period.

Several studies reported increases in transfers to higher level care post-implementation, with a wide range of estimates but absolute numbers of calls generally remaining low. One study reported higher transfer rates (from 12.8 to 45.4 per month) following implementation, but this included both staff and consumer-activated RRT calls.

#### 4.2.8.3 APPROPRIATENESS OF ESCALATION TO RRT

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Almost all (99%) of consumer-initiated calls were rated as appropriate (ie. meeting the criteria for RRT activation) (Gill et al 2016a); but a small number of studies reported that clinical staff considered some patient/family-activated RRT calls problematic (Albutt et al 2017). The proportion of calls initiated by consumers leading to higher levels of care or medical intervention was, however, quite low, for instance, estimated at about 1% (Gill et al 2016a) to 4% (Van Voorhis et al 2009).

Consistent with this finding, a single study reported in one review (Albutt et al 2017) comparing patient/ family-led escalation directly with clinician-led RRT activation (rather than as an add-on service), reported lower levels of patient transfer to ICU with patient/family-escalated RRT (24% of 40 versus 60% of 1,156 clinician-activated RRT). Authors noted that this may have been due to detection of deteriorating patients by patients/ family members that would otherwise have gone unnoticed.

#### 4.2.8.4 REASONS FOR CALLS TO ESCALATE CARE

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Aside from clinical deterioration, several reviews identified a number of additional reasons for patient/ family-initiated escalation. Communication breakdowns (such as lack of response, conflicts, dismissive interactions with clinicians, delays in assessment) were a commonly identified cause; concerns about medication or pain management, and care coordination (delays, care or discharge plans) were among the other reasons for calls to escalate care (Albutt et al 2017, Gill et al 2016a, Vorwerk & King 2015). Reasons for calls were not mutually exclusive (ie there may have been more than one reason for making the call to escalate care)(Gill et al 2016a).

Staff-activated RRT calls also increased with introduction of escalation systems (Vorwerk & King 2015). In several cases, family concern was noted as the reason for staff-initiated calls, with rates estimated at 5% (Vorwerk & King 2015) to 8% (Van Voorhis et al 2009).

One review noted that identification of previously unrecognised communication problem(s), which may have an impact on patient safety, may be an unintended positive outcome of introducing patient/ family-initiated escalation (Albutt et al 2017). Since communication breakdown was a major reason for patient/ family escalation, this review suggested that hospitals implement an additional escalation pathway in order to deal with such issues separately to RRT for clinical deterioration.

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## 4.2.9 PATIENT AND CARER EXPERIENCES

### 4.2.9.1 KNOWLEDGE OF THE PROGRAMME OR SYSTEM

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Knowledge of whom, how and when to activate a RRT call was variable, for instance, one review (Gill et al 2016a) reported knowledge ranging from 20 to 98%. Similarly, another review (Vorwerk & King 2015) reported mixed results with some studies reported high levels of consumer understanding of information (range 76-100%), others reporting lower mean levels, or smaller increases in knowledge, and one reporting high initial levels of knowledge (95%) about how to activate RRS but poor later recall (18%). Two reviews noted that clear messages for consumers about the process for escalating care in order to be able to action the information is critical (Gill et al 2016, Vorwerk & King 2015).

### 4.2.9.3 SATISFACTION WITH THE PROGRAMME OR SYSTEM

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Studies typically showed high levels of satisfaction with patient/family activated RRT from patients and family members. This included high levels of satisfaction with the process both amongst those who had and had not made a RRT call (Gill 2016a,b), satisfaction and a sense of safety or reassurance knowing that they were able to contact the RRT if needed (Albutt et al 2017, Vorwerk & King 2015), including families of patients discharged from ICU (Gill et al 2016a). Patients/ family members also indicated that they felt they had enough information about the RRT escalation pathway (83%) (Albutt et al 2017).

One review noted that interviews with family members raised concerns about the possible negative effects of escalating care on the relationship with staff (Gill et al 2016a), and another highlighted that the relatively low levels of RRT activation by patients and family members might reflect reluctance to engage in behaviours that may be interpreted as challenging hospital staff (Albutt et al 2017). The ability or willingness of patients and family members to be involved in patient safety more generally (i.e. not only RRS activation) may also be variable (Berger et al 2014).

Potential harms of introducing a patient/ family member activated RRT were not reported by included studies, and one review noted that should errors happen (whether or not related to RRS activation), patients and family members may feel guilt (Berger et al 2014).

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## 4.2.10 STAFF EXPERIENCES

### 4.2.10.1 ATTITUDE TO THE PROGRAMME OR SYSTEM

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Staff responses to patient/ family activated RRT introduction were varied. Some positively commented on the benefit of empowering patients and family members, and that the introduction of the pathway could be seen as contributing to prevention of patient deterioration, reduced complaints and improved patient experience (Gill et al 2016a).

All included reviews also noted that staff also expressed concerns about patient/ family-initiated RRT activation. These included the potential for overuse of the pathway for non-emergency situations, and that this might overwhelm the system; concern that introduction of the pathway conveyed to patients and family members that they should not talk to their medical team about their concerns; loss of control; being deskilled; increased scrutiny; increased workload; and that their decision-making or role in patient care might be undermined.

One review (Van Voorhis et al 2009) described a case study site where focus groups, communication and a pilot were used to educate staff about patient/ family RRT activation, and to address staff concerns that the system would be overwhelmed by non-emergency calls. These activities included the rule 'no false alarms' to reinforce the idea that serious concerns about the patient, whether from clinical staff or family members, is an appropriate reason to activate the system.



#### 4.2.10.2 IMPLEMENTATION AND TRAINING ISSUES

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Implementation strategies included combinations of guidelines, policy, reminders, education for staff and family, standardised scripts, written materials (brochures, posters), piloting, and audit and feedback (Vorwerk & King 2015). All reviews highlighted that education and training for staff, and for patients and families, are needed prior to implementation of the system.

#### 4.2.10.3 TRAINING FOR STAFF

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Education and training for staff was undertaken in order that they be well informed about details of consumer activation system, and so that they were confident and able to educate consumers about the escalation of care pathway (Albutt et al 2017). Staff education on the content and delivery of information for patients/ family members was noted as critical (Vorwerk & King 2015).

Staff were educated in small groups (Albutt et al 2017) or via individual meetings, through personal communications or shift change huddles (Vorwerk & King 2015). Several studies described comprehensive education packages which also included checklists, reminders, talking points and self-learning modules; several relied on scripted narratives to support staff to deliver information to consumers, and one educated all hospital staff using a communication toolkit (Vorwerk & King 2015).

Hospital bulletin board notices, regular newsletters or items, and intranet education were often used to promote and reinforce staff education (Vorwerk & King 2015). Some studies described electronic chart education or reminders for nurses in electronic medical records to ask about families' awareness of the escalation system at regular intervals in order to support information recall (Berger et al 2014, Van Voorhis et al 2009); with one study emphasising that educational opportunities taken up after admission improved information retention (Vorwerk & King 2015).

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#### 4.2.11 EDUCATING PATIENTS AND FAMILY MEMBERS

Strategies for informing and educating patients and family members about the escalation system typically used multiple approaches to promote understanding of the system, the process for activation, and to reinforce key messages. However, it is also worth noting that none of the studies included in these reviews have assessed how families would prefer to be informed about the process of escalating care, or their preferences for participation in such care processes (Gill et al 2016a)<sup>2</sup>.

##### 4.2.11.1 EDUCATION BY NURSES

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Patients and family members were often first informed about the process for escalating care upon admission, unit orientation or before transfer from the Intensive Care Unit (ICU). Education was typically undertaken by the admitting nurse, often via a standardised information script (Albutt et al 2017, Berger et al 2014, Van Voorhis et al 2009, Vorwerk & King 2015). Most studies described this one-to-one verbal education as critical.

##### 4.2.11.2 SUPPORTING INFORMATION FOR PATIENTS AND FAMILY MEMBERS

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Verbal information delivered by nursing staff was supplemented with additional information. Reviews indicated that providing information via passive means alone (e.g. via poster) was insufficient as consumers may not read the information unless prompted to do so by staff; and that multiple different active communication strategies (formats or modes) for informing patients/ family members about the RRT escalation system and how to access it were required (Gill et al 2016a, Van Voorhis et al 2009, Vorwerk & King 2015).

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<sup>2</sup> King L, Peacock G, Crotty M, Clark R. (2018). Consumers' perspectives on their involvement in recognizing and responding to patient deterioration—Developing a model for consumer reporting. *Health Expect.* 2018;00:1–11.



Printed educational materials were provided in most studies to reinforce key details of the system (Vorwerk & King 2015), with this additional information taking the form of information sheets, posters, flyers, brochures, FAQ sheets or signs and instructional labels for telephones (Berger et al 2014). Sometimes written information was included in the hospital guide given to families on admission (Van Voorhis et al 2009) or additional information was provided via video; in others, posters and leaflets provided in patients' rooms and/or in visiting and waiting areas served to reinforce information given verbally on admission (Albutt et al 2017). Printed educational materials, such as posters throughout the hospital, may serve to remind consumers what to do or what number to call if RRT activation is needed (Van Voorhis et al 2009).

A very small number of studies described providing bilingual information, for example, providing information through a translator upon admission, bilingual flyers, bilingual tear-off information cards or a Spanish information card to hand to an English speaker to activate the RRT (Van Voorhis et al 2009, Vorwerk & King 2015). Two reviews noted that translation of materials to non-English languages has lagged behind and that there is need to consider factors such as cultural diversity and health literacy levels when introducing any consumer-initiated escalation of care role to ensure the needs of all patients and their family members are met (Gill et al 2016b, Vorwerk & King 2015).

Information materials such as posters often described signs for patients and families to watch for, and how to escalate their concerns. Concern about the patient was a requirement for making a call to escalate care across studies, but only two actually provided education for patients and family members on specific signs to watch for (e.g. heart or respiratory rate, mental status, agitation) (Vorwerk & King 2015). A small number of studies in this review (3) also provided information explicitly on issues that were not to be managed through escalation of the RRS.

## SYSTEMATIC OVERVIEW SUMMARY THEMES

- Escalation programs may lead to improved health outcomes for patients, including reductions in mortality or serious morbidity, and are typically associated with high satisfaction for those using the programs.
- Communication issues were a frequent reason for patient/family-initiated escalation.
- Providing appropriate training and education for health services staff and potential users of the escalation service is critical.
- Promoting knowledge of the escalation system, and how to use it, amongst potential users needs to involve multiple channels and media and should include direct education and promotion by nursing staff and/or clinical teams.
- Escalation programs do not result in over burdening of health services, large numbers of calls, or large numbers of 'inappropriate' calls.
- Consideration of health literacy levels is essential when tailoring messaging and media to the cultural and linguistic diversity of the large audience.

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## 4.3 THE CARER EXPERIENCE

Partnerships between carers and hospital staff to improve patient safety are increasingly encouraged in patient safety policy. However, little is known about how these partnerships work in practice, particularly from the carers' perspective. To help understand a more personal perspective of the patient and carer experience we have drawn on the findings of Dr Bronwen Merner of the Centre for Health Communication and Participation, La Trobe University. This study aimed to understand carers' contributions to patient safety in hospital, from the carers' perspective and is intended to give a personal perspective to the themes and findings that emerged in the systematic review. Thirty-two carers who had patient safety concerns for their relatives during a recent hospital admission were interviewed in-depth. Each interview were transcribed and analysed using the constant comparative method simultaneously with data collection, collection ceasing when theoretical saturation was reached (Merner, 2017).

The final results demonstrated carers engaged in the process of 'patient-safety caring'. Patient-safety caring involved the following three intensities: 'caring without concern' (low intensity), 'being proactive about safety' (moderate intensity) and 'wrestling for control' (high intensity). Wrestling for control was associated with low trust and a high sense of personal responsibility whereas contributing without concern was associated with higher levels of trust and lower levels of personal responsibility.

The Merner study is not the only qualitative study that considers the carer perspective, but its strengths, findings and lessons are a strong supplement to the systematic overview findings, given the majority of participants came from Victoria.

In 2014 Western District Health Service (WDHS) conducted a focus group of consumers who had lived experience of rapid escalation as a patient or family member (McLaren, 2014). Although it is with a limited sample population, the focus group report identifies some important expectations, attitudes, behaviours and experiences of consumers engaging in patient safety caring including escalation.

This section draws on the findings of Merner's study and those of the WDHS focus group and have been used to inform the recommendations for Victorian best practice recommendations framework and central phone number for escalation.

### 4.3.1 VALUE OF CARER INPUT

Identifying and understanding the value that carers have in contributing to patient safety caring was explored in the Merner study. The findings highlight how carers' observations provide valuable input to service providers due to two main factors: 'Being There' and 'Knowing The Patient'.

#### 4.3.1.1 BEING THERE

Regular carer visits provide a level of consistency in a service reliant on multiple stages of information handover between departments/shift staff and can help resolve or address communication issues and misunderstandings when they arise. Some carers also saw "Being There" or being seen to be present as helping to prevent harm because health services knew someone was there, watching and following up.

Being present with the patient means carers have a very special perspective on the continuance of care, information transfer and how things are being communicated and understood.

### Being there

*"Quite often I'd be there (on the ward) and I'd have him crying in pain, and the nurses would come in a few minutes later and they'd say "Oh, do you want pain relief?" and he'd just say "No, I'm right". And I'd say to him "What was that answer about there?" and he said "Well, what did they ask me?" because they just asked him do you need pain relief and you've just told me you did but you've told them no. He said "Oh, I didn't really hear what they asked".*

*Danielle, (Merner 2017, p.109)*

#### 4.3.1.2 KNOWING THE PATIENT

"Knowing the patient" gives carers an intimate knowledge of the patient and their normal behaviours, symptoms and when there are any (even subtle) changes. Acknowledging this 'expertise' is important when observing and understanding a patient's possible deteriorating clinical status.

They can help resolve communication issues with the patient or help interpret any key information in a way the patient can understand (for example different interpretations of pain scales, when the patient is trying to be polite or not make a fuss rather than answer factually). This value of 'knowing the patient' came up during the WDHS focus group with participants describing how it would be important for clinical staff to "recognise the ability of patients themselves, and their family, friends and carers, to identify rapid changes in mood, mental state and personality as indicators of deterioration" (McLaren 2014).

### Knowing the patient

*"The family knows that person better than anyone else and they need to use that experience. Because here's someone who's so sick and (the hospital staff) don't know them from a bar of soap. They can look at all the charts and they can look at all the vital signs and whatever but they don't know the person."*

*'Because nothing was being done and Mum was getting worse. So day-by-day we'd go in, she was a bit worse. And I was just like "What is going on here?" you know "What's going on?" It was so frustrating because she was obviously really unwell and it was like they were completely oblivious. They didn't know her—I know that—and, but I just thought that it was bleedingly obvious there was something wrong, you know'.*

*Bernadette (Merner 2017).*

#### 4.3.2 A SPECTRUM OF PATIENT SAFETY CARING

Merner identified a spectrum of intensity for carer engagement in patient safety. The intensity level helps to identify the patient safety behaviours they engage in and their benefits to patient health outcomes. The spectrum covers low, medium and high intensity levels of patient safety caring (Merner 2017).

On this spectrum the ideal carer would be in the lower or medium intensity range but able to achieve the results of a high intensity carer. This combination would diffuse the more aggressive elements of high intensity carer's who see themselves as "protectors" of patients from or against health services, but maintains an effective degree of proactive engagement which increases patient safety outcomes.

Across all levels of increasing patient safety caring intensity of patient safety caring a very consistent wish was expressed to not upset or test relationships with health service providers. However, the less trust a carer had in a system and the more personal responsibility they felt for protecting the patient's life or their safety, the more they were willing to push the boundaries on their relationships with health services/clinical providers.

The levels of patient safety caring intensity are outlined below.

**Low intensity (contributing without concern):** Carers who are at the “contributing without concern” level of patient safety caring engagement tend to be less familiar with the hospital system, or have previously had positive hospital experiences. Due to a high level of trust in health providers, they almost entirely hand over responsibility for the patient's safety to clinicians and hospitals. Merner describes how carers at this low intensity level can experience high levels of guilt for not taking more responsibility with the patient's care when adverse events do occur.



**Low intensity (contributing without concern)**

*But I just think ... you trust doctor. You know what I mean? He's a doctor. So you trust".*

Rita, (Merner 2017)

**Medium intensity (being proactive about safety):** Carers who have increased their engagement to be more proactive about patient safety care have started to take on a 'protection against harm' role. They are more familiar with the health system and its weaknesses, have some levels of distrust, have taken back some responsibility for ensuring adequate care of patient, and will engage in discussion/questions about care.



**Medium intensity (being proactive about safety)**

*"So we have to fight for everything we do. So, and part of that is, when we go to hospital and she turns up with her adrenal crisis that needs urgent attention, with a protocol letter that says "Treat me urgently or I can die" three times out of the last four times we've gone to hospital we've had to fight with them about that, even though she has that letter. We've had to fight and fight and fight to get the help".*

Nina, (Merner 2017)

**High intensity (wrestling for control):** At the high intensity level of patient safety caring, carers had much lower trust in the health system. They had usually experienced an adverse event or were concerned that the staff were failing to resolve an imminent threat of harm. These experiences or perceptions meant they had developed highly assertive, and sometimes aggressive, strategies to prevent harm to the patient. This high level of patient safety caring, although more aggressive, did get results but it was at the expense of trust in health providers.

### High intensity (wrestling for control)

*"In the past, I've felt that, when you go (to the hospital), you just sort of like pass everything over and you just give it all up. Everything's given up to (the hospital staff) and they make all the decisions, and you just abide by them and say yes and no, and all this sort of thing because they are the people who are in charge whereas I think, from this experience, I've realised that I have to be able to step up and say what I think".*

Bella, (Merner 2017)

#### 4.3.3 PROTECTING THE PATIENT – WHEN CARERS PERCEIVE THEMSELVES AS PROTECTORS

As carers increased the level of intensity for patient safety caring, they took on more of a 'protector' or guard role as they took on more responsibility for protecting the patient's life. The more experiences and more health literate the carer's became, the more they transitioned to a protector role.

Areas where the protector role was often observed included checking clinical records included the right medications and allergy information.

*"And all night this nurse kept coming in, shoving stuff into his drip, and we kept saying "What's that?" "Diazepam ... diazepam ... diazepam ... just to stop the spasticity." And I said "But he doesn't have spasticity." "Yeah, look, we know what we're doing. We know what we're doing". Ingrid (Merner 2017, p.113).*

*"And you say "Go back (to the medical record)" and they say "Oh it's all in the computer" but it's not. They try and give him medication that you say "Well, no, he's allergic." Wendy (Merner 2017, p.95).*

*"So, I usually write it out, I make the staff aware when he first goes in and ask them to please pass it on during (handover)." But not completely trusting it would be passed on she also said, "So I felt I had to do that, that they wouldn't go to the file or go to the notes and see. Whereas putting it in a coloured post-it pad was, for me, just another reminder to them." Danielle (Merner 2017, p.108).*

#### 4.3.4 FIGHTING ASSUMPTIONS

Fighting assumptions by the clinical team about a patient's quality of life (particularly patient's with disabilities) resulting in decisions to not provide treatment was another area where carers felt they needed to be protectors.

*"I put together the stuff that I had on what Will had been doing up until he went into hospital. Will was on several committees. The Disability Advisory Committee for (the local area). Other committees similar to that. We had newspaper articles on things that Will had done so I put them all together in a folder. I took them in and I presented them to the head ICU doctor, and he had a flick through them, and he said to me "Oh well this paints a different picture then." And, after that, you know, his attitude changed." Susan (Merner 2017, p.126).*

#### 4.3.5 MAINTAINING RELATIONSHIPS WITH CLINICAL TEAMS

Keeping the health service and clinical team on side was a priority for all levels of patient safety caring. It is only when carers feel the life of the patient is in danger that they are willing to push the boundaries of the relationships to get the attention they need. As one carer described, they would determine whether the issue was something she could sort out once her mother was discharged, even if it meant a temporary impact on her mother's health, in order to maintain a positive relationship with the clinical team:

*"So, it was a matter (of) making judgments about knowing which fights to fight – that's a big one. Like with mum there were a number of times where I would just take a deep breath and say "Ok, let's just go through this, she'll be spat out at the other end and we can sort it all out". Because she had a really good GP, he and I*

*would sit down together and just get rid of all the crap that all the different medications and stuff ... we'd bring her back to where she was and we'd start again". Sally, (Merner 2017, p.95).*

The WDHS focus group also supports this desire to maintain strong relationships with clinical teams. The participants expressed that health service staff did take the best care possible with the patient, but if they had concerns they were often hesitant to 'trouble' or 'bother' staff in case they were perceived as too burdensome by seeking extra advice or care (McLaren 2014). The report surmised that sometimes this confidence in staff to be doing what is best and a reluctance to cause problems might result in the patient ignoring any concerns they might have (McLaren 2014).

#### 4.3.6 BEING LISTENED TO/FEELING VALUED

Many of the carers Merner talked to for the study reported how they tried to communicate with their health service staff about the patients but that what they had to say was dismissed.

*"I got told by the one charge nurse that the staff there are used to looking after unconscious patients. They know what's best for them. It was not up to me to tell them how to do their job. The consequence of that was that Will ended up with nerve damage to his left arm and he even now can't use the switch, the switches (on his wheelchair) in his left hand that he used to be able to use. So that limits what he can do" Susan, (Merner 2017 p 105)*

Carers stepped up their protection when the patient's views, concerns, interests or wishes were not being listened to. The "advocate" role was considered one they didn't want to take on, but needed to be done to get the message across. Carer 'S' took action when he perceived the hospital's actions of not providing nutrition for his wife (who had late stage multiple sclerosis) did not respect her care wishes:

*"Well, they (the hospital) failed (in letting my wife die) because I fed Brenda. I was in there with food every day. I was giving her roast pork, I was giving her chocolate, I was giving her drinks, I was giving her all sorts. And all these charts and things that are happening in and out fluid wise, they're all up to nothing because I wasn't going to let it (death) happen." She was later discharged and returned home." Sam, (Merner 2017, p.122).*

Merner outlines Tracey's experience requesting prophylactic pain relief for her brother:

*"The doctor was taken aback and tried to usher Tracey out of the office. When I asked Tracey why she felt the doctor had acted that way, she said 'This is the sort of thing that can happen when you're a carer, that people resent you and what they regard I guess as an intrusion on their domain, you know'. She described the incident further: '(The doctor) was very resentful and wouldn't even look at me. I'll never forget that. It's such a feeling of powerlessness'." (Merner 2017, p.113).*

#### 4.3.7 PRIORITIES ASSOCIATED WITH COMMUNICATION AND PATIENT NEEDS

A reoccurring theme in the experiences of the interviewed carers is wanting health teams to consistently recognise the patient and their needs as a person, including having read the patient's notes, understanding how the patient prefers to communicate and listening to the patient and/or carer. One situation describes how the focus of problem solving was on "malfunctioning" equipment, rather than the patient's needs:

*"So, by this stage (after the ventilator had been switched off), I'd got up, off the chair, gone around to the other side of the bed. That particular nurse (who had turned off the ventilator accidentally) had come back with a second nurse and they were trying to work out why the alarm was going off on the ventilator ... They were just focusing on the ventilator and that was it. And I ended up having to basically push past them to get to the second ventilator, turn it on, change his tubing over to that ventilator so he could breathe". Susan, (Merner 2017, p.122).*

Several carers reported being told to let health services do their job when they were trying to communicate the patient's particular needs and many carers had to take creative measures to make sure the messages got through. Some creative approaches that carers took to try and communicate the patient's needs to health services included sending postcards with "reminder" messages to his mother about her specific care needs (e.g. that she needs to ask the nurses to sit her up for meals) that he would send to her in hospital knowing the nursing team read them. Another carer used post-it notes to remind the health service team about the patient's needs and care requirements.

The WDHS focus group identified a few other factors that could be issues preventing people from raising their concerns with health services including the need to be confident to ask for help, an assumption that the best possible care is already being provided, inability to communicate needs, hospitals can be intimidating, staff may seem unapproachable and that for many years hospitals may have discouraged people from asking questions (McLaren, 2014). Timing of when information about escalation is provided was also highlighted in the focus group with WDHS. The participants described how information is often provided to patients on arrival in a ward when they are groggy or sick and that it may be more effective to ensure family, friends and carers have direct access to the information (McLaren 2014).

#### 4.3.8 A TEAM APPROACH TO TREATMENT AND CARE

When the carer described being consulted and included in the treatment decisions for the patient they felt more respected and informed about what was happening. They also highly appreciated when nursing staff demonstrated that they understood the patient's individual means of communication. This helped build confidence and faith in the care being provided as they felt that the records were accurate, updated, read and used.

*"We (me and the medical team) discussed the pros and cons of a particular medication and it can be an addictive pain relief. And because of the other medications he was on, we decided that we didn't want him on that particular medication, because then we had to go through the process of withdrawing it" Danielle, (Merner 2017, p.103).*

*"There would be staff who were really terrific and who really would know, I could tell with the way they would come in and they would come to the correct side of the bed, so that he could hear what they were saying, I could see that they were giving him response time, they were willing to listen to what he had to say." Danielle (Merner 2017, p.114)*

#### 4.3.9 ELEVATING CONCERNS AND COMPLAINTS

Merner describes several situations where carers attempted to elevate their concerns or complaints both within and outside the hospital setting. It appeared that those who elevated their concerns outside the hospital setting had more success. Internal escalation included raising the issue with the Nurse Unit Manager or doctor. External escalation included going to the Office of the Public Advocate and the Minister for Health.

**Internal escalation:** One carer interviewed in the study described how a doctor advised her to make a formal complaint when she raised her concerns about her mother being left off oxygen for a period of time. She recalled the doctor said:

*"Make sure you lodge a formal patient complaint because it doesn't matter what we (the doctors) say about things like their oxygen practices or anything like that, the hospital management won't really listen to us but they will listen to a consumer."*

It is important to note that in this situation she did write a letter of complaint but that she did not send it until her mother had passed away, fearing it would affect the level/quality of care her mother received. (Merner 2017, p.126)



**External escalation:** *"So, for example, the doctor comes in at six o'clock. He was a surgeon for the orthopaedic; he didn't care about the rehab side of it. And I remember even him one day I'm saying, you know "I can't even get him therapy because there's no (standing frame)." And he said "Well go to the bloody Minister!" Like, you know, I'm thinking "I'm in hospital!" Well, as it was, I did. I had (the Health Minister) come in and see because I was the president of (advocacy organisation) at the time". (Merner 2017, p.125)*

## CARER INVOLVEMENT SUMMARY THEMES

- Communication was identified as a common issue for patient/family involvement in management of patient safety caring.
- The value of carer in health related decision-making is linked to two main factors "Being There" and "Knowing the Patient".
- Carers have a strong desire to maintain good relationships with clinical teams but balancing their role as carer and protector with maintaining relationships can be difficult.
- Engaging carers in care and treatment decision-making improves communication, understanding and supports better patient safety caring outcomes.



## 4.4 PATIENT, CARER, FAMILY MEMBER OR FRIEND INITIATED ESCALATION IN AUSTRALIA

### 4.4.1 RYAN'S RULE – QUEENSLAND



#### 4.4.1.1 OVERVIEW

Ryan's Rule was initiated by QLD Health in consultation with the parents of toddler, Ryan Saunders, who tragically died in hospital in 2007 and whose death was found to have been preventable. The design, communications and roll out of the Ryan's Rule program were guided by a consultative and advisory committee involving health service representatives and consumers. Ryan's Rule intended to provide a secondary (or safety net) escalation process that complemented and provided a safeguard for carers and patients for when they feel most vulnerable and concerned about the deteriorating health of their loved one/patient. The lessons from the design and implementation of Ryan's Rule are instrumental in considering recommendations for a centralised escalation program in Victoria.

#### 4.4.1.2 IMPLEMENTATION

Ryan's Rule used a phased approach for the state-wide roll out of the program. While establishing a separate call service was considered, it was decided that using an existing health related call centre as the receiver of Ryan's Rule calls helped to reduce costs and integrate the program into an existing structure. The 13 HEALTH/ 1343 2584 call centre became the receiver/transfer centre for Ryan's Rule calls and has been very successful in this role. The guidelines were developed in 2011-2013, including the consumer testing of materials, website, and minimum criteria for health services to respond to a call and contracting Smart Service QLD to manage the calls (Smith K 2017). The initial pilot site went live in early December 2013. Over the next few years, additional sites were gradually added to the program and by 2015, 164 health services were actively using the Ryan's Rule program. In 2017 all 167 public acute hospitals and primary care facilities in Queensland were actively part of the Ryan's Rule program (Clinical Excellence Division 2017). Each new site undergoes a preparation period and testing before being incorporated into Ryan's Rule.

**Fig 1. Criteria for Health Service site to go live – Ryan's Rule**

- Able to provide a 24 hour response 7 days per week
- Oversight by a local governance committee
- A localised, internal procedure in place based on the guidelines
- 3 nominated staff/ roles able to receive a 'warm transfer' of the caller from 13 HEALTH and to initiate an independent clinical patient review

For each call made, the call centre follows a script. If it meets the Ryan's Rule criteria, a call to notify the health service will be made as well as notification emails to key management and medical staff. When a call is assessed to be related to a customer service complaint (a food service complaint, noise complaint, request for blankets or air conditioning control etc) or other non-clinical concern the caller is transferred to the relevant number or provided with the appropriate contact details and instructions. The call centre uses a Customer Relations Management software (CRM) to record each call. The data from the CRM system is downloaded every 24 hours to

the state-wide health database so that services can access details of the call quickly for their reports and additional follow up.

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#### 4.4.1.3 RESULTS AND RECOGNITION

Ryan's Rule has a very high rate of recognition among consumers and health service providers and has demonstrated very high satisfaction rates among consumers who have used it. In an evaluation of Ryan's Rule based calls made between 2015-2017 at a single site the majority (87%) of callers "agreed or strongly agreed that they would be comfortable activating an RR (Ryan's Rule) again" (Dwyer, Flenady, Khal & Quinney 2019). In addition to this, sites have reported that Ryan's Rule has helped to improve communications between patients, family members and clinical teams (Smith 2017). The caller follow up data for all calls documented in the Ryan's Rule CRM indicates that people who use the system are satisfied with how it works. Of those who used Ryan's Rule during 2015-2017, 272 (n=348) indicated that their concerns were being addressed (40% 'Strongly Agree' and 39% 'Agree' concerns are being met). 86% indicated that they would use Ryan's Rule again if needed (Clinical Excellence Division 2017).

The 2015 -2017 CRM data also indicates that less than 1% of Ryan's Rule calls resulted in patient transfer to an Intensive Care Unit (ICU) and that the reasons for calls were primarily related to concerns due to lack of knowledge or understanding (26%) or disagreement with treatment plans (50%). This was supported by the results of the recent evaluation where a third of calls were resolved by addressing communication issues between consumers and health services alone (Dwyer et al 2019). An important role that Ryan's Rule has played is in allowing carers and family members to identify potential issues or signs of deterioration early. For example, in one location a family was concerned about their relative who was paler than usual with no change after several days post a surgical procedure. The family raised their concerns with a nurse, before deciding to call Ryan's Rule. The call resulted in a medical review which revealed the patient's instructions had not been updated to indicate they be taken off Heparin after the surgical procedure.

An important finding from the 2019 evaluation was that there is a discrepancy in what is understood to be an adverse event, i.e. what is understood as a concern by consumers but a complaint by clinicians. The evaluation found that one in five activations were considered an inappropriate use of a Ryan's Rule and therefore did not have a completed post activation review. Explanations given included "this is not a Ryan's Rule, but rather a complaint" or in one case "...family were concerned patient getting worse and worried she will deteriorate and end up in ICU again" (Dwyer et al 2019). Addressing this mismatch in understanding about what is a legitimate call to an escalation service is an important area for further consideration.

The evaluation explains that patient-centred care can benefit substantially from understanding consumer experiences. Finding the right approach and tools to do this will be key to understanding how health services can address 'communication and behavioural trends that may represent future safety risks' (Dwyer et al 2019). The evaluation concluded that there is justification for implementing systems that make better use of data from consumers to inform clinical decisions, focus on strengthening relationships between consumers and clinicians and address communication needs and competency gaps.

## 4.4.2 REACH (NSW)

### 4.4.2.1 OVERVIEW

REACH was borne out of the recognition that patients, families and carers were not empowered to raise their concerns when they felt worried about patients in hospital. REACH (sometimes written as R.E.A.C.H) lists the steps involved in the escalation process as outlined in the Figure 2.

The REACH program in New South Wales (NSW) was established in 2013 by the Clinical Excellence Commission (CEC) as a “graded approach to patient and family activated escalation” (CEC 2017). The REACH program actively promotes families and patients to engage with the treating team before taking steps to escalate care. It was created based on a premise that the earlier deterioration is detected the more that can be done to reduce harm to patients. The REACH program is a decentralised model with each health service establishing their own escalation phone number and managing their own response structures, processes and data collection

The CEC provides state-wide leadership and support for health service implementation and evaluation.

**Figure 2: REACH**

**R** - Recognise  
**E** - Engage  
**A** - Act  
**C** - Call  
**H** - Help is on its way



Clinical Excellence Commission (CEC), <http://www.cec.health.nsw.gov.au/quality-improvement/people-and-culture/reach>

### 4.4.2.2 IMPLEMENTATION

The CEC led a gradual roll out of REACH throughout NSW health services, after a successful pilot. To support individual health services with implementation the CEC developed a Toolkit with guidance and resources, information/promotion materials for patients and family members, and education resources.

The Toolkit outlines that for REACH to be implemented successfully in a health service it needs to have clearly demonstrated support from senior leadership, it should not be seen as additional to other hospital systems but that it is integrated into existing initiatives and processes, and that the escalation process is recognised and promoted by senior medical staff.

**Figure 3: REACH Key Messages for Clinicians**

- REACH is a system that enables patients, carers, and families to raise their concerns about a worrying change in condition while in hospital.
- REACH is a system that enables patients, carers, and families to raise their concerns about a worrying change in condition while in hospital.

*REACH – Patient and Family Escalation, Information for Clinicians (Pamphlet)*

Other key enablers of successful implementation included partnership with patients, families, carers and local staff and education of health service staff, including clinician induction information. Clinician education messages focus on what the steps are, how REACH complements existing processes and systems, and the importance of empowering patients and families to raise any clinical concerns.

The CEC has worked closely with Grant and Naomi Day, who have become powerful patient safety advocates and determined supporters of the REACH program since the tragic death of their young son Kyran in 2013. Grant and Naomi were crucial to the extension of the program which encompassed the launch of a video featuring Kyran's story and two new REACH posters. This included a paediatric poster featuring Kyran's story.

The CEC is now focusing on further embedding REACH into mental health and emergency settings, strengthening evaluation and monitoring and improving engagement with CALD and ATSI communities.

REACH is implemented in the majority of NSW public hospitals, including all principal referral hospitals.

#### 4.4.3 YOU'RE WORRIED, WE'RE LISTENING (SOUTH AUSTRALIA)

##### 4.4.3.1 OVERVIEW

South Australia (SA) commenced an implementation strategy to introduce a newly developed consumer-initiated escalation of care model, known by the catch phrase 'You're Worried, We're Listening' in 2018. The accompanying newly developed and tested educational materials were also piloted at a metropolitan health service in Adelaide in 2018/2019. The SA Department of Health is progressing plans to introduce the model and educational materials throughout public health services in 2019.

This patient and carer escalation program was developed based on a commitment to identifying the consumer perspective in the earliest stages of model development. Researchers from Flinders University recently published their findings from research undertaken with patients and family members who had experienced reporting of patient deterioration; this study has provided the basis for SA's consumer initiated escalation of care model (King L, Peacock G, Crotty M, Clark R 2018).

##### 4.4.3.2 YOU'RE WORRIED, WE'RE LISTENING: CRITICAL THEMES

King et al's (2018) research identified three critical themes for the SA escalation model.

###### A. REPORTING PATHWAYS

Three pathways for escalation were included in the model:

- **Direct report to a Rapid Response System (RRS) when patient is in an unexpected state of severe deterioration:** This direct pathway is a phone number for patients and carers to request emergency escalation of care. The authors of the study did raise questions that have not been researched or studied in detail here or elsewhere about the socio-cultural factors that might prevent patients or family members from using the escalation phone service.
- **Direct report to a health care professional involved in the care of the patient:** The patient and family perspectives study found that this was the most commonly recommended pathway for escalation. However, for this to be effective the study also recommended actions on education for health services and promotion and communication methods to inform patients and carers about the escalation process.
- **Direct report to a patient liaison or advocate to assess the patient:** The patients and family members involved in the study indicated a preference to have access to a "liaison" or "advocate" with a high level of medical knowledge within the hospital / healthcare system (e.g. an outreach model involving a critical care based nurse responder) who could review the patient when they had concerns. This person would not be from the

patient's treating team or ward and would be called on if concerns were not responded to by the treating team in the first instance.

#### B. EDUCATION AND INFORMATION FOR CONSUMERS:

The patients and family members involved in the study highlighted the importance of education and materials being developed in consultation with potential users of the escalation system. They also highlighted that information about escalation should be provided using multiple channels and at times when they are more accepting or able to absorb information. Being informed verbally by health services staff was described as very important both during the admission process and regularly throughout a patient's hospital stay. Printed material was also indicated as helpful, but with the understanding that under stress the content may not be absorbed as effectively. Video communication that showcased studies or examples of how and when to use the escalation process were recommended and there was interest in use of mobile technology to share information at the right time for it to be absorbed and understood. The need for information to be clear and simple was also highlighted. The education and information content should cover:

- Making clear the role and position of a patient or family member in the escalation process
- What steps or response should be expected once an escalation step has been taken
- A simple flow-chart clearly outlining the steps.

#### C. EDUCATION OF HEALTH SERVICES STAFF:

- **Awareness and ability to respond to request to escalate:** The escalation process can only work if the health service staff themselves are aware of how it works, the steps involved and how it intersects with and supports other rapid response or escalation requirements.
- **Attitudes and views of patient and family members involved in requests to escalate:** Patients and family members described a fear of potential negative reactions from health services staff if they were to escalate care and concerns about how this would impact their relationships with their clinical teams and the patient's ongoing care and support. Education for health services staff is needed to help them recognise and actively demonstrate the value of patient and family member contributions to care.
- **Communication skills:** The study has incorporated into the model recommendations to provide education on communication skills of health services staff. This includes strengthening service provider listening skills, demonstration of the value a family member's knowledge of a patient and what this brings to care, and giving clear explanations and feedback about communicating the right information at the right time to maximise potential for information absorption and understanding.

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#### 4.4.3.3 IMPLEMENTATION

The implementation stage is not yet completed in SA, with plans to roll out the model and accompanying patient/family members' educational materials further in 2019. The consumer perspectives study (King et al 2018) helped to identify some key areas of focus for model evaluation and associated research topics. These include evaluating:

- Changes to consumer knowledge and confidence to report deterioration
- Health professionals' attitudes towards consumer reporting.

#### 4.4.4 PATIENT, CARER AND FAMILY-INITIATED ESCALATION SERVICES IN VICTORIA

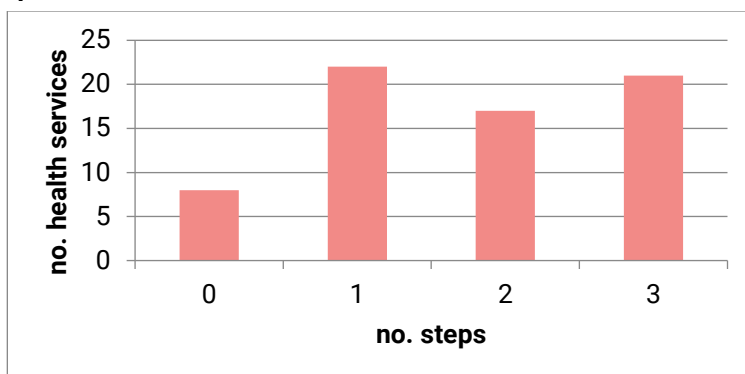
In 2017 SCV requested completion of a questionnaire on clinical escalation by 83 public health facilities. 68 responses were received and the responses indicated that while many Victorian hospitals have been developing and implementing patient or family-initiated escalation systems, there is much variation in models adopted and

their approach to implementation and reporting. SCV provided the authors with a list of 2017/18 Quality Accounts that had been received and these have been reviewed to identify if and how escalation was included in quality reporting.

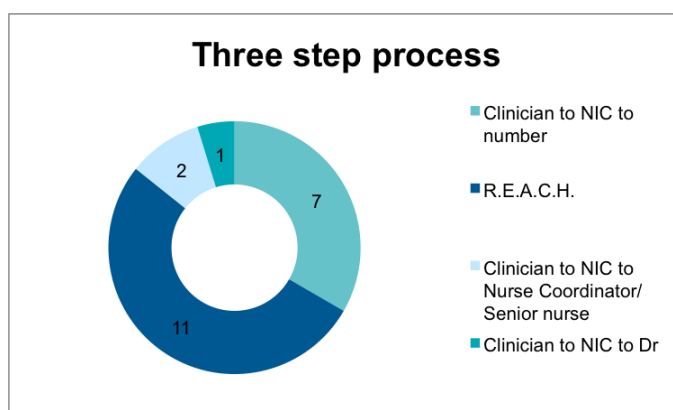
#### 4.4.4.1 VICTORIAN MODELS OF PATIENT AND FAMILY MEMBER INITIATED ESCALATION

Both the SCV questionnaire and the Quality Accounts reveal there is limited consistency in how Victorian health services have approached designing and implementing consumer- initiated escalation processes. The SCV results seen in Figure 4 demonstrates the different number of steps health services have incorporated into their escalation systems. Health services have adopted different models, including: no process for escalation, a 1-step process (usually encouraging use of the alert/emergency bedside button or buzzer), a 2-step process (inform a nurse, then inform a senior nurse or clinician) or a 3-step escalation process (using the NSW REACH model, or encouraging communication with a nurse then the treating team/ nurse in charge (NIC) and as a final resort to make a direct call for help; Figure 5) (SCV, 2017). 1-step processes appear to be the most prevalent and regional and rural health services make up most of those who reported this model. There is little publically available information that indicates whether or how consumers were involved in the design of these systems.

**Figure 4: Number of steps in escalation systems in Victorian public health services**



**Figure 5: Overview of models for 3-step escalation in Victoria (SCV 2018)**



#### 4.4.4.2 APPROACHES TO PROMOTION

The SCV survey results indicate that use of posters was the most common approach to promoting the escalation system with patients, family members and carers. The survey did not clearly identify where more than one method was used to promote awareness of an escalation process. Of those that did describe more than one



communication method, brochures, discussion at admission and including written information in the patient information booklet were most common.

Mercy Hospital reported in their 2016/2017 Quality Account report that an evaluation of their escalation program (based on the REACH model) was undertaken. This resulted in recommendations to utilise a single central phone number in their services that could be dialled from any phone, and to improve their communications and promotion approach to not rely on posters as the main method of communication and instead adopt multiple communication channels (Mercy Hospitals Ltd, 2017). This is supported by a focus group of consumers who had a lived experience of rapid deterioration (as patient or family member) held for Western District Health Service (WDHS). The discussion about promotion of escalation for consumers emphasised the need to not rely on written sources of information. The focus group participants did agree that information should be provided “verbally often and repeatedly during the hospital stay: ‘Every possible time’ and ‘at every shift change’.” (McLaren 2014). Interestingly the facilitator points out in the report that none of the focus group participants indicated that the first place they would look for information was in the pre-admission information packs or bedside drawers; notably these were the places the information about escalation were being provided (McLaren 2014).

There is some evidence that materials have been translated into languages other than English in some locations. The Health Translations Hub ([www.healthtranslations.vic.gov.au](http://www.healthtranslations.vic.gov.au)) has only one escalation-related translated document for the Peter Mac PEER program. Very limited information is available about how materials and messaging were designed to take into account CALD needs and preferences beyond translation of documents.

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#### 4.4.4.3 APPROACHES TO EDUCATION AND TRAINING

Very little information is available about the education and training provided to staff about consumer-initiated escalation processes. It is assumed that those services that have adopted the REACH model have incorporated some efforts to ensure staff are aware of the process, given the emphasis on this in the Toolkit, but no documented evidence of this has been identified.

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#### 4.4.4.4 DATA COLLECTION AND REPORTING

The 2017/18 Quality Account reports received by SCV by November 2018 reveal that the names for these processes are also wide ranging but with most health services drawing on the lessons of REACH in NSW. Very few of the Quality Account reports included information about rates of use of the internal consumer escalation system. Of those that did report numbers of calls, all had low numbers ie, less than 10.

The 2017 SCV survey indicated a lack of consistency in data collection and reporting for escalation. The most consistent response was that any consumer-initiated escalation data was not captured at all. 68% (15/22) services with a 1-step process, 6 (35%) of 2-step process services and 4 (19%) of the 3-step services indicated that they did not collect data or that the escalation data was underreported (SCV 2017).

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#### 4.4.4.5 ZERO TOLERANCE – 2016 REVIEW OF QUALITY AND SAFETY IN VICTORIAN HOSPITALS

The 2016 report, Targeting Zero: Supporting the Victorian hospital system to eliminate avoidable harm and strengthen quality of care, considers the balance between decentralisation and allowing freedom for individual services to explore innovative systems and improvements in care with the benefits of having consistent approaches to support the implementation of best practice (Department of Health and Human Services 2016). The report’s final recommendations reflect that while freedom to innovate is valuable it is also important to aim for consistent best practice. They highlight the role that centralised guidance on best practice can play in raising standards of quality and safety.

Other key points raised in the report that are relevant to establishing a central framework and phone service for consumer-initiated escalation include the recommendation that new and experimental activities need to ensure they are using clear and measurable goals to monitor impact, and that learning is integrated and implementation

adapted accordingly. Any data collected needs to be shared in a way that is timely and can be used effectively by health services. The systematic sharing of data between services, and throughout the state, is highly recommended to encourage collective improvement and strengthening of services to represent best practice.

The complexities and necessity of cultural change are also highlighted in the report. This is very relevant consumer-initiated escalation programs as systems can be designed to provide opportunities for people to become more engaged in care, but for them to be motivated and confident to use such programs requires a much broader perspective. An environment for open and positive engagement with consumers needs to be created in health services. As the report describes, this means fostering a culture of openness and disclosure of issues rather than fear and defensiveness to questions, criticisms and concerns.

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#### 4.4.4.6 CORONER'S REPORT FINDINGS RELEVANT TO FAMILY/PARTNER COMMUNICATION OF CONCERNS

A brief review of Victorian Coroner's reports was undertaken using the online AustL11 database. There were few mentions of cases where family involvement in the communication of concerns or request for escalation was documented as part of care, or could have changed the outcomes of care.

One Victorian inquest found that while the hospital in question did have clinician guidelines to give weight and value to carer and family opinions in making discharge decisions, this was not implemented comprehensively or consistently (Victorian Coroner's Report 2013). A similar finding was found by a NSW inquest that found that REACH was reported to be implemented in the patient's hospital but that there was low awareness (among consumers and staff) of the program and steps involved for consumers to escalate care (McLaren 2018). Both these findings indicate that adopting a process or protocol for consumers to escalate their concerns requires more than development of a policy, protocol or process document. Ongoing attention and priority need to be given to how the process or protocol is being implemented, the knowledge and capacity of staff involved, the awareness of consumers and the environment in which it is implemented.



## AUSTRALIAN EXPERIENCES WITH ESCALATION SUMMARY THEMES

- Communication was identified as a common issue for patient/family involvement in patient safety caring.
- Escalation pathways do not result in significant increases in health service workload.
- All clinical concerns are relevant concerns. Escalation systems are important tools to strengthen patient, carer and family member engagement in care and to support early detection of deterioration or concerns.
- Identifying the right local response team that can respond quickly, has the relevant medical skills and experience, and are within the health service but independent from the patient's clinical team is critical.
- Resourcing and prioritising education and training for all relevant health services staff to be aware of the consumer-initiated escalation principles and steps and to effectively support consumers to use the steps to communicate concerns is essential.
- Messaging and materials need to be developed in close consultation with members of the diverse community they are intended to reach.
- Committed executive and senior medical leadership is important in creating supportive environments (changes to systems, cultures, behaviours) for successful consumer engagement in care and escalation.
- Commitment to collection, analysis and timely sharing of relevant data, evaluation findings and best practice recommendations is required.

## 5 Plans for a central escalation phone service in Victoria

### SECTION SUMMARY

- SCV is developing a principles-based implementation framework to support roll out of consumer-initiated escalation for health services in Victoria.
- The principles-based framework is closely aligned with and supports implementation of the SCV Partnering in Healthcare Framework and efforts to meet required accreditation criteria – e.g. National Safety and Quality Standard 8 – Recognising and responding to acute deterioration..
- HEAR ME principles promote the use of a three-step consumer-initiated escalation process with a focus on steps 1 and 2 - building strong relationships and communication between consumers and health services.
- The third step of the escalation process is to provide a phone number for consumers to call. SCV will be establishing 1300 HEAR ME as a state-wide central number that will notify health services if consumers wish to escalate care or request an independent review (i.e., reviewer from within the health service, but not the patient's medical/treating team).
- The HEAR ME central phone number does not replace existing numbers used by health services – but it does provide a common infrastructure throughout Victoria for those health services without their own working, efficient and effective escalation phone numbers.

## 5.1 INTRODUCTION

As presented in Section 2, the existence of consumer-initiated escalation processes can be linked to improved health outcomes and better detection of pre-critical deterioration, and help to address communication issues.

Consumer engagement in health care is a strategic priority for Safer Care Victoria as demonstrated by the newly released *Partnering in Healthcare Framework*. This framework identifies priorities and approaches for all Victorian health services to strengthen consumer participation in health care.

The State Government has been motivated to establish a consistent state-wide framework and central phone number for consumer-initiated escalation for the following reasons: recent adverse and sentinel events; the accreditation requirement of National Standards criteria to have systems of consumer-initiated escalation in place; the lessons and compelling success of escalation programs in QLD (Ryan's Rule) and NSW (REACH); an understanding that most Victorians will access multiple health services according to their geographic area and health needs; and the current inconsistencies in approaches to escalation and messaging effectiveness of local implementation of escalation in Victoria.

HEAR ME has been proposed by SCV as the service name. Discussions are ongoing as to appropriate acronym/definitions for each letter to help spell out the steps and program principles. Finalising the title and acronym will involve consultation with patient, carer and family member community groups on an escalation Expert Reference Group (ERG).

HEAR ME does not replace existing efforts of health services to meet their accreditation requirements under Standard 8. All health services will have the independence to tailor their own consumer-initiated escalation systems to their service but are strongly recommended to utilise the SCV principle-based implementation framework as a support or guide. A HEAR ME central escalation phone number will be established as a safety net that adds value to existing local consumer-initiated escalation systems. Having a central number has the added benefit of enabling the collection and sharing of data and learning about consumer use of escalation opportunities and experiences of partnering in healthcare.

This section provides a description of the SCV vision and ideas for how HEAR ME will work in Victoria and is based on materials provided by SCV and from interviews with key SCV personnel.

## 5.2 STAKEHOLDER INVOLVEMENT

Early stage thinking for the consumer-initiated escalation program was presented to the Victorian hospital executives in 2018, and a proposal was presented and circulated to SCV's Patient and Family Council for comment and input (November 2018). As part of compiling this report, the authors consulted with individuals involved in consumer health participation, Carers Victoria and health service providers.

In developing the HEAR ME proposal SCV has consulted with executive health service leaders in consumer experience and participation, the Public Health and Well-Being branch of Department of Health and Human Services (DHHS), Ambulance Victoria and the Victorian Managed Insurance Authority (VMIA). Further consultation and stakeholder engagement is expected to take place to support planning and evaluation of a pilot initiative. An Advisory Committee was formed to review and provide input to this report and members included health service staff with relevant expertise and consumer representatives with experience in escalation issues. (See Appendix 3.2 for a list of members). Members may join the forthcoming ERG.

SCV will be establishing a Steering Committee to oversee the implementation of the escalation service and an ERG to guide the planning, implementation, evaluation and adaptation of the initial phase in preparation for state-wide implementation.

### 5.3 VICTORIAN ESCALATION STEPS

SCV's proposed consumer-initiated escalation process reflects the priorities of the Partnering in Healthcare framework. The Victorian best practice escalation process recommendations are entirely based on building and supporting open communication between patients, carers and family members with their health services.

The central 1300HEARME phone number and communications/promotion support process is a safety net for consumers based on a three-step escalation process. To meet the national standard, all private and public hospitals are required to implement a robust consumer-initiated escalation process.

In Victoria, SCV recommends this should include a minimum of 3 steps:

- **Step 1:** Encourage raising concerns with your nursing team or doctor.
- **Step 2:** If still concerned, raise questions or concerns with the nurse/midwife in charge of the ward or area you are being treated.
- **Step 3:** If your concerns for patient safety are still not resolved, then a patient, carer or family member can make a phone call to initiate an independent rapid review.
  - For larger health services with established escalation numbers the established number will continue to be the default third step in the process. In these situations, HEAR ME will be described as an additional safety net or alternative number to call no matter where a consumer is receiving treatment in Victoria.
  - For health services that do not have their own internal escalation number, the HEAR ME number can be promoted as the third escalation step.

### Proposed Messaging for consumers: Escalation Steps

ARE YOU CONCERNED OR WORRIED ABOUT THE WELLBEING, SAFETY OR MEDICAL CARE OF YOURSELF OR A PATIENT?

IT IS VERY IMPORTANT TO SHARE YOUR CONCERNS WITH THE TREATING TEAM.

YOU KNOW YOURSELF, OR YOUR FAMILY, PARTNER OR FRIEND BEST.

IF YOU ARE CONCERNED IN ANY WAY TELL THE TREATING TEAM.

THEY WILL IDENTIFY THE SIGNS AND SYMPTOMS THAT NEED MEDICAL ATTENTION.

TOGETHER WE CAN MAKE SURE ALL PATIENTS GET THE RIGHT CARE AT THE RIGHT TIME.

**STEP 1:** TELL THE TREATING NURSE OR DOCTOR

**STEP 2:** IF YOU ARE STILL CONCERNED:

TALK TO THE NURSE/MIDWIFE IN CHARGE

**STEP 3:** IF YOU ARE STILL CONCERNED: WE NEED YOU TO CALL FOR HELP OR ASK FOR A REVIEW

**CALL [HOSPITAL ESCALATION NUMBER] OR 1300HEAR ME (1300 498 169)**

## 5.4 WHO DO PEOPLE CALL?

Most patients do not attend only one health service in their lifetime for a range of reasons including referrals, ensuring the right service for their health needs or geographic mobility. It is therefore important that there be a consistent and coherent process that everyone knows how to follow or access when they are concerned or worried about a patient's health status or care, irrespective of the service they find themselves in.

HEAR ME will form part of the central 1300 phone number, 1300HEAR ME<sup>3</sup> has been registered as an easily recognisable state-wide number for patients, carers, family members or friends of patients to access 24/7, if they need to activate the third step in the process because of concerns about a patient's condition, symptoms or care.

Based on the call volume experience of other escalation programs the number will be integrated into an existing health call-centre staffed by qualified nurses. This will be Nurse On Call. A call script, communication and notification protocol, data collection and reporting requirements and promotion will all be managed through the contracted relationship with Nurse On Call.

Call centre staff at Nurse on Call will be trained in and use a call script that allows the receiver to identify who the patient is, who the caller is, the patient bed location within a health service and the concern, question or issue. If it is a clinical concern then this will trigger a HEAR ME notification call to the health service to mobilise a rapid review by a third party (not the patient's current clinical treating team). This review is expected to take place no more than 30 minutes after the notification. The expected minimum time frame will be reviewed in consultation with the ERG. The health service's internal system should then determine what level of clinical response is needed, for example, a MET call may be triggered.

The Nurse On Call receiver will also send email notifications to the relevant Medical Director, executive staff and Quality and Safety units, and the SCV escalation project manager to alert them to the HEAR ME call and mobilise follow up action.

For calls received that are not related to a clinical concern or treatment issue, the caller will be transferred or referred to the relevant complaints number/contact within that health service.

The Nurse On Call call centre will collect as much basic information about the patient as they can. This should include the patient's and caller's name, the patient's bed number, ward, health service and details of the concern. This information will be included in the notification provided to the relevant service and their rapid response team. Post-call follow-up with callers to 1300 HEAR ME will need to be integrated into the quality assurance for the service and reviewed by the ERG.

## 5.5 PREPARING FOR HEAR ME

All health services should be prepared and ready to respond to a HEAR ME notification if one is received. SCV staff will work with health services involved in the initial implementation phase to ensure that adequate awareness of the process, the number, and response protocols are in place and that reporting requirements are able to be met. This will include undertaking test calls to check for gaps in the process and preparation that could result in miscommunication or slow response times. This experience will help inform how much support SCV will need to provide to health services in subsequent implementation phases.

Preparation to respond to a HEAR ME notification will be important for all participating health services. SCV has taken in to consideration the review of barriers and enablers (See Section 6) to propose how health services can be prepared for HEAR ME:

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<sup>3</sup> 1300 HEAR ME is 1300 498169

- A phone number that is active and manned 24/7 by personnel with authority to activate an independent<sup>4</sup> rapid review by a qualified medical staff member of the relevant patient and their care within 30 minutes.
- Identification of escalation callers should be considered under consumer or patient privacy policy and guidelines of the health service (e.g. is a silent alert of a HEAR ME required rather than a public PA announcement).
- The information and skills required for staff to be able to promote, and respond to an escalation process, should be integrated into existing training or education initiatives.
- Nomination of motivated consumer partnership champions who can help promote steps for consumer escalation throughout the service.
- A communications and promotion plan involving multiple communications channel but with a focus on verbal direct communication from staff to patients, family members and carers.
- Processes developed and in place to conduct prompt, multidisciplinary clinical reviews of all HEAR ME calls that ensure critical learning is identified, reported and addressed.
- Establish a system to report measures of success, and impact. Identify what information can be shared as part of state-wide learning for consumer-initiated escalation.

## 5.6 WHO CAN CALL?

Anyone can call. This means calls can be made by the patient themselves or by another. The Victorian escalation process is based on a foundation that “all concerns or worries about medical status or care are important”. Many of the recommendations for the implementation framework provided in Section 8 of this report are focused on how to communicate this message in a way that will motivate and empower consumers to utilise opportunities for help, if and when they need it.

The target audience for escalation calls is not constrained by the definition of carer stipulated in the 2012 Victorian Carers Recognition Act. The escalation process is intended to be used by anyone who is connecting with a health service as a patient, visitor, carer, friend, family member, guardian, partner or have any relationship with the patient that gives them additional insight or intuitive concern about a patient’s behaviour, cognitive state, symptoms or changes in their clinical status, well-being and care. Their value to quality comprehensive health care is not dependent on who a person is, but is founded on the knowledge, awareness and insight their relationship with the patient gives them about what is normal, expected and their intuitive recognition when things ‘do not seem right’.

### **Who can call? The patient or anyone who knows the patient and has concerns about their symptoms, health status or decisions about their care.**

HEAR ME recognises the value and role of anyone who knows the patient in a way which gives them additional insight or intuitive concern about the patient’s behaviour, cognitive state, response to treatment, clinical status or general well-being, in providing quality care.

This can be the patient themselves, a parent, guardian, sibling, family member, friend, same-sex partner, pastor or spiritual mentor, complementary therapist or allied health professional. They do not need to be in a formally recognised relationship or caring role to escalate their concerns.

<sup>4</sup> ‘Independent’ in the context of the consumer initiated escalation recommendations implies that the rapid review is conducted by a qualified medical team member who has not reviewed the patient before. This means a qualified medical staff member within the health service, but who isn’t part of the patient’s current clinical or treating team.

## 5.7 SCV ESCALATION PRINCIPLES

HEAR ME complements and supports existing services, efforts and frameworks related to strengthening consumer participation in health care. A set of core principles underpin the service and have been drawn from initial discussions about the evidence review for this report and the Partnering in Health Care Framework:

### HEAR ME PRINCIPLES

#### **Principle 1: Patients and carers feel empowered through HEAR ME**

Patients, carers, family members and friends are empowered and supported to raise and directly escalate concerns about care and treatment.

#### **Principle 2: Clinicians and health service managers feel ready and enabled to participate in HEAR ME**

Health service clinicians are supported by health services to learn about and engage with patient/carers-initiated escalation at all levels of the process.

#### **Principle 3: Patients and carers are confident in the quality and safety of the Victorian healthcare system**

HEAR ME contributes to ongoing system learning and assurance of the quality and safety of patient care, experience and outcomes.

#### **Principle 4: HEAR ME has strong and transparent governance, coordination and management processes**

HEAR ME provides true value for consumers, health services and the community.

## 5.8 HEAR ME COMMUNICATIONS AND EDUCATION

SCV intends to undertake a central promotion campaign to help raise awareness of consumer-initiated escalation opportunities and steps in Victoria. Materials and resources to introduce the steps and central escalation number to health services staff so that they are informed about consumer-initiated escalation are also intended to be developed by SCV.

## 5.9 DATA COLLECTION AND REPORTING

SCV is in the process of identifying how to leverage existing reporting and data collection systems to record and monitor consumer-initiated escalation, particularly calls made to the HEAR ME number. Initial plans reflect the system used for Ryan's Rule in QLD. This includes establishing a database to record call data and ensure health services have access to data relevant to their service on as close to a 'real-time basis' as possible.

## 6 Barriers and enablers for effective escalation processes

### SECTION SUMMARY

- Three interconnected priorities were identified as areas critical to design and implementation of a consumer-initiated escalation system: 'Communications', 'Interpersonal Relationships' and 'Systems and Structures':
- Communication is about more than sharing of information. The skills, knowledge and capabilities required to manage consumer/health service relationships as partnerships are key.
- Active recognition of the value of the consumer in healthcare requires substantial effort to change system, cultures and practices. To do so effectively requires long-term, multidisciplinary, systematic change management.
- Ensuring recognition that any consumer request to escalate care or share a concern is relevant.
- The three-step escalation process allows for the focus of efforts to strengthen consumer partnerships for healthcare to be held within each individual service. This is done through promoting the importance of communication and relationships between consumers and their health service in the first two steps of the three step process. The third and final step is a final resort, but when used can help identify things that may have been missed and can prevent acute deterioration and save lives.
- Consumers need to have a role in the design, implementation and evaluation of escalation systems and how partnerships in healthcare are supported by health services.



## 6.1 INTRODUCTION

This section outlines the barriers and enablers to the implementation of a consumer-initiated system, drawing from the material in Sections 2-4.

Consumer partnerships for health care are complex and their implementation requires an understanding of the influences, impact and management of behaviour and systems change. To simplify this complexity, three key interconnected and interdependent components were used to help understand key barriers and enablers for an effective escalation process.

These interconnected components are 'Communications', 'Interpersonal relationships' and 'Systems and structures'.

- **Communications:** Knowing what, how and when to communicate information about care and opportunities to engage in health care is a critical area for this program. Communication issues have been found to be the most common reason calls are made by consumers and can cause significant distress, concern and breakdown in relationships and care. Communication strategies are also needed to encourage consumers to voice their concerns initially through internal systems or subsequently through the third safety net step of an escalation phone call if required.
- **Interpersonal relationships:** Maintaining positive, supportive relationships between health services and consumers that reflect a movement toward genuine opportunities for consumer partnerships in health care is a critical and complex area.
- **Systems and structures:** The systems and structures that guide provision of health services. These include clinical guidelines and protocols, education and training, handover protocols, reporting systems and requirements, executive and management leadership for change.

Being able to understand and balance the relationships between each component was an important approach used in identifying the recommendations and priorities in this report. The components were also informed by themes drawn from the National Safety and Quality Health Care Standards (NSQHS) and SCV's Partnering in Health Care Framework.

## 6.2 COMMUNICATIONS

### 6.2.1.1 IDENTIFYING AND ADDRESSING COMMUNICATION ISSUES

The evidence review in Section 2 clearly indicates that communication issues are the most common reason why escalation calls have been made by patients or carers in Australia and overseas. These issues have included not understanding the diagnosis, treatment and recovery trajectory, or new or changed medications. Escalation programs have also helped services to identify where efforts need to be made to improve communication between patients and health services/teams. This includes the SA study which highly recommends that health services provide communication training to staff that focuses on listening as an important communication skill.

The SCV central escalation number is intended as a secondary safety and support pathway for patients, carers, family members and friends to raise their concerns. It is also a means for learning and strengthening clinical care where communication issues may have contributed to concerns about an in-patient's clinical status, care or treatment trajectory.

### 6.2.1.2 UNDERSTANDING THE SPECTRUM OF CONSUMER WILLINGNESS TO ENGAGE IN CARE AND ESCALATION

Consumer willingness to engage and participate in care partnerships is not static, it fluctuates and changes according to individual circumstance and experience. Understanding when and how best to offer opportunities to participate in care, or to utilise escalation steps, is critical to any promotional campaign for healthcare partnerships and escalation.

Factors affecting a consumer's willingness to engage could include health literacy, cultural familiarity, or levels of experience with health services or in advocating for care. The evidence review, and in particular Merner's 2017 study, appear to indicate that as health literacy and experience with the health system increase, consumers are more likely to take advantage of opportunities to engage in care.

It is therefore important that consumers be proactively invited to engage with health care teams and discuss concerns, questions or worries about clinical conditions and care on an ongoing basis. Integrating this into practice will help build confidence and ensure that when consumers are ready to engage they are aware of who to approach and how to do so.

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### 6.2.1.3 RECOGNISING DETERIORATION – WHEN IS IT RIGHT TO GET INVOLVED

The value of carer input in health care decision making is largely based on the intimate insight they have about a patient's physical and cognitive well-being and what is 'normal' for that person. One of the concerns expressed by health services outlined in the systematic overview in Section 2 is the fear that patients and carers will escalate care when it is not clinically recognised as deterioration.

The reality of escalation processes has actually been that most of the calls do not trigger a MET response. However, concern of a family member or carer for the clinical condition of a patient is important given their personal insight into a patient's traits, behaviours, responses and changes. Their concerns should be recognised as valuable enough to trigger a rapid review as they provide an important perspective for care-related decisions and monitoring. Responding to these concerns helps mobilise early intervention when things go wrong, identify where there are communication issues to be addressed and can strengthen the quality of care provided.

As outlined in the evidence overview, education for health services and pilot initiatives needs to incorporate a message of 'no false alarms,' reinforcing that having a concern about a patient is enough to justify a carer or family member to make an escalation call. Consultations with the project Advisory Committee suggested language of "every concern is important" to be communicated with consumers and health services.

Consultations with other escalation programs and the Advisory Committee also indicated that more work could be done to test the effectiveness of messaging that maintains a general sense of "every concern is important" but provides some guidance as to what broad things consumers might be concerned about and should feel confident to raise with health services or the escalation number. Examples include changes in cognitive state, behaviours, response to pain, appetite, attitude and emotional shifts.

Making sure that the Nurse On Call staff have a script they can use and the right referral information available will enable them to connect callers with the right help channel for their concern, even if it is not a clinical issue that does not require activation of an escalation response (e.g. complaints about temperature of ward, request for extra blankets, food complaints, waiting times etc).

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### 6.2.1.4 INVOLVEMENT IN DESIGN AND DEVELOPMENT

Development of all materials and messaging needs to involve considerable engagement with the intended audience. As was found in the SA study for the 'You're Worried, We're Listening' escalation model, consumers want to be involved in the design of systems, messaging and materials. Involving consumers in design, development and evaluation will also help to ensure understanding of communications and willingness to use escalation processes for people with a range of health literacy levels.

Insufficient evidence was identified to clearly state that there is a lack of direct consultative engagement with CALD and ATSI communities in development of escalation processes and communications. However, the gap in documentation for these processes, and level of translation for existing materials seem to indicate that where CALD needs are considered it is only in terms of direct translation of written materials. Meeting CALD communication needs to empower participation in an escalation program will require more in-depth considerations, including visual representation in materials and resources and appropriate representation of other social-cultural factors.

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### 6.2.1.5 AWARENESS AND PROMOTION – CHANNELS AND MESSAGING

For consumer escalation to work, there needs to be a high level of awareness of what it is, when to use it, who can use it and how to use it. In Queensland the recognition of Ryan's Rule is very high although comprehensive health promotion campaigns have not been carried out. However there has been strong coverage in the media and social media about cases where Ryan's Rule has been used and how it has helped. Hearing about escalation processes through a social media network appears to have been very effective in Queensland and should be explored further for Victoria. Having a simple, consistent state-wide message and approach makes mobilising this kind of informal community promotion more possible and likely.

Given the broad audience that needs to be reached and informed about the three core steps to consumer-initiated escalation processes, an integrated approach will be needed. Evidence reviewed in Section 2 highlights some key channels that should be included in an integrated promotion model:

- Direct verbal communication by health services to consumers
- Social media networks (Facebook, Instagram etc)
- Community networks in partnership with health services
- Media (TV, multicultural programs, radio, podcasts, local and larger news media (print and online)).
- Champions within health services and for the general public

Images and video need to reflect an appropriately diverse community. Communication and promotion plans need to incorporate thorough consultation and integration of social-cultural messaging, representation and information needs. This includes consideration of various "carer" identities, and visual representation of the broad and diverse population who attend health services (eg CALD, ATSI, LGBTIQ+, people with disabilities).

Timing is a critical consideration for communications and promotion about escalation processes. Hospital experiences can be very stressful and using the right channel with the right message at the right time to enhance communication effectiveness needs to be integrated into promotion planning and strategies. The consultations conducted for the SA 'Your'e Worried, We're Listening' program indicated an interest in exploring use of digital communications and technology. This could help aid the provision of information to people in a form and at a time when they are seeking answers. Exploration of ideas including how to maximise opportunities for Search Engine Optimisation of a HEAR ME landing page or targeted promotion of HEAR ME number to audiences in a hospital area are recommended.

Leveraging trusted and respected sources of information are also critical. Personal recommendations are very powerful and SCV is encouraged to explore working in partnership with community organisations and networks to help spread information and guidance about when, where and how to use HEAR ME. Examples of networks that could be used include Carers Victoria, Rotary, non-government organisation and health foundations, maternal and child health clinics/mothers' groups and other community health related or carer support networks.

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### 6.2.1.6 COMMUNICATION SCRIPTS

SCV is working in partnership with the VMIA and BehaviourWorks to develop communication scripts to assist health service staff to respond to and request an escalation of care for a patient. It is recommended that health service staff and consumers should be consulted in development of the script to ensure the tone, content and delivery reinforces the relevance and value of taking this step in care. BehaviourWorks is piloting a program for VMIA to develop a script that could be used as a foundation for this work. Script training is recommended to utilise role-play and "real-life" case examples where possible.

## 6.3 INTERPERSONAL RELATIONSHIPS

Underpinning both the communication and systems and structures components is the interpersonal relationships component. Consumer-initiated escalation processes are reliant on strong relationships between health services teams and consumers and also the relationships between health services and SCV.

### 6.3.1 MAINTAINING POSITIVE RELATIONSHIPS WITH CLINICAL TEAMS

A common theme from the evidence has been that consumers want to maintain strong, productive and effective relationships with clinical teams. They don't want to raise issues or cause a disturbance. There can be concerns that clinical teams will see consumers' questions as a threat and as a result not provide the highest level of support. This is an area that SCV Partnering in Healthcare Framework and the escalation support process is seeking to address by promoting approaches including:

- Empowering patients, carers, family members and friends to know their insights are of value in clinical decision making and to take advantage of opportunities to engage.
- Educating and supporting health services staff to recognise and proactively seek the added value from improved communication for/ in clinical care.
- Supporting development of organisational cultures that are open and welcoming of disclosure of issues and concerns.

### 6.3.2 CHAMPIONS

Leaders and champions for change will play an important role in fostering support, awareness and commitment for integrating how consumer concerns and input are considered valuable to care partnerships and how requests for escalation are responded to. Champions will need to be representative of the many different stakeholders involved in escalation from medical professional leaders, senior and mid-level management of health services, to health service consumers and respected and recognised influencers with public profiles. Identifying committed champions in each service and providing a clear description of what a champion is expected to do will give structure to help maintain momentum throughout implementation. SCV may wish to explore how to create an online community of practice for health service champions who are passionate about consumer partnerships in care and escalation.

## 6.4 SYSTEMS AND STRUCTURES

### 6.4.1.1 A THREE-STEP CONSUMER ESCALATION MODEL INTEGRATING LOCAL SYSTEMS WITH CENTRAL SUPPORT

Each health service is responsible for meeting their accreditation requirements and escalation response systems need to be tailored to their individual systems, workforce and capacity. Any central escalation support service therefore represents support for what is implemented and managed locally. This independence helps foster an environment for health service innovation and creativity to meet the needs of their specific populations. However, the degree of inconsistency in approach that is currently present in Victoria is not moving towards building best practice. As outlined in the Targeting Zero report (DHHS 2016), a balance is recommended of opportunities for localised innovation with centralised framework and guidance for best practice, data collection, reporting and sharing of learning.

The SCV consumer-initiated escalation process aims to find this balance by providing central support for local processes and response.

### 6.4.1.2 CREATING OPPORTUNITIES TO HEAR CONSUMERS' CONCERNS

Creating formal and informal opportunities within existing systems for communication and engagement about treatment and care is essential to consumer-initiated escalation processes. Ideally, if consumers feel they have opportunities to be heard, and their concerns and value are acknowledged, they are less likely to seek alternative

escalation options. The priority is that they feel able to escalate internally – but if not, that there is a back-up safety net service to help address their clinical concerns. Some health services have begun experimenting with how to incorporate these efforts within existing systems. Eastern Health now includes a question for patients/carers in observation records which means that any questions, concerns or worries they are willing to ask can be included in information used to make clinical decisions. Similar pro-active approaches are recommended state-wide.

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#### 6.4.1.3 COMMUNICATION AND HANDLING OF PATIENT INFORMATION

Evidence reviewed in Section 2 indicated that the way information was being handled at shift handover was a source of concern for patients and carers. This was particularly in regard to instructions for treatment, changes in medication, not recording allergies or other potential risks to patient safety. Finding ways to build confidence of consumers that critical information is consistently being recorded and used to provide the appropriate care is an important area for creating trusting relationships. Inviting patients and/or carers to participate in shift or ward information handover processes was one practical way suggested to move towards such trusting relationships. Independent rapid reviews as a valuable part of care

Section 2 identified that in many cases patients, carers or family members want to request an independent review from a staff member outside their clinical team, while at the same time being sure that this request won't negatively impact the quality of care being provided by the team. The evidence review identified that there was a concern that patient or carer escalation calls could undermine the clinical team's decisions about care. Education programs and service leadership efforts need to demonstrate and promote that a request for an independent rapid review is a positive contribution to patient safety caring rather than a challenge to a clinician's expertise. Providing positive public recognition to clinical teams that promote and embrace consumers to be part of clinical decision making will be an important role for health service managers and leadership.

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#### 6.4.1.4 EDUCATION REQUIREMENTS

In almost all aspects of the evidence review the importance of education and awareness of health services was raised. It is of vital importance that clinical teams (nursing staff, consultants, surgeons, MET teams and ICU staff) understand that a centralised phone number is a safety net that supports and enhances the care provided to patients. It is also important that the process and response to an escalation call is common knowledge for all health service staff (administration and reception, nursing teams, medical teams etc).

Any education initiatives should also emphasise the value that consumers contribute to care. The Advisory Committee highly recommended integrating modules or sections about patient-centred care, effective communication skills and escalation processes within existing competency training requirements. Integration into existing competency training would ensure all relevant health services staff are aware and able to promote escalation, build relationships to strengthen patient-centred models of care and respond appropriately to an escalation request if received. It has been suggested that this shouldn't be an additional education burden but integrated into existing learning and core competency training including orientation and induction programs, qualification education and existing, relevant annual competency training requirements.

Ensuring that there is sufficient allocation of time and financial resources to ensure that all relevant administration/reception and clinical staff are aware of the state-wide HEAR ME program and how it integrates/is responded to within internal escalation systems is critical to success. This includes sufficient resources for staff to undertake real case study based role-play training to learn and review escalation scripts and responses.

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#### 6.4.1.5 MANAGEMENT REPORTING AND DATA

To better understand the impact, lessons and benefits of consumer-initiated escalation systems consistent data will need to be collected. As described in Section 2, Ryan's Rule has been able to use the centralised phone number with a supporting CRM system to help collect the data needed to review and improve the system and response. Since NSW health services have unique REACH numbers and calls are managed locally, the collection and monitoring of state-wide data is likely to be more difficult. The better the data, the better the lessons that can be integrated into strong, higher quality and consistent services throughout Victoria. Navigating the differences in data collection, reporting and sharing practices across services will be an important role of the SCV ERG.

Ensuring executive and management are aware of the call rates, causes and responses will support how changes to systems and structures are managed within health services pursuing stronger patient-centred care models and effective escalation processes. SCV highly recommends that key data, changes, progress and impact regarding escalation be included as an item in executive, management and ward level meetings.

Some Victorian services have already begun sharing escalation information by reporting on use, recognition, recall and types of calls made in annual Quality Account Reports. Expanding on this reporting to ensure all health services include further detail in their Quality Accounts about the effect, efficiency and awareness of escalation processes is highly recommended.

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#### 6.4.1.6 LEADERSHIP CHAMPIONS

Embracing the value that consumers can contribute to the care process will take time. Establishing effective systems to proactively invite and seek input, strengthening staff ability to view escalation as step to improve care rather than a personal challenge, and building better communication skills (including listening) will also take time. Implementing these changes will be most effective if the right member of the leadership and management teams is actively championing the benefits and processes for change. In QLD it was found that when the Medical Director championed Ryan's Rule this helped build momentum for change.

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#### 6.4.1.7 POSITIVE RECOGNITION AND REWARD

Highlighting and sharing high profile positive recognition for clinical teams and services that promote and support consumers to take advantage of opportunities to be part of the clinical team and decision making process, including escalation, will be an important role for health service managers and leadership and SCV.

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#### 6.4.1.8 FOSTERING ORGANISATIONAL CULTURE THAT SUPPORTS DISCLOSURE OF ISSUES

Section 2 outlines the importance of health service organisational culture in strengthening quality and safety. In particular, strong recommendations were made as part of the Targeting Zero report (DHHS 2016) for Victorian services to prioritise efforts to foster organisational cultures that welcome disclosure of issues which can lead to more open problem solving and learning, rather than environments of blame which often lead to concealment of issues.

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### 6.5 OTHER BARRIERS AND ENABLERS

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#### 6.5.1.1 PILOT PROGRAM DESIGN AND EVALUATION

SCV will need to provide hands on support and resources to work with pilot sites in the preparation and initial implementation phases of the escalation program. The capacity of support SCV is able to provide will also help determine the number of sites SCV should invite to participate in the pilot. Selection of initial implementation sites should at a minimum consider factors such as the size of service, location of service, profile of service population, current status in accreditation process, their nomination of consumer-initiated escalation champions and willingness to share information and data to support state-wide learning for escalation practice.

The formal evidence gap regarding escalation among members of CALD and ATSI communities will be critical to start addressing in the initial implementation phase. A specialised site is planned for the initial phase to focus on documenting how to effectively promote escalation with ethnically and linguistically diverse communities including ATSI communities. Undertaking a specialised pilot that aims to document and share these results formally will be a leading initiative in Australia that will not only inform Victorian promotional activities but will become a potential resource for escalation programs everywhere.

Pilot planning and communications material messaging and visual design needs to incorporate stakeholder participation and input. A planning workshop with essential stakeholders is recommended. This might include patient, carer or family member representation, and representation from community networks, education and professional bodies, and senior metropolitan and regional health services, including medical, nursing and quality and safety staff.

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#### 6.5.1.2 REPLICATION OF HEAR ME FOR OTHER HEALTH SERVICE AREAS

Throughout the pilot and evaluation, consideration should be made for what lessons and information are needed to inform how the escalation process could be adapted for use in other health service areas. Suggested areas to be considered include Emergency Departments, hospital in the home, aged care and for patients who have been recently discharged from hospital.

It will also be important to document how the escalation process is used as a tool to encourage consumer involvement in care and if this influences changes in communication, relationships and clinical outcomes in other areas of health services.

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## 7 Evaluation, evidence and learning

### 7.1 OVERVIEW

HEAR ME represents an opportunity for SCV to take a leading role in documenting, analysing, and disseminating publishing research into the implementation of consumer-initiated escalation in Victoria, its impacts on patient care and outcomes and impacts on consumer-clinical partnerships.

### 7.2 EVALUATION OF THE PILOT INITIATIVE AND STATE-WIDE PROGRAM

#### 7.2.1 EVALUATION FRAMEWORK

The evaluation framework for HEAR ME should be tested as part of the initial implementation phase. Given the range of data required to measure the progress and effectiveness of consumer empowerment to escalate their concerns a mixed quantitative and qualitative approach is recommended.

The evaluation framework should be developed in collaboration with stakeholders and tested as part of the initial implementation phase with pilot sites in 2019.

#### 7.2.2 EVALUATION AND LEARNING WORKING GROUP

It is recommended that a select but representative group of ERG members be identified to form an ERG Evaluation and Learning Working Group. An initial evaluation and learning planning workshop should be held early in the initial implementation phase to identify what information should be collected that will be most useful to SCV and to stakeholders.

#### 7.2.3 UTILISING EXISTING SYSTEMS AND DATA

Integration with existing data collection tools and systems where possible is highly recommended. It will be important to explore how questions in the VHES or VAHI data sets could capture the following: consumer recognition of steps and messaging, willingness and confidence to use the steps and overall satisfaction or experience of raising medical concerns, minimising any additional administrative burden.

This framework should be tested as part of the initial phase of implementation with pilot sites and then updated for the state-wide roll out of HEAR ME.

Measurement and learning that will be important to capture include:



## EXAMPLE EVALUATION AND LEARNING MEASUREMENT AREAS

### Awareness

- Message recognition and retention among consumers and health service staff
- Audiences targeted and reached with promotion campaign
- Effectiveness of different channels of promotion for different audiences
- Effectiveness or feasibility of embedding escalation communication in pre-admission or ward round documentation
- Effectiveness of different messages and channels for different sub-groups (service providers, CALD communities, ATSI communities, age groups, metro/regional/rural locations).

### Calls

- Number, frequency and duration of HEAR ME calls
- Types or reason for HEAR ME calls
- Demographic profile of HEAR ME calls and patients
- Caller relationship to patient
- Effectiveness of call script
- How caller knew about escalation steps and number to call
- Services related to call (ward type, service type etc)

### Communication and relationships

- Confidence and willingness of consumers to raise medical concerns
- Frequency of communication issues as motivators for consumers initiating Step 3 (escalation call)
- Confidence and quality of relationships between consumers and health services

### Systems and structures

- Average response time to notification of a Step 3 call
- Implementation of efforts that integrate consumer concerns into existing patient records/observation/rounds
- To what extent consumer-initiated escalation of concerns are documented and reported within systems
- To what extent health service staff training/competency requirements/expectations incorporate critical knowledge, skills and behaviours associated with promoting consumer partnerships in health care and escalation of concerns.
- Overall satisfaction rates of HEAR ME callers and willingness or confidence to use HEAR ME again
- Effectiveness of HEAR ME management systems

### Other areas of learning/evaluation

- Impact on patient mortality, rate of adverse events and transfers to Intensive Care Unit (ICU) or other escalation of care.
- Number and type of all adverse and sentinel events linked to communication and/or concerns regarding patient, carer and family-initiated escalation.

## 7.3 RESEARCH

It is important that the pilot program move ahead quickly to ensure that Victoria takes action to address the lack of cohesive approach to consumer escalation throughout the state. Maintaining a learning approach to the pilot and scaled up program will be important given the key research and evidence gaps identified in Section 2. Victoria has an opportunity to demonstrate leadership in both local and global escalation programs and promotion of opportunities for strengthened consumer engagement in care if research, documentation and dissemination of results is resourced and a culture of learning drives this priority.

### 7.3.1 KEY RESEARCH QUESTIONS

There are a number of priority research questions that will directly inform community partnerships for better care. These questions include:

- **What patients, carers and family members need to know to be confident to mobilise escalation:** Are broad messages about having clinical concerns actually empowering people to make escalation calls when they are needed? Research is needed that consults with patients, carers and family members about what information and messaging needs they have that would give them the confidence to make an escalation call at the right time.
- **Communication as a priority in clinical care:** Further analysis and understanding of the causes of communication issues, their impact on quality of care and safety, and identification of potential ways health services can address these challenges.
- **How consumer concerns are captured and used in treatment planning and decisions:** What are the experiences and expectations of consumers and health services regarding consumer-initiated escalation of concerns?
- **Promoting consumer-initiated escalation opportunities with different communities:** How can messages be tailored effectively to meet the cultural, linguistic and social needs of different populations to recognise and use the three step process?

## 8 Recommendations

### OVERVIEW

Based on the analysis of evidence and experiences described earlier, recommendations have been identified to support successful implementation of consistent consumer-initiated escalation processes in Victoria. All recommended priorities for implementation are based on the SCV escalation principles outlined in Section 3.

All recommendations aim to strengthen possibilities for Victorian consumers to successfully engage or request an escalation of care, when they have concerns about the medical status or care of a patient, i.e. when 'things are not quite right'.

The recommendations are a guide to support and inform SCV's development of the principles-based implementation framework for HEAR ME. The recommendations are not mandatory actions for Victorian health services. Instead they are intended to inform and support health services with their ongoing efforts to improve health outcomes by meeting quality and safety requirements for consumer participation or partnership in health care identified in the National Safety and Quality Health Service Standards, the SCV Partnering in Healthcare Framework and the Australian Charter of Healthcare Rights in Victoria.

### HEAR ME PRINCIPLES

#### **Principle 1: Patients and carers feel empowered through HEAR ME**

Patients, carers, family members and friends are empowered and supported to raise and directly escalate concerns about care and treatment.

#### **Principle 2: Clinicians and health service managers feel ready and enabled to participate in HEAR ME.**

Health service clinicians are supported by health services to learn about and engage with patient/carer-initiated escalation at all levels of the process.

#### **Principle 3: Patients and carers are confident in the quality and safety of the Victorian healthcare system**

HEAR ME contributes to ongoing system learning and assurance of the quality and safety of patient care, experience and outcomes.

#### **Principle 4: HEAR ME has strong and transparent governance, coordination and management processes.**

HEAR ME provides true value for consumers, health services and the community.

## PRINCIPLE 1: PATIENTS AND CARERS FEEL EMPOWERED THROUGH HEAR ME

### OVERVIEW

The evidence presented in Section 2 identified many different factors that can contribute to a carer's willingness to pro-actively raise concerns or seek a higher level of care for a patient. The SCV Partnering in Healthcare Framework highlights the need for health services to strengthen consumer/health service partnerships to support stronger health outcomes and experiences for patients.

Creating supportive environments to build confidence to question and raise concerns is complex and requires consideration of multiple factors. Consumers need to be aware of the options available to them, health services need to be ready to respond when notified and the impact of historical systems, structures and relationships between consumers and health services all need to be considered.

The recommendations for this principle focus on five main areas:

- Understanding the communication needs, priorities, channels and timing to build strong awareness and confidence among consumers to raise their medical concerns when needed and for health services responses to be respond timely and appropriate.
- Recognising the value 'knowing the patient' can contribute to overall health care and decision making.
- Having responsive systems to notice, listen and respond to a consumer seeking escalation of medical concerns.
- Socio-economic, cultural and linguistic needs of consumers are integrated into efforts to strengthen consumer partnerships in healthcare and escalation of medical concerns.
- Measurement of consumer confidence in, ability to and satisfaction with opportunities for them to escalate medical concerns.

### RECOMMENDATIONS

| SAFER CARE VICTORIA  |
|--|
| CRITICAL RECOMMENDATIONS   |
| Work with consumers to identify cultural and linguistic barriers and enablers for effective communication to strengthen partnering in health care and escalation.                                |
| Establish an initial implementation site to focus on CALD and ATSI community experience and engagement in escalation throughout the initial implementation phase.                                |
| Co-design effective messages promoting escalation opportunities and empowering consumers to take the escalation steps when and if needed.  |
| Develop support information for health services to promote escalation steps and develop strong health service/consumer relationships.  |
| Develop a multi-channel integrated communications strategy to raise awareness of the three-step escalation process and opportunities for consumers to raise or escalate their clinical concerns. |

## **HIGHLY RECOMMENDED CONSIDERATIONS**

Ensure sufficient diverse representation of consumers, services and leadership/decision makers are active on an Expert Reference Group to guide implementation of state-wide escalation processes.

Document and share examples of health services that test, trial and evaluate methods to proactively offer opportunities for consumers to communicate their concerns and to partner in care.

## **HEALTH SERVICES**

### **CRITICAL RECOMMENDATIONS**

Proactively offer consumers opportunities to engage in care and decisions about care by adapting/integrating efforts into existing communication and decision making system (for example adding question to observation records, making efforts to ensure carers are present during rounds etc).

### **HIGHLY RECOMMENDED CONSIDERATIONS**

Internal plans and processes use co-design with diverse representation including people with lived experience of escalation, diverse carer relationships, CALD backgrounds, ATSI communities, LGBTIQ+ and disability.

Implement and evaluate policies to strengthen consumer partnerships in care.

Proactively foster organisational culture that supports disclosure of issues or concerns internally, and between patients/carers and staff.

Nominate as an initial implementation site for the 2019 pilot (either as a general pilot site or CALD or ATSI focused site)

Leverage community networks and partnerships to promote the escalation steps and build relationships for care partnerships.

If patient advocates or GP liaisons are used in the health service, integrate them into promotional and educational networks to inform consumers how to raise or escalate their concerns.

## PRINCIPLE 2: CLINICIANS AND HEALTH SERVICE MANAGERS FEEL READY AND ENABLED TO PARTICIPATE IN HEAR ME

### OVERVIEW

The SCV Partnering in Health Care Framework is designed to guide health services to increase opportunities for consumers to work in partnership with clinical teams to improve patient care and outcomes. Consumer-initiated escalation is one of these opportunities.

Consumers throughout Victoria should be able to recognise that a final step to escalate their medical concerns is available to them (i.e. a phone number to call), but that first priority is to communicate their concerns to their medical team. Consumers need to feel confident that they can raise their concerns when they need to and without negative consequences. To do this will require changes to systems, structures, work cultures and strengthening of core competency training modules for all medical, allied health, nursing staff and relevant administration staff.

Escalation of concerns cannot exist as a separate or isolated process. Escalation processes need to be built on efforts to adapt existing systems, clinical protocols and strengthen communication and guidelines toward patient-centred models of care – all of which health services are currently doing to meet NQSS accreditation criteria, align with the SCV Partnering in Healthcare Framework and to reflect the Australian Charter of Healthcare Rights in Victoria. HEAR ME is a tool and offers guidance and support for these efforts, but does not replace them.

The recommended actions for this principle are:

- Integrate partnership in health care related skills and awareness within core competency requirements for health services staff.
- Strengthen communication skills as key skills in consumer partnerships for healthcare and escalation.
- Make available tools and resources to prepare for HEAR ME and support development of local systems to encourage consumer initiated escalation of concerns.
- Identify and use champions to promote and support strengthening of partnerships in healthcare and consumer initiate escalation of concerns.

### RECOMMENDATIONS

| SAFER CARE VICTORIA   |
|---|
| CRITICAL RECOMMENDATIONS  |
| Establish central HEAR ME phone number with experienced health call centre provider.  |
| Develop implementation framework to support health services demonstrate consistent health care partnership and escalation practice principles in Victoria.  |
| Conduct a public awareness/ promotion campaign utilising popular social and health sector champions that present success stories of consumer-initiated escalation concerns.   |
| Utilise existing health, social and support networks in Victoria to raise awareness of consumer initiated escalation and how it can be activated and used for strengthen consumer participation in care and health outcomes |
| Establish a data collection mechanism to capture and learn from state-wide data on patient, family member and carer initiated escalation – including post call follow up.   |

## HIGHLY RECOMMENDED CONSIDERATIONS

Work in partnership with professional bodies to integrate indicators regarding managing relationships and communication with consumers into professional core competency criteria.

Work in partnership with health services, training institutions and professional bodies to review existing or incorporate new training modules to build competency in managing consumer health partnerships and communication with consumers focused on consumer escalation of medical concerns.

## HEALTH SERVICES

### CRITICAL RECOMMENDATION

Tailor discussions and questions about care and concerns to cultural and linguistic needs of consumers.

Ensure all staff are aware of and can respond to notification of a consumer concern.

Ensure all staff can promote the process and opportunity for escalating consumer concerns to consumers.

### HIGHLY RECOMMENDED CONSIDERATIONS

Identify and develop comprehensive communication skills as a core competency area for all health service staff.

Utilize training scripts developed by SCV/BehaviourWorks to build communication skills for escalation call/request receivers.

Identify internal champions to promote consumer partnerships in healthcare – including escalation steps.

Integrate protocols for inviting consumers to share concerns and document response in existing formal records: i.e. into observation notes, inclusion of question at end of each rounds consultation, or updated handover protocols.

Use role-play or scenario based training methods to measure preparedness and readiness for consumer communication of concerns or requests/notification of escalation.

## PRINCIPLE 3: PATIENTS AND CARERS ARE CONFIDENT IN THE QUALITY AND SAFETY OF THE VICTORIAN SYSTEM

### OVERVIEW

Being able to measure the effectiveness of HEAR ME as a support system for consumers and health services is an integral part of the system design. As identified by SCV, the principle-based HEAR ME system needs to include an emphasis on evidence, ongoing learning and adapting the system to better meet consumer and health service needs.

In most cases health services are already collecting and managing their own relevant data to meet the data requirements of accreditation and other quality and safety reporting criteria. This information, however, is not informing the collective strengthening of how consumers engage in care or escalate their concerns. HEAR ME aims to help understand a broader picture of what is taking place, the issues involved and effective practice that health services can use to update, adapt and strengthen their own escalation processes and relationships with consumers.

The evidence highlights that there are limitations in the range and quality of primary evidence available. This presents an opportunity for Victoria to take a strong role in supporting research activities that will inform both the implementation of the SCV Partnering in Health Care Framework and strengthening of escalation services.

The recommended actions for this priority area focus on two key areas:

- Collaborating to ensure relevant data is available to monitor and evaluate efforts to strengthen consumer involvement in escalating medical concerns.
- Distributing and sharing information and experiences that contribute to learning and strengthening of quality and safety for all Victorians.
- Collaboratively review evidence to identify changes and approaches to consumer partnerships in healthcare.

### RECOMMENDATIONS

| SAFER CARE VICTORIA  |
|--|
|  |
| CRITICAL RECOMMENDATIONS   |
| Establish an evaluation working group within the HEAR ME Expert Reference Group.   |
| Promote recommended information criteria that health services could voluntarily provide to support state-wide sector learning on consumer partnerships in healthcare and escalation. |
| Ensure HEAR ME data relevant to each individual health service is made available to the health service in a timely way on an existing information or reporting platform.             |
| Collate case studies and experiences of consumer escalation of concerns for use in evaluation, learning and promotion.   |
| Integrate measure(s) to evaluate awareness and use of escalation for example in Health Experience Surveys and evaluations.   |



## HIGHLY RECOMMENDED CONSIDERATIONS

Support sharing of lessons, evaluation and research data to support strengthening of escalation steps and consumer participation/partnerships in care.

Develop scripts for health service staff to respond to a request for escalation or expression of concern from a patient, carer or family member.

Identify and support strategic research priorities to strengthen partnerships in care, health communication with consumers and barriers and enablers for consumer-initiated escalation.

Maintain an up-to-date register of Victorian health service efforts to implement consumer-initiated escalation.

Establish partnership with the Victorian Coroner's Court to identify how considerations of consumer partnerships in care and opportunities for consumer-initiated escalation can be more clearly identified in findings, recommendations and other proceedings.

## HEALTH SERVICES

### CRITICAL RECOMMENDATIONS

Include descriptions of consumer-initiated escalation process and rates of use, case studies of use and results within Quality Account reporting.

### HIGHLY RECOMMENDED CONSIDERATIONS

Voluntarily provide information to support sector learning about consumer partnerships in healthcare and escalation.

Request participation on the ERG evaluation group to support how success, impact and learning are measured and communicated.

Include and share evaluation of consumer awareness, confidence and use of escalation steps as part of regular discharge surveys, evaluations.

## PRIORITY 4: HEAR ME HAS STRONG AND TRANSPARENT GOVERNANCE, COORDINATION AND MANAGEMENT PROCESSES

### OVERVIEW

Implementation of a recommended three-step escalation process that emphasises strong communication and consumer partnerships in care requires strong stakeholder ownership and engagement. HEAR ME is a supplementary support phone number designed to make safe systems safer.

A coordinated collaborative approach is needed for the implementation of HEAR ME, given the broad range of relevant interested consumer and implementing stakeholders. Collaboration and partnership with consumers is a foundation principle of HEAR ME and this also needs to be reflected in the governance and management systems.

SCV can facilitate this in several different ways including the establishment of the multi-sector ERG, consultation on evaluation framework design, and participatory processes for development of materials and guidelines. The ERG in particular will be an opportunity for health services to play a key role in decisions about how the escalation program is managed, its messaging and evaluation should they choose to participate.

The recommended actions for this priority are focused on four key areas:

- The need for strong communication and stakeholder ownership of a state-wide approach to consumer partnering in healthcare and escalation.
- Transparent and accountable governance systems that empower stakeholders to participate and inform plans, review and consumer partnering in health care and escalation effectiveness are developed and used.
- Health outcome achievements of consumer participation in health care and escalation are celebrated and shared by all state-wide stakeholders.
- Participation in pilot and evaluation initiatives

### RECOMMENDATIONS

#### SAFER CARE VICTORIA

##### CRITICAL RECOMMENDATIONS

CRM or similar system is used to capture critical call data and health services are given access to data to complement accreditation and other required reporting.

ERG established to oversee quality, learning and planning for the three step escalation process and HEAR ME number.

ERG Evaluation group established with broad/relevant stakeholder representation.

Initial funded 5 year plan confirmed to give program stability and time to establish, adapt and embed itself within public awareness, systems and services.

##### HIGHLY RECOMMENDED CONSIDERATIONS

Highlight positive achievements in partnering in health care, and specifically efforts in effective consumer-initiated escalation processes with Quality Excellence awards.

Consult and liaise with other health service sectors to identify information, service and consumer needs for possible adapted expansion of HEAR ME service.

Provide financial support to sites willing to participate in the initial implementation and evaluation phase.

## HEALTH SERVICES

### HIGHLY RECOMMENDED CONSIDERATIONS

Integrate reporting of escalation notifications, progress, and evaluation into management meetings, Quality Accounts and other existing reporting.

Nominate senior administrative and/or medical personnel to participate in the SCV led HEAR ME ERG.

Volunteer service(s) to participate in the initial implementation phase or pilot initiatives for HEAR ME.

# APPENDICES

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## APPENDICES

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## APPENDIX 1 – SYSTEMATIC REVIEW OF HIGH-LEVEL EVIDENCE SUMMARY

### OBJECTIVES

To summarise high-level (review-level) evidence of the effects of patient/ carer-initiated escalation of care services in hospital.

To identify main features of such escalation care services, including major barriers and facilitators to implementation, and if possible, differences between localised and centralised services, with a focus on outcomes for patients and carers.

### METHODS

#### INCLUSION AND EXCLUSION CRITERIA

The selection criteria in Table 1 were applied to identify relevant high-level evidence for this rapid review.

**Table 1: Selection criteria**

|   | Included  | Excluded  |
|---|---|---|
| <b>Type(s) of study</b>                       | Systematic review, narrative review, qualitative evidence review (synthesis)                              | Primary studies   |
| <b>Types of primary study</b>                 | Quantitative studies, qualitative studies   |   |
| <b>Population</b>                             | Patients and carers (family members, friends, others with an interest in and/or knowledge of the patient) | Health professionals  |
| <b>Setting</b>                                | Hospital  | Community, primary care                                       |
| <b>Intervention or phenomenon of interest</b> | Patient and/or carer escalation of care<br>Factors affecting patient/carers escalation of care            | Clinical RRS/T activation with no consumer-initiation present |
| <b>Date range</b>                             | Searches run 2017-2018<br><br>Additional searching not restricted by date                                 |   |

#### SEARCH ACTIVITIES

Major activities included searches of the following databases and sources:

- Databases (CINAHL, Medline, Embase, the Cochrane Library);

- Two existing reference libraries for reviews on related topics (Merner, Mackintosh);
- Forward citation searching of references in a related review (Mackintosh);
- Scopus searching for citations of relevant papers;
- References by selected authors.

All results were limited to 2017.

Keyword searches of systematic review databases (PDQ, Health Systems Evidence) were also performed, without date restrictions. Several websites were searched for systematic reviews and related grey literature.

All searches were performed in November 2018. See **Appendix 1A** for details of all search activities and sources.

---

## STUDY SELECTION AND DATA EXTRACTION

### SCREENING AND STUDY SELECTION

One reviewer (RR) applied the selection criteria to citations identified from search activities. Screening was done in the first instance based on title and abstract. For studies identified as potentially relevant, full text copies were assessed against the selection criteria.

### DATA EXTRACTION AND ANALYSIS

The same reviewer extracted data, including existing assessments of the quality of the included reviews. Review quality was not reassessed but was used as a guide for interpretation of findings.

Findings were synthesised narratively by identifying major recurrent themes in findings relevant for policy and implementation. Overlapping scope and included studies across reviews were assessed as part of this synthesis process and informed the interpretation of findings.

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## RESULTS

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### SCREENING OF SEARCH OUTPUTS

704 citations were identified from major search activities. Of these, 689 were excluded based on title and/or abstract, 12 were assessed in full text but excluded (see **Appendix 1.2** for reasons for exclusion) and 3 reviews were included.

Additional searches of review-level databases (PDQ, Health Systems Evidence), and cross-searching of government and agency websites yielded several possibly-relevant documents (see **Appendix 1.1**), with a further 2 reviews identified for inclusion from these searches.

In total, 5 reviews were included in this summary (Albutt et al 2017, Berger et al 2014, Gill et al 2016a, Van Voorhis et al 2009, Vorwerk & King 2015); see Appendix 1a. In four reviews there was a focus on patient and carer or family-initiated escalation of care; one review took a broader focus on consumer engagement in hospital patient safety, of which some findings related more specifically to escalation of care by patients/ families (Berger et al 2014).

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## INCLUDED REVIEWS

### MAIN FEATURES

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Five reviews were included in this evidence summary. Reviews were published between 2009 and 2017, most were based on published, English-language research, and typically both adult and paediatric hospital populations were studied. The majority of studies were conducted in the USA. Reviews were of generally moderate quality, with the exception of Van Voorhis 2009, which reported few details of the methods or of the included studies and so was not quality assessed.

See **Appendix 1C** for data extracted from included reviews.

In four reviews there was a focus on consumer-initiated escalation of care; one review took a broader focus on consumer engagement in hospital patient safety, of which some findings related more specifically to escalation of care by patients/ families (Berger 2014).

Numbers of relevant studies included in the reviews ranged from an unspecified number (Van Voorhis et al 2009) to 11 (Vorwerk & King 2015). However, it is important to note that there was a great deal of duplication of included studies, and across all 5 reviews only 13 unique empirical studies were identified.; see appendix 1a This relatively sparse evidence base resulting from extensive searches reflects the conclusions of several of the included reviews themselves (ie that further high-quality research is needed in this area to build a more convincing evidence base on effectiveness and impacts).

None of the included primary studies were of rigorous design for assessing effectiveness, and methodological limitations of the studies may limit confidence in the certainty of the findings.

### FEATURES OF POPULATIONS (PATIENTS)

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Studies examined patient/ family escalation of services for both paediatric and adult patient populations. One review (Albutt 2017) noted that earlier studies tended to focus on escalation of care for paediatric patients, possibly as children may tend to deteriorate more rapidly than adults. One review (Van Voorhis 2009) presented two case study sites involving paediatric hospitals; the remaining reviews included studies of adult and paediatric populations.

### SETTINGS OR UNITS

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Most studies involved patient/ family escalation occurring across units or wards within a hospital; one studied patients discharged from ICU to a hospital ward.

Almost all studies described patient/ family escalation systems that were provided as 'add-ons' to existing clinician-activated RRT mechanisms. A single study (in Albutt 2017) reported a comparison between separate patient/ family-activated and clinician-activated systems.

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## MAIN FINDINGS FROM INCLUDED REVIEWS

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### FEATURES OF ESCALATION SERVICES IMPLEMENTED

#### DIRECT OR INDIRECT ACTIVATION

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Included reviews described patient/ family-initiated escalation processes that were both direct (ie patients and/or family members could directly activate the RRT) and indirect (ie patients' and/or family members' concerns were triaged through staff or a dedicated system (eg Condition Help) to determine whether a RRT was required).

One review (Van Voorhis 2009) described a paediatric system piloted as an indirect escalation mechanism, where family members were asked to immediately raise any concerns about their child with staff. Subsequent evaluation (1 year) showed that family concern was a reason for RRT activation in 8% of cases, with over half requiring ICU transfer; the system was subsequently expanded to allow direct family RRT activation through the same mechanism as staff.

One review (Albutt 2017) reported that indirect activation systems were used more often than RRT systems requiring direct patient/ family member activation.

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## CRITERIA FOR ESCALATION OF CARE

One review (Gill 2016a) discussed criteria in place to help patients/ family members to decide whether or not to escalate care. Studies identified up to four separate criteria for patients/ family members to consider when making the decision to escalate patient care, these being: clinical deterioration or a noticeable change in the patient's condition, breakdown of communication with clinicians/ staff, perceived error, and concerns about the planning, delivery or management of care.

Another review noted that consumers responded favourably and appreciated increased knowledge about changes in physical signs to watch for taught to them by clinical staff (Vorwerk 2015) – yet only a very small number of studies educated patients/ family members on specific signs.

Several reviews noted that clear criteria for patients and family members are needed, for instance, clarity about whether patient/family-initiated escalation is based on clinical deterioration or concerns about care (Gill 2016a, Vorwerk 2015). Further, consumers' ability or confidence to detect clinical deterioration in order to activate care escalation has been little studied (Albutt 2017, Gill 2016a, Vorwerk 2015), despite its centrality to the system of escalation of care.

---

## USAGE OF ESCALATION SERVICES AND REASONS FOR USE

### NUMBERS OF CALLS (ACTIVATION)

Typically, numbers of calls were recorded in order to monitor for over use of patient/ family activation of care escalation (Albutt 2017). Reported rates were generally low, a pattern reflected by estimates captured in the grey literature (ie from institutional websites; Albutt 2017).

Overall, patient/family-initiated RRT activation rates were low but increased after introduction of the escalation function. One review (Albutt 2017) reported a mean of 15.33 calls per year across studies: findings from primary studies showed increases post-implementation of the patient/family escalation function, such as an increase from 3 to 5 calls to Condition H, and an increase from 16 to 24 calls per 1000 discharges. Another review (Vorwerk 2015) reported a small increase from 0.08 to 2.46 calls per month following implementation in 10/11 included studies, with a higher rate of 11.5 calls/ month reported in one study.

Numbers of calls made by staff also increased (Gill 2016a, Vorwerk 2015) with introduction of patient/ family-initiated RRT systems. Numbers were variable, ranging from a small increase of 2.34 calls per month to 193 calls per month, with a small proportion (25/193, 13%) reflecting calls made by patients or family members (Gill 2016a).

---

### CLINICAL OUTCOMES OF CALLS (ACTIVATION OF ESCALATION)

Clinical outcomes were reported in some studies. Single studies reported decreased mortality (from 31 per 1000 discharges with RRS programme to 22.9/1000 discharges for RRS programme with consumer activation), reduced



non-ICU adverse events (codes), and increased survival following codes (Vorwerk 2015, Gill 2016a), compared with the pre-implementation period.

Several studies reported increases in transfers to higher level care post-implementation, with a wide range of estimates but absolute numbers of calls generally remaining low. One study reported higher transfer rates (from 12.8 to 45.4 per month) following implementation, but this included both staff and consumer-activated RRT calls.

## APPROPRIATENESS OF ESCALATION TO RRT

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Almost all (99%) of patient/family-initiated calls were rated as appropriate (ie. meeting the criteria for RRT activation) (Gill 2016a); but a small number of studies reported that clinical staff considered some patient/family activated RRT calls problematic (Albutt 2017). The proportion of calls initiated by patients/ family members leading to higher levels of care or medical intervention was, however, quite low, for instance, estimated at about 1% (Gill 2016a) to 4% (Van Voorhis 2009).

Consistent with this finding, a single study (Albutt 2017) comparing patient/ family-led escalation directly with clinician-led RRT activation (rather than as an add-on service), reported lower levels of patient transfer to ICU with patient/family-escalated RRT (24% of 40 versus 60% of 1,156 clinician-activated RRT). Authors noted that this may have been due to detection of deteriorating patients by patients/ family members that would otherwise have gone unnoticed.

## REASONS FOR CALLS TO ESCALATE CARE

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Aside from clinical deterioration, several studies identified a number of additional reasons for patient/ family-initiated escalation. Communication breakdowns (such as lack of response, conflicts, dismissive interactions with clinicians, delays in assessment) were a commonly identified cause; concerns about medication or pain management, and care coordination (delays, care or discharge plans) were among the other reasons for calls to escalate care (Albutt 2017, Gill 2016a, Vorwerk 2015). Reasons for calls were not mutually exclusive (ie there may be more than one reason for making the call to escalate care)(Gill 2016a).

Staff-activated RRT calls also increased with introduction of escalation systems (Vorwerk 2015). In several cases, family concern was noted as the reason for staff-initiated calls, with rates estimated at 5% (Vorwerk 2015) to 8% (Van Voorhis 2009).

One review noted that identification of previously unrecognised communication problem(s), which may have an impact on patient safety, may be an unintended positive outcome of introducing patient/ family-initiated escalation (Albutt 2017). Since communication breakdown was a major reason for patient/ family escalation, this review suggested that hospitals implement an additional escalation pathway in order to deal with such issues separately to RRT for clinical deterioration.

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## PATIENT AND CARER EXPERIENCES

### KNOWLEDGE OF THE PROGRAMME OR SYSTEM

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Knowledge of whom, how and when to activate a RRT call was variable, for instance, one review (Gill 2016a) reported knowledge ranging from 20 to 98%. Similarly, another review (Vorwerk 2015) reported mixed results with some studies reported high levels of consumer understanding of information (range 76-100%), others reporting lower mean levels, or smaller increases in knowledge, and one reporting high initial levels of knowledge (95%)

about how to activate RRS but poor later recall (18%). Two reviews noted that clear messages for consumers about the process for escalating care in order to be able to action the information is critical (Gill 2016, Vorwerk 2015).

---

## SATISFACTION WITH THE PROGRAMME OR SYSTEM

Studies typically showed high levels of satisfaction with patient/family activated RRT from patients and family members. This included high levels of satisfaction with the process both amongst those who had and had not made a RRT call (Gill 2016a,b), satisfaction and a sense of safety or reassurance knowing that they were able to contact the RRT if needed (Albutt 2017, Vorwerk 2015), including families of patients discharged from ICU (Gill 2016a). Patients/ family members also indicated that they felt they had enough information about the RRT escalation pathway (83%) (Albutt 2017).

One review noted that interviews with family members raised concerns about the possible negative effects of escalating care on the relationship with staff (Gill 2016a), and another highlighted that the relatively low levels of RRT activation by patients and family members may reflect reluctance to engage in behaviours that may be interpreted as challenging hospital staff (Albutt 2017). The ability or willingness of patients and family members to be involved in patient safety more generally (ie not only RRS activation) may also be variable (Berger 2014).

Potential harms of introducing a patient/ family member activated RRT were not reported by included studies, and one review noted that should errors happen (whether or not related to RRS activation), patients and family members may feel guilt (Berger 2014).

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## STAFF EXPERIENCES

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### ATTITUDE TO THE PROGRAMME OR SYSTEM

Staff responses to patient/ family activated RRT introduction were varied. Some positively commented on the benefit of empowering patients and family members, and that the introduction of the pathway could be seen as contributing to prevention of patient deterioration, reduced complaints and improved patient experience (Gill 2016a).

All included reviews also noted that staff also expressed concerns about patient/ family-initiated RRT activation. These included the potential for overuse of the pathway for non-emergency situations, and that this might overwhelm the system; concern that introduction of the pathway conveyed to patients and family members that they should not talk to their medical team about their concerns; loss of control; being deskilled; increased scrutiny; increased workload; and that their decision-making or role in patient care might be undermined.

One review (Van Vioorhis 2009) described a case study site where focus groups, communication and a pilot were used to educate staff about patient/ family RRT activation, and to address staff concerns that the system would be overwhelmed by non-emergency calls. These activities included the rule 'no false alarms' to reinforce the idea that serious concerns about the patient, whether from clinical staff or family members, is an appropriate reason to activate the system.

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## IMPLEMENTATION AND TRAINING ISSUES

Implementation strategies included combinations of guidelines, policy, reminders, education for staff and family, standardised scripts, written materials (brochures, posters), piloting, and audit and feedback (Vorwerk 2015). All reviews highlighted that education and training for staff, and for patients and families, are needed prior to implementation of the system.

## TRAINING FOR STAFF

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Education and training for staff was undertaken in order that they be well informed about details of consumer activation system, and so that they were able and confident to educate consumers about the escalation of care pathway (Albutt 2017). Staff education on the content and delivery of information for patients/ family members was noted as critical (Vorwerk 2015).

Staff were educated in small groups (Albutt 2017) or via individual meetings, through personal communications or shift change huddles (Vorwerk 2015). Several studies described comprehensive education packages which also included checklists, reminders, talking points and self-learning modules; several relied on scripted narratives to support staff to deliver information to consumers, and one educated all hospital staff using a communication toolkit (Vorwerk 2015).

Hospital bulletin board notices, regular newsletters or items, and intranet education were often used to promote and reinforce staff education (Vorwerk 2015). Some studies described electronic chart education or reminders for nurses in electronic medical records to ask about families' awareness of the escalation system at regular intervals in order to support information recall (Berger 2014, Van Voorhis 2009); with one study emphasising that educational opportunities taken up after admission improved information retention (Vorwerk 2015).

## EDUCATING PATIENTS AND FAMILY MEMBERS

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Strategies for informing and educating patients and family members about the escalation system typically used multiple approaches to promote understanding of the system, the process for activation, and to reinforce key messages. However, it is also worth noting that no studies have assessed how families would prefer to be informed about the process of escalating care, or their preferences for participation in such care processes (Gill 2016a).

## EDUCATION BY NURSES

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Patients and family members were often first informed about the process for escalating care upon admission, unit orientation or before transfer from the ICU. Education was typically undertaken by the admitting nurse, often via a standardised information script (Albutt 2017, Berger 2014, Van Voorhis 2009, Vorwerk 2015). Most studies described this one-to-one verbal education as critical.

## SUPPORTING INFORMATION FOR PATIENTS AND FAMILY MEMBERS

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Verbal information delivered by nursing staff was supplemented with additional information. Reviews indicated that providing information via passive means alone (eg via poster) was insufficient as consumers may not read the information unless prompted to do so by staff; and that multiple different active communication strategies (formats or modes) for informing patients/ family members about the RRT escalation system and how to access it were required (Gill 2016a, Van Voorhis 2009, Vorwerk 2015).

Printed educational materials were provided in most studies to reinforce key details of the system (Vorwerk 2015), with this additional information taking the form of information sheets, posters, flyers, brochures, FAQ sheets or signs and instructional labels for telephones (Berger 2014). Sometimes written information was included in the hospital guide given to families on admission (Van Voorhis 2009) or additional information was provided via video; in others, posters and leaflets provided in patients' rooms and/or in visiting and waiting areas served to reinforce information given verbally on admission (Albutt 2017). Printed educational materials, such as posters throughout the hospital, may serve to remind consumers what to do or what number to call if RRT activation is needed (Van Voorhis 2009).

A very small number of studies described providing bilingual information, for example, providing information through a translator upon admission, bilingual flyers, bilingual tear-off information cards or a Spanish information card to hand to an English speaker to activate the RRT (Van Voorhis 2009, Vorwerk 2015). Two reviews noted that translation of materials to non-English languages has lagged behind and that there is need to consider factors such as cultural diversity and health literacy levels when introducing any patient/ family-initiated escalation of care role to ensure the needs of all patients and their family members are met (Gill 2016b, Vorwerk 2015).

Information materials such as posters often described signs for patients and families to watch for, and how to escalate their concerns. Concern about the patient was a requirement for making a call to escalate care across studies, but only two actually provided education for patients and family members on specific signs to watch for (eg heart or respiratory rate, mental status, agitation) (Vorwerk 2015). A small number of studies in this review (3) also provided information explicitly on issues that were not to be managed through escalation of the RRS.

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## APPENDIX 1A SEARCH ACTIVITIES AND SOURCES

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### 1 DATABASES AND RELATED SOURCES

Sources for this rapid review were varied

1. Two Endnote libraries were searched: these were previously developed for the two related Cochrane reviews:

Mackintosh NJ, Davis RE, Easter A, Rayment-Jones H, Sevdalis N, Wilson S, Adams M, Sandall J. Interventions to increase patient and family involvement in escalation of care for acute life-threatening illness in community health and hospital settings. Cochrane Database of Systematic Reviews 2017, Issue 10. Art. No.: CD012829. DOI: 10.1002/14651858.CD012829.

Merner B, Hill S, Colombo C, Xafis V, Gaulden CM, Graham-Wisener L, et al. Consumers and health providers working in partnership for the promotion of person-centred health services: a co-produced qualitative evidence synthesis (protocol). Cochrane Database of Systematic Reviews [in press]

2. Web of Science forward citation searching for relevant references in the Mackintosh 2017 Cochrane protocol was conducted.

3. Scopus was searched for citing articles of the three reviews identified by the REACH program:

2016 Gill Fenella J., Leslie Gavin D., Marshall Andrea P, World Views on Evidence Based Nursing: Vol 13, (4) 303-13. The Impact of Implementation of Family-Initiated Care on for the Deteriorating Patient in Hospital: A Systematic Review

2016 Albutt Abigail K., O'Hara Jane K., et al. Health Expectations (On Line Sept 2016) Is there a role for patients and their relatives in escalating clinical deterioration in hospital? A systematic review

2015 Vorwerk Jane & King Lindy. Journal of Clinical Nursing: Vol 25, (1-2) 38-52 Consumer participation in early detection The Impact of Implementation of Family-Initiated Care on for the Deteriorating Patient in Hospital of the deteriorating patient and call activation to rapid response systems: a literature review

4. References by the following authors were searched:

C Vincent

R Davis

F Gill

A Albutt

5. Simple searches were also conducted in CINAHL, Medline, Embase and the Cochrane Library.

All results were limited to 2017.

Searches were run November 2018.

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## 2 ADDITIONAL REVIEW-LEVEL DATABASES SEARCHES

### PDQ:

*Searched November 22 2018*

- 'escalation': identified Gill 2016 review; related articles:
  - Berger 2014 (SR). Included.
  - Winters 2013 (SR, mentions patient/ carer escalation in 2 included studies, not definitive, not a major finding). Now excluded clinical focus
  - Other related SRs focus on consumer engagement in care as safety measure but not specifically focussed on escalation of care as a result of deterioration.
- 'activation of care': identified Chua 2018 (SR) (factors affecting activation of rapid response systems; all health professional considerations, consumer-initiated escalation outside the scope of this review). Excluded.

### Health Systems Evidence:

*Searched November 22 2018*

- 'escalation' identified:
  - Gill 2016 SR (NB AMSTAR rating 4/9): related articles identified:
    - Vorwerk 2015 SR (AMSTAR rating 5/9). Included.
    - McGaughey 2017 (already excluded; clinical focus); Chua 2018 (excluded, clinical focus); Winters 2013 (excluded, clinical focus)
    - Maharaj 2015 (excluded, clinical focus).
- 'consumer initiated' identified no relevant reviews
- 'activation of care' identified
  - Vorwerk 2015 SR (AMSTAR rating 5/9): related articles identified:
    - Gardener 2014 (SR protocol). JBI has not record of the review; protocol available on PROSPERO only

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## 3 WEBSITE SEARCHES

### Clinical Excellence Commission

<http://www.cec.health.nsw.gov.au>

REACH program. [Recognise, Engage, Act, Call, Help]

Developed 2013; revised 2017.

Toolkit available; includes implementation plan for health services.

Aligns with ACQS National Safety and Quality Standards, standard 9.9

CEC has a range of evaluation measures (see p.11 toolkit), including no. REACH calls, reason for each call; no. patients transferred to higher care/ change of treatment, awareness on staff and patients, etc.

References: two SRs, one literature review [all to be included in evidence summary]:

- 2016 Gill Fenella J., Leslie Gavin D., Marshall Andrea P, World Views on Evidence Based Nursing: Vol13, (4) 303-13. The Impact of Implementation of Family-Initiated Care on for the Deteriorating Patient in Hospital: A Systematic Review
- 2016 Albutt Abigail K., O'Hara Jane K., et al. Health Expectations (On Line Sept 2016) Is there a role for patients and their relatives in escalating clinical deterioration in hospital? A systematic review
- 2015 Vorwerk Jane & King Lindy. Journal of Clinical Nursing: Vol 25, (1-2) 38-52 Consumer participation in early detection The Impact of Implementation of Family-Initiated Care on for the Deteriorating Patient in Hospital of the deteriorating patient and call activation to rapid response systems: a literature review

### **Ryan's Rule (Patient Safety and Quality Improvement Service, Clinical Excellence Division)**

<https://clinicalexcellence.qld.gov.au/priority-areas/safety-and-quality/ryans-rule>

Developed through extensive and ongoing consultation with wide range of stakeholders, occurring since 2011.

The following are encouraged to use: patients, families, guardians, carers.

Stakeholders involved in developing:

- Health Consumers Queensland
- Clinicians - representation from each Hospital and Health Service to form a Ryan's Rule working group
- Recognition and Response to Clinical Deterioration (RRCD) statewide reference group
- Clinical governance units - representation from each Hospital and Health Service
- Queensland Health Quality and Complaints Commission (HQCC)
- Australian Commission on Safety and Quality in Health Care
- 13 HEALTH
- Smart Services Queensland

The Patient Safety and Quality Improvement Service provides training and ongoing support to local Ryan's Rule coordinators.

'This brochure has been adapted with permission under a Creative Commons Attribution from the 'Call and Respond Early (CARE) for patient safety' (Publication No 12/0040), produced by the © Australian Capital Territory, Canberra, September 2013 [www.health.act.gov.au](http://www.health.act.gov.au) | [www.act.gov.au](http://www.act.gov.au)'

Links to the following programme of work and evaluation: <https://www.health.act.gov.au/compass>

Sections by patient (adult, paediatric etc); also one on family escalation: refers to CARE. No further SR-level citations provided

### **ACSQ National Standards**

<https://www.safetyandquality.gov.au/our-work/assessment-to-the-nsqhs-standards/>

Second edition (November 2017)

Recognising and responding to acute deterioration (and escalating care)

Applies to all patients (from babies to adults)

Standard 8.7: the health service organisation has processes for patient, carers or families to directly escalate care.

Australian Commission on Safety and Quality in Health Care. National consensus statement: essential elements for recognising and responding to acute physiological deterioration. 2nd ed. Sydney: ACSQHC; 2017

- Principle 7: Recognition and response systems should encourage a positive, supportive response to escalation of care, irrespective of circumstances or outcome. No one should be criticised for escalating the care of a deteriorating patient.
- Essential element 2: escalation of care.
  - Protocol must be in place, tailored to the health service (eg size, location, resources).
  - 2.9 The escalation protocol should allow the concerns of the patient, family or carer to trigger an escalation of care.
- Element 3: rapid response delivery: Rapid response providers should communicate with the attending medical officer or team about the consequences of the call, in an appropriate, detailed and structured way. The patient's family or substitute decision maker should also be informed about the occurrence and consequences of the call
- Element 4 communication for safety:
  - 4.2 Information about possible deterioration should be sought from the patient, family or carer when possible.
  - 4.3 Information about deterioration should be communicated to the patient, family or carer in a timely and ongoing way.
- Element 6 health professional education:
  - All doctors and nurses should be able to: initiate appropriate early interventions for patients who are deteriorating...; communicate information about clinical deterioration in a structured and effective way to the attending medical officer or team, to clinicians providing emergency assistance and to patients, families and carers
- From this document, possibly relevant documents (all checked for relevance/ references; none included)
  - Victorian Department of Human Services. *Safer Systems – Saving Lives, Implementing a Rapid Response System 2006*.
  - Jacques T, Fisher M, Hillman K, Berry M, Hughes C, Lam D, Manasiev B, Morris R, Nguyen N, Pandit R, Pile A, Saul P. *DETECT Manual: Detecting deterioration, evaluation, treatment, escalation and communicating in teams*. Clinical Excellence Commission and NSW Health, 2009.
  - National Institute for Health and Clinical Excellence. *Acutely Ill Patients in Hospital: Recognition of and Response to Acute Illness in Adults in Hospital 2007*, <https://www.nice.org.uk/guidance/cg50>, accessed 22 November 2018.
- National Patient Safety Agency, *Recognising and Responding Appropriately to Early Signs of Deterioration in Hospitalised Patients 2007* <http://www.nrls.npsa.nhs.uk/resources/?entryid45=59834>, accessed 22 November 2018.
- NHS Patient Safety First Campaign, *The 'How to Guide' for Reducing Harm From Deterioration 2008*, <http://www.norf.org.uk/Resources/Documents/Resources%20documents/patientsafetyfirst.nhs.uk%20%20Deterioration%20Guide.pdf>, accessed 22 November 2018.
- NSW Health, *Recognition and Management of Patients who are Clinically Deteriorating, Policy Statement and Standard 2013*, [http://www0.health.nsw.gov.au/policies/pd/2013/pdf/PD2013\\_049.pdf](http://www0.health.nsw.gov.au/policies/pd/2013/pdf/PD2013_049.pdf), access November 22 2018.
- Sebat F (Ed.) *Designing, Implementing and Enhancing a Rapid Response System*. Society of Critical Care Medicine, January 2009.
- Scottish Intercollegiate Guidelines Network (SIGN). *Care of deteriorating patients 2014*, <http://www.sign.ac.uk/pdf/SIGN139.pdf>, accessed 21 November 2018



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## APPENDIX 1B: DETAILS OF STUDIES EXCLUDED BASED ON FULL-TEXT ASSESSMENT

### Studies excluded (from database and related searches)

| Citation   | Reason for exclusion; notes  |
|--|--|
| Bavare 2018  | Primary study  |
| Bavare AC, Thomas JK, Elliott EP, Morgan AC, Graf JM. Family-Initiated Pediatric Rapid Response: Characteristics, Impetus, and Outcomes. <i>Journal for Healthcare Quality</i> ; 2018; 40 (2) 103–9.                           | Analysis of family-initiated versus clinician-initiated rapid responses; paediatric hospital.<br><br>From Abstract, main findings:<br><br>'Of the 1,906 RRs events reviewed, 49 (2.6%) were FIRRs. All FIRRs had appropriate clinical triggers with the most common being uncontrolled pain. Chronic conditions and previous admissions were present in 61%. More than half of FIRRs had a vital sign change that should have qualified C-RR activation. Seventy-six percent FIRRs needed at least one or more interventions. Twenty-seven percent of FIRRs needed transfer to intensive care unit compared with 60% transfer rate for C-RRs.' |
| Bell 2018  | Primary study (survey)   |
| Bell SK, Roche SD, Mueller A, Dente E, O'Reilly K, Sarnoff Lee B, et al. Speaking up about care concerns in the ICU: Patient and family experiences, attitudes and perceived barriers. <i>BMJ Qual Saf</i> ; 2018; 27: 928-36. | Family members of patients in ICU (and country-wide internet based survey of people with ICU experience); 'concerns' about care rather than escalation of care   |
| Considine 2018   | Primary study.   |
| Considine J, Hutchison AF, Rawson H, Hutchinson AM, Bucknall T, Dunning T et al. Comparison of policies for recognising and responding to clinical   | Assessment of features of no. health services re clinical deterioration. Clinical parameter focus, clinician implications focus; patient/ carer escalation a common feature but not examined in detail.  |

deterioration across five Victorian health services.  
Australian Health Review; 2018; 42: 412–9.

References include ACSQHC National Standards 2012; Gill 2016

Gill FJ, Leslie GD, Marshall AP. Family initiated escalation of care for

the deteriorating patient in hospital: family centred care or just 'box

ticking'. *Aust Crit Care* 2016; 29: 195–200.  
doi:[10.1016/j.aucc.2016.](https://doi.org/10.1016/j.aucc.2016.07.004)

[07.004](#)

Eden 2017

Primary study

Assessment of calls made under Condition H (distribution, numbers, reasons)

Eden EL, Rack LL, Chen LW, Bump GM. Condition Help: A Patient- and Family-Initiated Rapid Response System. *Journal of Hospital Medicine*; 2017; 12(3) :157-161

Gill 2018

Qualitative primary study.

Assessment of barriers/ facilitators for Calling 4 Help (parent escalation of care process introduced 6 months previously)

Gill FJ, Leslie GD, Marshall AP. Barriers and facilitators to implementing a process to enable parent escalation of care for the deteriorating child in hospital. *Health Expectations*; 2018: 1–9.

Low levels of parental awareness identified. Parent involvement in escalation identified in 18% events.

C4H considered to add to patient safety.

'Key barriers were the low level of awareness, doubt about

parent capabilities, concern about parents' information overload, anticipated overuse of resources, staff unease about possible repercussions and anticipated difficulty for parents to question staff with potential negative effects on parent-staff relationships. Overall C4H presents a challenge to traditional hospital hierarchy and culture.'

Guinane 2018

Qualitative primary study

Guinane J, Hutchinson AM, Bucknall TK. Patient perceptions of deterioration and patient and family activated escalation systems-A qualitative study. *J Clin Nurs*; 2018; 27:1621–31.

Haines 2017

Systematic? Review. 'expert-based review'

Consumer involvement in critical care but focus is on higher-level involvement and not on escalation of clinical care.

Haines KJ, Kelly P, Fitzgerald P, Skinner E, Iwashyna TJ. The Untapped Potential of Patient and Family Engagement in the Organization of Critical Care. *Crit Care Med*; 2017; 45:899–906.

Mackintosh 2017

Protocol for SR; full review not yet available.

Mackintosh NJ, Davis RE, Easter A, Rayment-Jones H, Sevdalis N, Wilson S, et al. Interventions to increase patient and family involvement in escalation of care for acute life-threatening illness in community health and hospital settings. *Cochrane Database of Systematic Reviews*; 2017, Issue 10. Art. No.: CD012829. DOI: 10.1002/14651858.CD012829.

Community settings as well as hospital.

May include evidence related to populations outside hospital.

Oxelmark 2018

Qualitative primary study

Oxelmark L, Ulin K, Chabover W, Bucknall T, Ringdal M. Registered Nurses' experiences of patient participation in hospital care: supporting and hindering factors patient participation in care. *Scand J Caring Sci*; 2018; 32: 612–21.

Nurses' views on patient participation/ partnership, including in safety measures but no focus on escalation of care measures

Pain 2017

Primary study

Pain C, Green M, Duff C, Hyland D, Pantle A, Fitzpatrick K et al. Between the flags: Implementing a safety-net system at scale to

Description of implementation (and some evaluation) of the BTF safety system introduction. Not a specific focus on consumers/ role in escalation of care. Focus is

recognise and manage deteriorating patients in the New South Wales public health system. *International Journal for Quality in Health Care*; 2017; 29(1), 130–6.

Thrasher 2017

Thrasher J, McNeely H, Adrian B. When Nursing Assertion Stops: A Qualitative Study to Examine the Cultural Barriers Involved in Escalation of Care in a Pediatric Hospital. *Crit Care Nurs Clin N Am*; 2017; 29: 167–76.

clinician escalation of care and communication between clinical teams.

Primary qualitative study

Nurses' perceptions of barriers to care escalation, including interaction with physicians

Tobiano 2018

Tobiano G, Bucknall T, Sladdin I, Whitty J, Chabover W. Patient participation in nursing bedside handover: A systematic mixed methods review. *International Journal of Nursing Studies*; 2018; 77: 243–58.

Systematic mixed-methods review

Focus is transitional care ie handover, not escalation of care

### **Studies excluded (from other supplementary search activities)**

Chua 2018

Chua WL, See MTA, Legio-Quigley H, Jones D, Tee A, Liaw SY. Factors influencing the activation of the rapid response system for clinically deteriorating patients by frontline ward clinicians: a systematic review. *International Journal for Quality in Health Care*; 2017; 29(8), 981–98.

Focus on clinicians; no consumer involvement in escalation of care.

Gardner 2014

Gardner J, Hampton M. The effectiveness of rapid response teams activated by patients or family members of patients admitted to inpatient hospital units: a systematic review protocol. Available at:

PROSPERO, protocol registered 2014.

Unable to locate full text/ full review.

<http://www.joannabriggslibrary.org/index.php/jbisri/r/editor/submission/1405>

Maharaj 2015

Clinical focus on rapid response teams; no consumer initiation of escalated care.

Maharaj R, Raffaele I, Wendon J. Rapid response systems: a systematic review and meta-analysis. *Critical Care*; 2015; 19:254. DOI 10.1186/s13054-015-0973-y.

Winters 2013

Focus is not on patient/ carer initiated escalation; rather on staff activation of RRS and clinical outcomes of this.

Winters BD, Weaver SJ, Pfoh ER, Yang T, Cuong J, Dy SM. Rapid-Response Systems as a Patient Safety Strategy: A Systematic Review. *Ann Intern Med*; 2013; 158(502): 417–25.

### Studies excluded (from website searches)

Victorian Department of Human Services. *Safer Systems – Saving Lives, Implementing a Rapid Response System 2006*.

Could not access; likely to be clinical systems rather than consumer-initiated focus

Jacques T, Fisher M, Hillman K, Berry M, Hughes C, Lam D, Manasiev B, Morris R, Nguyen N, Pandit R, Pile A, Saul P. *DETECT Manual: Detecting deterioration, evaluation, treatment, escalation and communicating in teams*. Clinical Excellence Commission and NSW Health, 2009.

Book, not assessed but likely to be clinical response systems.

National Institute for Health and Clinical Excellence. *Acutely Ill Patients in Hospital: Recognition of and Response to Acute Illness in Adults in Hospital 2007*, <https://www.nice.org.uk/guidance/cg50>, accessed 22 November 2018.

Clinical guideline; reviewed and updated 2016. No additional evidence. Critical care clinical guidelines; no consumer-initiated escalation.

National Patient Safety Agency, *Recognising and Responding Appropriately to Early Signs of Deterioration in Hospitalised Patients 2007*,

Patient incident and safety reports, data collection. Not consumer-initiated escalation.

<http://www.nrls.npsa.nhs.uk/resources/?entryid45=59834>, accessed 22 November 2018.

NHS Patient Safety First Campaign, The 'How to Guide' for Reducing Harm From Deterioration 2008,  
<http://www.norf.org.uk/Resources/Documents/Resources%20documents/patientsafetyfirst.nhs.uk%20%20Deterioration%20Guide.pdf>, accessed 22 November 2018.

NSW Health, Recognition and Management of Patients who are Clinically Deteriorating, Policy Statement and Standard 2013,  
[http://www0.health.nsw.gov.au/policies/pd/2013/pdf/PD2013\\_049.pdf](http://www0.health.nsw.gov.au/policies/pd/2013/pdf/PD2013_049.pdf), access November 22 2018.

Sebat F (Ed.) Designing, Implementing and Enhancing a Rapid Response System. Society of Critical Care Medicine, January 2009.

Scottish Intercollegiate Guidelines Network (SIGN). *Care of deteriorating patients 2014*,  
<http://www.sign.ac.uk/pdf/SIGN139.pdf>, accessed 21 November 2018

Clinical response systems for deteriorating patients. No consumer role for initiation of escalation.

Clinical implementation of Between the Flags. No consumer-initiated escalation role.

Clinical focus, health services planning from this perspective.

Consensus recommendations (Delphi process) on identification and care of deteriorating patients. Clinical focus; no mention of patient/family-initiated escalation.

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APPENDIX 1C: DATA EXTRACTED FROM ELIGIBLE REVIEWS (N=5)

| Study citation  | Aim  | Search dates & features<br>No. included studies<br>Settings, populations<br>Quality of review<br>Quality of included studies  | Main findings   |
|---|--|---|---|
| <b>Albutt 2017</b>  |  |   |   |
| Albutt AK, O'Hara JK, Connor MY, Fletcher SJ, Lawton RJ. Is there a role for patients and their relatives in escalating clinical deterioration in hospital? A systematic review. <i>Health Expectations</i> (On Line Sept 2016); 2017; 20: 818-25. DOI: 10.1111/hex.12496 | To systematically review studies describing interventions to engage patients and carers to escalate patient deterioration to a rapid response team (describing the system and its implementation), and to evaluate the effectiveness of these interventions. | 1990 to February 2015<br><br>English language only<br><br>Peer reviewed and grey literature<br><br>9 empirical studies, 36 grey literature studies (included descriptive studies, reports of interviews and surveys)<br><br>Empirical studies: majority in USA (8/9), in paediatric settings (6/9). | Several features of patient/carer-led escalation systems are discussed:<br><br><i>Patient/ carer roles</i> <ul style="list-style-type: none"> <li>• Escalation systems were both direct (ie direct activation of RRT) and indirect (eg triaged through Condition Help to determine whether RRT needed).</li> <li>• Indirect pathways activated more often than direct pathways.</li> <li>• Composition of RRT teams was variable: both in terms of number of clinicians and types of clinicians involved in the response.</li> <li>• Paediatric and adults services were involved. Earlier studies tended to focus on paediatric escalation of care (possibly as children may deteriorate faster than adults); but both populations were represented in the samples studies.</li> </ul> |
| Systematic review   |  |   |   |

Grey literature: predominantly websites, aimed at patient/ carers, explaining purpose of and how to activate escalation to RRT at particular health service/ organisation.

Quality of review: 7/13\*

Quality included studies: overall, low quality (mean score 31% on Quality Assessment Tool for Studies with Diverse Designs).

[note several included studies in Albutt 2017 also included in Gill 2016 and Berger 2014: unique studies for Albutt 2017 are Brady 2014, McCawley 2013]

Other notes:

- Effects of patient/ family led RRT activation mostly not able to be isolated and evaluated; would require large-scale studies to do so.
- Possible confounding re increased vigilance of staff

### *Implementation*

- Education for clinicians, patients and families was provided prior to implementation.
  - Clinician education was often group based; educated in order to be able to inform and educate patients and carers re escalation of care.
  - Patients/ carers often first informed about escalation process by admitting nurse (based on formalised teaching script). Posters and leaflets provided in patient's room to serve as reminder of information given by admitting nurse.
- A number of small pilot studies were identified; many assessed barriers to use of escalation pathway. Clinician barriers included concern that patients/ carers would use the escalation pathway for non-serious reasons. Patient barriers were not reported.

*Effectiveness:*

Clinical outcomes:



where patient/ family activation has been introduced.

- Patient/ family low levels of RRT activation may reflect their unwillingness to engage in behaviour that may be perceived as challenging staff.
- Identifying unknown communication problems may be an unintended positive outcome from introduction of patient/ family led RRT activation (in terms of impact on patient safety). May also be positive that RRT activation brings in different staff to the patient's bedside.
- Included studies did not assess patient/ family members' ability to monitor for deterioration – yet this the foundation of the introduction of such systems. There is a need to improve ability to detect/ understand clinical changes in order to participate in these activation-type activities.

For patient and family-led escalation added alongside existing clinician-led RRT activation:

- One survey study reported significant increase in transfers to high level care and decrease in non-ICU adverse events and mortality after implementation (compared with pre-implementation period).
- One survey reported an increase in days between cardiac arrest (increasing from 34 to 104 days) after implementation.

For separate examination of patient and family-led escalation compared with clinician-led RRT activation:

- One study reported 24% of 40 patient and family-activated RRT, compared with 60% of 1,156 clinician-activated RRT, led to patient transfer to ICU. Lower rate of transfer to ICU from patient/ family-led activation, but noted that this may have escalated care for a subset of patients deteriorating but missed by health care professionals.

Non-clinical outcomes: number of RRT activations:

- As patients/ family members often activated RRT due to communication issues (non life-threatening), recommendation is that hospitals put in place another escalation pathway in order to escalate such problems/ receive a timely response
- Typically assessed by studies in order to monitor for over-use.
- Mean across studies 23/ 1.5 years (15.33/year).
  - One study reported patient/ family-led activation as percentage of all RRT activations at 2.9% (this increased over the study period).
  - One reported an increase from 3 to 5 Condition H calls after introduction of education for patient, family members and staff.
  - Another reported an increase from 16 to 24 calls per 1,000 discharges following introduction of family activation of RRT.
  - Grey literature (where program was evaluated) typically shows fairly low rates of use of patient/ family-led RRT activation.

Non-clinical outcomes: reasons for activation:

- Reasons for activation by patients/ family members often assessed as

appropriate (ie meeting the criteria for activation of RRT).

- Small number of studies reported that some patient/family activated RRT were considered to be problematic by staff.
- All studies identified communication breakdown as a reason for RRT activation (eg lack of response or communication from clinicians, dismissive interactions), ie. clinical deterioration not the trigger but rather concerns re care plan, medication, pain control, dietary status, discharge.

Non-clinical outcomes: other:

- Survey in one study showed high levels of satisfaction with patient/family activated RRT.
- In another, patient feedback surveys showed that most felt they had enough information about the RRT escalation pathway (83%) and felt reassured by the service's availability (90%).

## Berger 2014

Berger Z, Flickinger TE, Pfoh E, Martinez KA, Dy SM. Promoting engagement by patients

To review controlled studies of patient engagement as part of selected hospital-based patient safety practices (PSP), where

2000 to 2012

English language only

- All three studies included implementation of patient engagement strategies as part of RRS intervention, where patients/ family were encouraged to directly call the RRT.

and families to reduce adverse events in acute care settings: a systematic review BMJ Qual Saf; 2014; 23: 548–55.

## Systematic review

engagement aims primarily to increase patient/ family involvement in order to improve safety.

NB Broader perspective than only escalation of care but does include a focus on patient/ family involvement in RRS (as one of four PSPs).

USA, UK, Canada, Australia only

Published only

6 included studies (for patient engagement as an independent PSP) [none RRS]

12 examples of patient engagement as part of broader PSP [includes RRS; 3/12]

[note: 3 studies identified as focussed on RRS: these are included in Albutt 2017 review and summarised above but additional findings not reported in the Albutt 2017 review are reported in the table here]

Quality of review: 4/13\*

Quality included studies: generally low (survey etc); small number included studies

- Barriers identified included the following:
  - Concern that the system would be overused
  - Physician concern that their position/ role in patient care would be undermined.
- Facilitators included:
  - Leadership and provider involvement
  - Clinician understanding that the RRS was an extension to the care they already provided.

One study: paediatric, direct family activation; direct phone line for RRS activation, could be reached from any telephone.

Families educated about system via posters/ flyers. Nurses trained in explaining the RRS activation system to families, reminders in EMR to ask about levels of family awareness of the system at regular intervals.

Another paediatric study integrated the RRS activation system by encouraging family members to call the RRS if there was: noticeable unaddressed medical change, breakdown in care or uncertainty about treatment, medication administration

Other notes:

- Authors note that for patients/ family members to be involved in patient safety depends on willingness and ability to detect and report clinical errors.
- Authors note the review's major weakness is lack of research assessing the effectiveness of PSP interventions and whether they improve outcomes for patients/ families (engagement and safety outcomes);

leading to an adverse event or that the patient/ family did not think had been explained adequately, or treatment meant for another patient or went against the patient's doctor's intention. Admitting nurse provided explanation to patient and family (script); also video and leaflet.

One further study described implementation of direct patient/ family-activated RRS (adult trauma centre; same RRS as that activated by clinicians). System involved dedicated phone line; written educational materials, signs and instructional labels for phones, together with scripted education for family members from trained staff.

Costs and harms not assessed; authors note ability or motivation of patients/ family member to be involved in patient safety may be variable, may also feel guilt should errors happen [not specifically related to RRS activation]

**Gill 2016a**

To assess the impact of implementation of family-initiated care

2005 to April 2015

Criteria for escalation were assessed, there being up to 4 for patients/ family members to initiate escalation of care [clinical

|   |   |  |   |
|---|---|--|---|
| Gill FJ, Leslie GD, Marshall AP. The Impact of Implementation of Family-Initiated Care on for the Deteriorating Patient in Hospital: A Systematic Review. World Views on Evidence Based Nursing; 2016; 13 (4) 303-13. | escalation for deteriorating patients in hospital, in terms of outcomes for families, patients, clinicians and health services. | English language only<br>Published only<br><br>Majority of studies (9/10) USA, 1 UK  | deterioration/ noticeable change, communication breakdown, perceived error, concern about care delivery/ management/ planning].   |
| Systematic review   |   | 10 studies; descriptive (level IV evidence)  | <ul style="list-style-type: none"> <li>All (10/10) systems included clinical deterioration as trigger; 5/10 communication breakdown; 1/10 perceived error; 6/10 concern about care.</li> </ul>  |
| Gill 2016b  |   | 5 studies adults, 4 paediatric, 1 mixed adult + paediatric   | <i>Evaluation of systems (survey, interview, audit, case review)</i>  |
| Gill J, Leslie GD, Marshall AP. Family initiated escalation of care for the deteriorating patient in hospital: Family centred care or just "boxticking". Australian Critical Care; 2016; 29: 195-200.                 |   | 5 direct activation (ie same system as clinicians triggered), 5 triaged or separate response (eg condition H)  | Impact on patient   |
|   |   | 7 described systems able to be activated by patients, parents or family; 3 paediatric studies described systems able to be initiated by parents/ family. All added onto existing RRS approaches for staff. | <ul style="list-style-type: none"> <li>420/426 (99%) total patient/ family-initiated calls assessed as appropriate.</li> <li>5/426 led to medical intervention or higher care level</li> <li>Most frequent reasons for call (other than clinical deterioration): communication breakdown, delays, concern about medication/ pain management. Reasons for calling may be multiple.</li> <li>3 papers reported increased RRT calls after implementation. Of these papers, one reported a decrease in mortality</li> </ul> |

[note several included studies in Albutt 2017 also included here: unique studies for Gill 2016 are Van Voorhis 2009, Dunning 2010, Baird 2011]

(31 to 22.9 deaths/ 1000 admissions) and a decrease in non-ICU codes in the 2 years post implementation. Increase in total number of staff calls over the 2 years, from 47 to 193/ month, with 25 calls made by patient/ family.

Impact on family:

Quality of review: 4/11<sup>#</sup>

Quality included studies:

Mixed methods appraisal tool used; assessment shows the included studies were of variable quality.

Other notes:

- No study reported how families would prefer to be informed about the escalation of care process; their preferences for participation; or whether they felt able to recognise patient deterioration adequately.

- Assessed by audits (proportion of families instructed on escalation process, levels of understanding when and how to escalate) and survey/ interviews (satisfaction).
- Awareness varied 20-98%.
- Patients/ family members who had made a call reported high satisfaction levels (with process).
- People with family member discharged from ICU were reassured that the service was available.
- Family interviews indicated some concerns about possible negative effects of escalation on relationship with healthcare providers.

Impact on providers:

- Assessed by survey, interview, audit (awareness of understanding, attitude to family escalation process). 4 studies reported.

- Skills to respond to the broader range of call criteria (eg communication breakdown) differ to those required for immediate clinical deterioration. Staff training to provide the most appropriate response not discussed by any of the studies reviewed. ie skills needed may be very different to those required for RRT
  - Clarity is needed to determine whether patient/family initiated escalation is based on clinical deterioration or on patient/ family concerns about care.
  - High levels of patient/family awareness of escalation process achieved when active, repeated measures used.
  - Number of calls for clinical deterioration small so not possible to determine the effects on patient outcomes. Further research is needed on this.
  - Positive comments included empowering benefit to patients/ families, process seen as contributing to prevention of deterioration, reduced complaints, improved patient experience.
  - Concerns included: overuse for non-emergency situations; message that patients/ families should not talk to their medical team about concerns; repercussions if call made about a patient in their care; loss of control; being deskilled; decision-making undermined by families.
- Impact on health services:
- Implementation strategies varied, included guidelines, policy, reminders, education (staff and family), standardised scripts, written materials (brochures, posters), piloting, audit and feedback.
  - Posters in patients' rooms alone insufficient strategy for informing families; multiple required for effective communication, including staff informing families as routine measure.
  - Number of calls: 0.17-11.5 per month (reflects calling criteria that



are broader than deterioration alone).

- One study reported 69 calls in 6 months with broader criteria for calls (based on deterioration, communication breakdown, concern about care). This process used hospital administrative associate manager as first response.

Additional points from Gill 2016b discussion paper: refers to this review and implications of the findings:

- It will be important in future studies to measure outcomes relevant to families and patients, such as satisfaction after implementation of patient/family-initiated escalation of care. This was not commonly measured by the included studies (4 only), but family members reported feeling reassured that the service was available, and high satisfaction levels, whether or not they had actually made use of the escalation service.
- Future evaluations need to ensure that the intervention reaches those who are the target (ie patients and

families). Does of intervention and fidelity are two further important features needing consideration.

- An important point for future evaluations is that patients/ family members need not only to be aware of the presence of an escalation service but also of the process for escalating care (ie they need to be able to action the care escalation if needed). No studies have been identified about the best ways to inform patients/ family members about how to escalate care.
- Any patient/ family-initiated escalation of care systems need to consider cultural diversity (ie CALD populations) and how to meet the needs of all families in hospital, not just those who are best able to make use of services (eg those with lower health literacy).
- Barriers and facilitators to use of patient/ family initiated escalation of care functions need to be systematically assessed and used to develop evidence-based implementation approaches.

## Van Voorhis 2009

Van Voorhis KT, SchadeWillis T.  
Implementing a Pediatric Rapid Response  
System to Improve Quality and Patient  
Safety; *Pediatr Clin N Am*; 2009; 56; 919–  
933

doi:10.1016/j.pcl.2009.05.017.

To discuss the evidence  
underpinning RSS  
systems in hospitals  
(adults and paediatric  
patients) and to outline  
some of the main  
features of case studies  
of paediatric RSS  
systems with family-  
initiated activation.

Searches unclear; no  
systematic searching.

Unpublished findings and  
published reported.

Focus is case studies in  
paediatric hospitals (USA).

No. included studies: unclear.

Paediatric.

Quality of review: N/A (narrative;  
no methods reported)

Quality included studies: not  
discussed but likely low, given  
ratings by other reviews which  
also include these studies.

[note Dean 2008 is one of the  
cited case examples, also

- One of the two case studies described (Levine Children's Hospital) encourages family members to notify staff immediately if they are concerned about their child.
- After the first year of implementation, family concern was one of the reasons for activation of the paediatric RSS in 8% of cases; more than half required transfer to ICU.
- Subsequently implemented across the institution, where family member can directly activate the RRT (same mechanism as staff).
- At other case study site, medical staff were concerned that family activation would overwhelm the system with non-emergent situations. Focus groups, communication, followed by a pilot of family activation on two units reassured staff. Includes the rule 'no false alarms', reinforces that any serious concern (family member of medical team) is an appropriate reason for system activation.
- On admission, patients and family members are educated about the RRT (nurse); supported by staff education and mock scripts, bilingual flyers in visiting areas and waiting rooms, electronic chart education and nurse

included in Albutt 2017; Gill 2016]

Other notes:

- Paediatric RRSs have been evaluated using many different outcomes; there is need for further recommendations re standardised outcome measures.
- Two case studies described of implementation of RRT (provider-initiated): outcomes included increased days between cardiac arrests (non ICU); decreased median time of instability before assessment by ICU personnel; increased direct activation of early response team.
- Assessment of family member understanding showed poster alone insufficient education; many families did not read the information unless prompted to do so by their nurse, but without poster may be difficult for families to remember what number to call.
- Since introduction, mean number of RRT calls has increased from 16 to 24 calls per 1000 discharges. Number of RRS calls made directly by family is very low; many prefer a staff member to call on their behalf.
- Family concern continues to be a reason for RRS activation in 6% of calls.
- Education for patients/ families about RRS helps to move towards recognition of family members as critical member of the medical team.

reminders, and large colourful, bilingual poster in each patient room. Tear-off card for non-English speaking families accompanies the poster. Information on RRT also included in hospital guide given to families upon admission.

## Vorwerk 2015

Vorwerk J, King L. Consumer participation in early detection of the deteriorating

To assess the effects of consumer early recognition and response to patient deterioration via RSS activation, in terms of

2006 to 2014

English language only

Thematic analysis identified 4 major themes:

|   |  |  |   |
|---|--|--|---|
| patient and call activation to rapid response systems: a literature review. | patient outcomes, consumer knowledge and staff knowledge and satisfaction. | Published only   | <i>Call activation and outcomes</i>   |
| Journal of Clinical Nursing; 2015; 25 (1-2): 38-52.                         |  | 11 included studies  | <ul style="list-style-type: none"> <li>All 11 studies reported data on this theme</li> <li>Number of patient/family activated calls: small increase after implementation (0.08 to 2.46 calls/month)(10 studies), higher rates in 1 study (11.5 calls/month).</li> <li>Also increased staff-activated calls, ranged from small increase (2.34/month) to large increase (146/month) [pre to post implementation]. Three studies reported increases in staff-activated calls in response to family concerns; one other reported increased staff-activated calls but family concerns was identified as reason in 5%.</li> <li>Transfer to higher level of care reported in 5 studies; wide range of estimates (from 0-100% but absolute numbers were typically low). One study reported increase transfer (12.8 to 45.4/month) resulting from both staff and consumer-activated RRS calls.</li> <li>Two studies reported clinical outcomes: one reported decreased mortality (from 31 per 1000 discharges with RRS programme to 22.9/1000 discharges for RRS programme with consumer activation); the other reporting reduced non-ICU code</li> </ul> |
| Systematic review with thematic analysis of studies                         |  | 10 (USA), 1 (UK)   |   |
|   |  | [survey, chart review, audit, process evaluations]   |   |
|   |  | 10 related to patient/ family call activation of RRS (across units/ hospitals); 1 on consumer call activation after discharge from ICU to hospital unit.   |   |
|   |  | [note: 9/11 included studies are also included in the reviews by Albutt 2017 and/or Gill 2016. Zix 2012 and Bybee 2008 are unique to this review but note both studies were reported very briefly and decisions about rigour difficult for the review authors to make] |   |
|   |  | Quality of review: 5/9 <sup>#</sup>  |   |

numbers and increased survival following codes.

Quality included studies:

Critical appraisal using Long's (2002) tool for mixed methods studies. 2/11 studies met 9/9 quality criteria; remaining 9 had limitations but were judged as sound and consistent with the findings of the 2 most robust studies.

*Consumer knowledge and satisfaction with programme*

Other notes:

- Clear messages about when, to whom, and how to report concerns is important.
  - Criteria used as a basis for consumers to activate calls were variable, often not replying on physical criteria. Clear criteria for consumers are needed.
  - Successful implementation of consumer-activated RRS calls relied on hospital education of consumers; may require multiple formats/ modes; may need co-development or close
- All 11 studies reported data on this theme
  - Six studies reported mixed results in terms of consumer knowledge levels of whom, how and when to activate RRS call. 3 studies reported high levels consumer understanding of information provided (76-100%). Others reported lower mean understanding levels, or lower levels of increases, with variability; another reported high levels of understanding how to activate RRS initially (85%), recall was subsequently poor (18%).
  - Reasons for consumers to activate RRS call were most often related to management/ communication of care or deterioration.
  - Management/ communication included a number of reasons, including pain management and care coordination or planning most frequently. Communication issues were often cited as reason for other concerns, as was dissatisfaction or conflict with staff

collaboration with consumers.

- Health professional education on content and delivery of consumer information was critical.
- Translation to non-English languages has lagged behind.
- Formal evaluation of consumer programmes is needed, incorporating measures not only on satisfaction but outcomes such as knowledge.

responses or delays in services or assessment.

- Concern often expressed as 'something doesn't feel right', with breathlessness the most often-described symptom.
- Three studies reported consumers appreciated increased knowledge of possibly changing physical signs taught to them by staff.
- Consumer satisfaction: 7 studies reported positive responses from callers including satisfaction, sense of safety/ empowerment with consumer-activated RRS. High rates of satisfaction with the programme was also noted by 5 studies (84-100%), with one further reporting families were satisfied with the knowledge that they were able to contact the RRS.

*Programme content – delivery of education on consumer involvement*

- All 11 studies reported data on this theme
- Education and training of staff: 8 studies provided wide range of materials; 4 provided comprehensive staff education packages, additions to which included checklists, reminders, talking points, completion of self-learning modules. Programmes

included individual and small group meetings, personal communications and shift change huddles. Five described using scripted narratives to help deliver consumer information; another study undertook staff-wide education based on communication toolkit. Hospital bulletin board notices, monthly newsletters, weekly news briefs and intranet education were used in 3 studies to promote staff education.

- Consumer education by nurses:
  - All studies educated consumers on admission, orientation to the unit or before transfer to ward (from ICU); concern about the patient was a requirement for calling in all studies, only 2 educated on specific signs (eg heart or respiratory rate, mental status, agitation).
  - Different approaches were used across studies, including: daily rounds, information sheets with FAQs, verbal and written information with reiteration by nurses, continually encouraging consumers to relay concerns, likening activation of RRS as similar to calling 911 from home, electronic chart



reminders with explanation by nurses.

- One study reported the need for survey to assess programme understanding and provide opportunity for re-education (highlighting that use of additional educational opportunities after admission improved retention of information).
- One study specifically addressed information needs on non-English speakers, providing information through translator at admission, Spanish information card to hand to an English speaker to activate RRS call.
- Mode of information for consumers:
  - All studies provided printed educational materials together with verbal explanation on consumer activation and RRS.
  - Delivery mode included nurse explanation plus other materials (eg education packages, information sheets, posters, flyers, brochures, FAQ sheets- and/or video-based approaches), outlining signs to watch for and how to escalate concern.

- Admitting nurse providing one-to-one verbal information was reported as critical; 10 studies highlighted this plus written materials to support key details of the programme; these often included posters showing early signs for consumers to be alert for (throughout hospital and across hospital beds); one study had bilingual (English and Spanish) tear-off cards in all bed units.
- Several studies provided videos (rationale and case examples) of activation following patient deterioration. Issues not to be managed through RRS activation were highlighted in 3 studies; 2 planned further information to be provided through TV-based education; 1 provided phone stickers with instructions on how to activate RRS call.

*Staff concerns with consumer involvement programmes*

- Inappropriate calls overwhelming system:

- Inappropriate calls overwhelming system identified as common shared concern of nursing and medical staff before programme introduction (6 studies); family activated call overloading system (4 studies).
- Communication about the programme to dispel staff concerns about inappropriate activation of system used in 6 studies; one promoted 'no false alarms'.
- Increased staff workload: concern expressed about time needed to educate patients/ families on process (1 study); one feasibility study reported minimal workload increase with programme introduction.
- Undermine professionals' judgement: physicians and nurses expressed concern that their patient care approach would be undermined (1 study); another described nurses' fear of scrutiny of their patient care; one further addressed these concerns by highlighting that the programme added to care rather than focusing on identifying poor staff practices.
- Staff confidence and receptivity: two studies explored these aspects but with unclear results; one reporting that

providing a FAQs sheet improved staff confidence and delivery of information.

Quality of review assessed using the AMSTAR scale (scoring 0-11, where 11 is highest quality, or 0-9 where 9 is the highest quality) or AMSTAR II tool (scoring 0-13, where 13 is highest quality).

\* For reviews marked with \* we adopted the quality assessment ratings (AMSTAR II tool) given in the following report: Lennox A, Wright B, Bragge P. How can we improve escalation of patient deterioration in the hospital setting? Briefing Document. Melbourne, Australia: BehaviourWorks Australia, Monash University. November 2018. ISSN: 2208-5165

# For reviews marked with # we adopted the quality assessment ratings given by Health Systems Evidence ([www.healthsystemsevidence.org](http://www.healthsystemsevidence.org)), which are performed by McMaster University and are available online.

PSP: Patient safety practice

RRS/T: Rapid Response System/ Team (used interchangeably)

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## APPENDIX 1D UNIQUE PRIMARY STUDIES IDENTIFIED FROM INCLUDED REVIEWS

Baird SK & Turbin LB. Condition concern: an innovative response system for enhancing hospitalized patient care and safety. *Journal of Nursing Care Quality*. 26: 199–207.

Bogert SC, Ferrell C & Rutledge DN. Experience with family activation of rapid response teams. *Medsurg Nursing*; 2010; 19, 215–222.

Brady PW, Zix J, Brilli R, et al. Developing and evaluating the success of a family activated medical emergency team: a quality improvement report. *BMJ Qual Saf*. 2015; 24: 203-11.

Bybee D Family activation of the rapid response team. *Critical Care Nurse*. 2008; 28(2): e8.

Dean BS, Decker MJ, Hupp D, Urach AH, Lewis E, Benes-Stickle J. Condition help: a pediatric rapid response team triggered by patients and parents. *J Healthc Qual*. 2008; 30: 28–31.

Dunning E, Brzozowicz K, Noel E, O’Keefe S, Ponischil R, Sherman S, et al. FAST track beyond RRTs. *Nursing Management*. 2010; 41: 38–41.

Gerdik C, Vallish RO, Miles K, Godwin SA, Wludyka PS, Panni MK. Successful implementation of a family and patient activated rapid response team in an adult level 1 trauma centre. *Resuscitation*. 2010; 81: 167616–81.

Greenhouse PK, Kuzminsky B, Martin SC & Merryman T. Emergency. Calling a condition h(elp): one facility gives patients and families the ability to summon a rapid response team. *American Journal of Nursing*. 2006; 106: 63–6.

Hueckel RM, Mericle JM, Frush K, Champagne MT. Implementation of condition help family teaching and evaluation of family understanding. *J Nurs Care Qual*. 2012; 27: 176–181.

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Odell M, Gerber K, Gager M. Call 4 concern: patient and relative activated critical care outreach. *Br J Nurs*. 2010; 19: 1390–5.

Ray EM, Smith R, Massie S, et al. Family alert: implementing direct family activation of a pediatric rapid response team. *Jt Comm J Qual Patient Saf*. 2009; 35: 575–80.

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Wellard, S., et al. "Consumer participation in acute care settings: an Australian experience." *International Journal of Nursing Practice*. 2003; 9(4): 255-260.

## APPENDIX 3.1 – CONSULTATION LIST

| Name            | Organisation   | Position  | Date     | Format                  | Topics   |
|-----------------|--|---|----------|-------------------------|--|
| Naomi Poole     | Australian Commission on Safety and Quality in Health Care               | Director, Partnering with Consumers             | 15/01/19 | Phone                   | Consumer-initiated escalation  |
| Anne Muldowney  | Carers Victoria  | Senior Policy Advisor                           | 3/12/18  | Phone                   | Issues and priorities related to carers in escalation processes                              |
| Bronwen Merner  | Centre for Health Communication and Participation, La Trobe University   | Research Fellow                                 | 13/11/18 | Meeting                 | Carer experience with care and escalation, key thesis findings and use of case studies       |
| Bradley Lloyd   | Clinical Excellence Commission, NSW Health                               | Program Coordinator, Patient Centred Care       | 18/12/18 | Phone                   | R.E.A.C.H  |
| Shaune Gifford  | Patient Safety and Quality Improvement Service, QLD Department of Health | Principal Project Officer, Programs Team        | 4/01/19  | Phone                   | Ryan's Rule  |
| Jo Miller       | Safer Care Victoria  |   | 27/11/18 | Phone                   | Establishing the Western Health escalation program   |
| Louise McKinlay | Safer Care Victoria  | Director of Consumers and Partners              | 15/11/18 | Briefing meeting        | Patient, carer and family involvement in escalation, project plans and expectations          |
| Vickie Veitch   | Safer Care Victoria  | Principal Policy Advisor, Consumers as Partners | 15/11/18 | Briefing meeting, phone | Patient, carer and family involvement in escalation, project plan, expectations and progress |
| Khanh Do        | Western Health   | Manager, Consumer Partnerships and Diversity    | 4/12/18  | In person               | Western Health escalation, CALD community engagement and considerations                      |
| Lindy King      | University of South Australia  | Senior Lecturer, Division of Health Sciences    | 13/12/18 | Phone                   | You're Worried, We're Listening  |



## APPENDIX 3.2 – ADVISORY COMMITTEE MEMBERS

| Name              | Organisation        | Position  |
|-------------------|---------------------|---|
| Kirsten Weinzierl | Bass Coast Health   | Operations Manager                                      |
| Hilary Kerrison   | Bass Coast Health   | Consumer  |
| Anne Muldowney    | Carers Victoria     | Senior Policy Advisor                                   |
| Andrea Doric      | Eastern Health      | Clinical Lead, Clinical Deterioration and Resuscitation |
| Cherann Edwards   | Safer Care Victoria | Senior Project Officer, Consumers as Partners           |
| Vickie Veitch     | Safer Care Victoria | Principal Policy Advisor, Consumers as Partners         |
| Adriana Mulla     | Western Health      | Consumer  |
| Khanh Do          | Western Health      | Manager, Consumer Partnerships and Diversity            |

## APPENDIX 4 – SUMMARY OF LINKS BETWEEN NSQHS STANDARDS AND HEAR ME

### SUMMARY OF KEY LINKS BETWEEN NSQHS STANDARDS AND HEAR ME ESCALATION

#### STANDARD 1: CLINICAL GOVERNANCE

Escalation and strengthening partnering in health care approaches can only be achieved with strong leadership at all levels of a health service. It will require cultural and organisation change over the long-term as systems and quality and safety processes adapt to patient centred care

- Know how consumer partnerships and communication with consumers is integrated and implemented as part of the clinical governance frameworks at all services.
- Services measure and understand the differences in approach, impact and need of their diverse populations

#### STANDARD 2: PARTNERING WITH CONSUMERS

- HEAR ME promotes the empowerment and strengthening of consumer confidence to engage as partners in care – including the design of escalation processes, measuring of impact and as partners in their own care. It does not enforce a partnership, but is an opportunity for building relationships with a phone number that helps make existing safety mechanisms even safer if there are ongoing concerns about care, communication and a patient's clinical well-being.

#### STANDARD 5: COMPREHENSIVE CARE

- Development and delivery of comprehensive care needs to involve collaboration with patients, carers and families.

#### STANDARD 6: COMMUNICATING FOR SAFETY -

- As reflected in Actions 6.7, 6.8, 6.10 the standards describe involving patient and carers and involved in handover communication and are aware or understand decisions, options and discharge plans.
- Ensuring all relevant information about a patient's condition are recorded in health records (Actions 6.11)
- Implementing actions to ensuring adequate information is included in medical records for a patient, including current communications about care
- Identifying what, when and how to communicate critical information to patients and carers and who they can communicate with if concerned (Action 6.10)

#### STANDARD 8: RECOGNISING AND RESPONDING TO ACUTE DETERIORATION

- Protocols are in place to escalate care when needed and include responding to patient, carer and family member subjective concerns about a patient's care, condition or well-being. Relevant actions are 8.6, 8.7, 8.8
- Recommendations for strategies to improve escalation under Action 8.9 clearly indicate educating clinicians is critical to strengthening protocols and implementation of escalation. This includes communication skills, roles and capacity of responders and establishing criteria for patient pain and distress if how to respond if a patient or family member asks for help.

## APPENDIX 5 – QUALITY ACCOUNT MAPPING OF VICTORIAN CONSUMER INITIATED ESCALATION PROCESSES

### Source: Quality Accounts (2017/18)

Note: The table summarises the information provided in the 2017/18 Quality Accounts related to patient, carer or family initiated escalation. Reporting was discretionary and as such this is not a representation of all escalation efforts that exist in Victoria.

| Health Service          | Program name                                    | Evaluation/review?  | Phone number? | Steps   | Staff Education approach                      | Promotion approach   | Other Quality Account notes  |
|-------------------------|---|---|---------------|---|---|--|--|
| Alfred                  | Let Me Know                                     | No mention in QA but have seen an earlier presentation describing review results. | 1800 901 445  | 1. Talk to nurse;<br>2. Talk to doctor<br>3. Make call - team will respond within 15 minutes. | Not reported                                  | Not reported   | Reported 45 calls received in 2017/18. Patient Experience Feedback indicated 71% were able to raise concerns with a staff member.  |
| Austin Health           | PACE  | Yes - survey  | Yes           |   | Campaign to educate clinicians (post survey). | Posters, educate clinicians.   | 15 calls during 2017/18. Surveyed 122 patients with only 30% recognising PACE process but of those that did, they overwhelmingly felt it would meet their needs. Changes to promotion materials were made as result of survey. |
| Western Health          | Call for Help: if you're worried, we're worried | Yes (report not accessed). Regularly reviews call and feedback data.              | Yes           | 1. Talk to your nurse or midwife<br>2. Talk to nurse in charge<br>3. Make a call.             | Not reported                                  | Posters, online video, banner at entrance, brochures in health information centre. | Reported 56 calls received since Nov 2016.   |
| Albury Wodonga Health   | R.E.A.C.H                                       | Not reported  | Not reported  | Not reported  | Not reported                                  | Not reported   |  |
| Ballarat Health Service | R.E.A.C.H                                       | Not reported  | Not reported  | Not reported  | Not reported                                  | Not reported   |  |

| Health Service                | Program name   | Evaluation/review? | Phone number?   | Steps  | Staff Education approach   | Promotion approach   | Other Quality Account notes  |
|-------------------------------|----------------|--------------------|-----------------|--|--|--|--|
| East Grampians Health Service |                | Not reported       | Not reported    | 1. Talk to nurse or doctor<br>2. Talk to nurse in change of shift<br>3. Contact the Nurse Supervisor.  | Onsite training of staff to handle patient concerns and request for escalation (in-patient and residential). | Posters, information at admission, and brochure in patient folder. |  |
| Northeast Health Wangaratta   | No name        | Not reported       | Not reported    | Call Nurse Supervisor  | Not reported   | Not reported   |  |
| Castlemaine Health            | REACH          | Not reported       | Yes             | Not reported   | Not reported   | Brochure   |  |
| Barwon Health                 | PACE           | Not reported       | Internal: 444   | 1. If you notice a worrying change, alert the nurse in charge and request a review.<br>2. Still concerned, call 444 from any Barwon Health phone to activate the MET team. | Not reported   | Not reported   | Patient experience survey 2017/18 showed that patients want to be more involved in their healthcare. |
| Royal Eye and Ear Hospital    | REACH          | Not reported       | Not reported    | Not reported   | Not reported   | Not reported   | Reported that no patients or families have used the service yet.                                     |
| Bairnsdale Health             | MET activation | Not reported       | Yes             | 1. Talk to your nurse<br>2. Talk to your doctor<br>3. Call for MET.  | Not reported   | Not reported   | Not activated frequently but when has been used feedback has been positive.                          |
| Peninsula Health              | Care Call      | Not reported       | Internal: 43499 | 1. Talk to your nurse<br>2. Talk to your doctor<br>3. Make a CARE call.  | Not reported   | Not reported   |  |

| Health Service                   | Program name                                 | Evaluation/review? | Phone number? | Steps  | Staff Education approach  | Promotion approach  | Other Quality Account notes  |
|----------------------------------|--|--------------------|---------------|--|---|---|--|
| Peter Mac                        | Patient Emergency Escalation Response (PEER) | Not reported       | Yes           | 1. Speak to nurse<br>2. Speak to nurse in charge<br>3. Call PEER.                                    | Not reported  | Printed materials – multilingual.<br>Translated materials only say – Tell us if they are getting worse since they arrive. Does not promote the call.<br>All language translations combined on one page. |  |
| Mildura Base Hospital            | Ramsay Rule                                  | Not reported       | Call 50223343 | 1.Talk to your nurse<br>2. Talk to the nurse in charge.  | Trained in what Ramsay's Rule is and their role in a Call for Help. | Posters in foyers, rooms and clinical hallways.   | In place since 2017.<br><br>Hospital Access Manager answers the call.  |
| Central Gippsland Health Service | Feeling Worse? Call the Nurse                | Not reported       | Not reported  | 1.Speak to your nurse<br>2. Speak to the nurse in charge<br>3. Call the nurse coordinator.           | Not reported  | Not reported  |  |
| Swan Hill District Health        | Felling Worse? Call the Nurse                | Not reported       | Not reported  | 1.Talk to nurse or family member<br>2. Talk to nurse in charge<br>3. Call for MET.                   | Not reported  | Not reported  | Based on and acknowledges REACH  |
| West Gippsland Healthcare Group  | REACH  | Not reported       | Not reported  | R: Recognise deterioration<br>E: Engage with staff<br>A: Ask for a Clinical Review<br>C: Call for... | Not reported  | Posters in wards.<br><br>Information provided on admission.   | Redefined REACH steps from NSW version.<br><br>Initially for paediatric unit then rolled out to surgical, medical and maternity Units. |

| Health Service             | Program name                  | Evaluation/review?   | Phone number? | Steps   | Staff Education approach | Promotion approach    | Other Quality Account notes  |
|----------------------------|-------------------------------|--|---------------|---|--------------------------|-----------------------|--|
|                            |                               |  |               | H: Help to activate a response.   |                          |                       |  |
| Alexandra District Health  | Feeling Worse? Call the Nurse | Not reported   | Not reported  | 1. Encouraged to speak to a nurse or the nurse in charge<br>2. If required their GP is called to the bed. | Not reported             | Not reported          |  |
| Bass Coast Health          | REACH                         | Not reported   | Call 56713384 | 1. Speak to a nurse or doctor<br>2. Call the REACH number and request a Clinical Review.                  | Not reported             | Not reported          | Clinical Review team should be at bed within 30min.  |
| La Trobe Regional Hospital | REACH                         | Noted that patients and carers are not aware of process/number in surveys. | Not reported  | Not reported  | Not reported             | Posters and brochures |  |
| Royal Eye and Ear hospital | REACH                         | Not reported   | Not reported  | Not reported  | Not reported             | Not reported          | Implemented Jun 2017, not used at time of QA reporting.                                      |
| Beechworth Health Service  | No name                       | Not reported   | Not reported  | Not reported  | Not reported             | Not reported          | Quality Account indicates patients and carers can initiate escalation if they are concerned. |

| Health Service                      | Program name                                 | Evaluation/review? | Phone number? | Steps   | Staff Education approach | Promotion approach  | Other Quality Account notes   |
|-------------------------------------|--|--------------------|---------------|---|--------------------------|---|---|
| Benalla Health                      | No name                                      | Not reported       | Not reported  | If concerned inform your nurse or the nurse in charge and the patient will be reviewed.                 | Not reported             | Not reported  |   |
| Djerriwarrh Health Service          | Not reported                                 | Not reported       | Not reported  |   | Not reported             | Not reported  | No mention in Quality Account. Does describe training provided for staff in ViCTOR and Track and Trigger              |
| Kyabram District Health Service     | Not reported                                 | Not reported       | Not reported  | Encourage patients to "talk to us" if they have a concern or worry.                                     | Not reported             | Posters and journey boards.<br><br>Focus months on display boards etc encouraging patients and families to ask questions. |   |
| Maryborough District Health Service | PACE - Patient and Carer Escalation          | Not reported       | Not reported  | Call a senior nurse using escalation number if there is a concern/request for escalation.               | Not reported             | Not reported  |   |
| Numurkah District Health Service    | 'Alert Check Talk (ACT) - We listen, we care | Not reported       | Not reported  | Not reported  | Not reported             | Not reported  | Encourage patients and family to raise concerns.  |
| Omeo District Health                | Not reported                                 | Not reported       | Yes           | 1. Have you talked to your nurse?<br>2. Still concerned then make a call and ask for a clinical review. | Not reported             | Posters with information about escalation and steps.  | Provides 2 internal bed phone contact numbers and 1 number from mobile. Also indicates different staff they can call. |

| Health Service                     | Program name  | Evaluation/review?                                    | Phone number? | Steps  | Staff Education approach | Promotion approach                     | Other Quality Account notes  |
|------------------------------------|---|---|---------------|--|--------------------------|--|--|
| Orbost Health                      | Not reported  | Not reported  | Not reported  | Press the buzzer and ask to see a nurse or/then ask to see a doctor. | Not reported             | Not reported                           | They ask their patients if they know how to escalate with 100% accuracy response.  |
| Robinvale District Health          | Not reported  | Not reported  | Not reported  | Not reported   | Not reported             | Not reported                           | Trained in ViCTOR  |
| Seymour Health                     | Feeling Worse? Call the Nurse                           | Not reported  | Not reported  | Not reported   | Not reported             | Posters and informed during admission. | Reported call rate, but no details on purpose and outcomes of calls.   |
| South Gippsland Hospital           | Alert Check Talk  | Not reported  | Not reported  | Not reported   | Not reported             | Not reported                           | Patient and family escalation represents the principle of 'partnership' and recognises families as key members of the care team. |
| Yarrawonga Health                  | Not reported  | Not reported  | Yes           | Not reported   | Not reported             | Not reported                           |  |
| Yea and District Memorial Hospital | REACH: Recognise, Engage, Act, Call, Help is on its way | Not reported  | Not reported  | Not reported   | Not reported             | Not reported                           | Reported non staff initiated call rate (0)   |
| Beaufort & Skipton Health Service  | Are You Worried?  | Not reported  | Not reported  | Call contact number for senior person if worried.                    | Not reported             | Posters                                |  |
| Cobram District Health             | REACH   | Annual audit and review of all escalation incidences. | Not reported  | Not reported   | Not reported             | Not reported                           | 100% of senior medical staff have completed Advance Life Support training and 85% of nursing staff and 4 GPs.                    |



| Health Service                            | Program name                          | Evaluation/review? | Phone number?                    | Steps  | Staff Education approach | Promotion approach                               | Other Quality Account notes   |
|---|---------------------------------------|--------------------|----------------------------------|--|--------------------------|--|---|
| Cohuna District Hospital                  | If you are worried, we are worried    | Not reported       | Not reported                     | Not reported   | Not reported             | Patient information booklet; posters at bedside. | Monthly audit of alerts including unplanned Readmissions < 28 days, all inpatient and Urgent Care Centre transfers from Cohuna District Health. |
| Kyneton District Health Service           | REACH                                 | Not reported       | Not reported                     | 1. Tell the nurse<br>2. Tell senior nurse/nurse in charge<br>3. Press the emergency button by the bed. | Not reported             | Posters by bedside.                              |   |
| Lorne Community Hospital                  | No name                               | Not reported       | Not reported                     | 1. Ask to speak to the nurse in charge<br>2. Request to be seen by a doctor to the nurse in charge.    | Not reported             | Not reported                                     | No-one used process in 2017/18 period.  |
| Moyne Health Services                     | No name                               | Not reported       | Not reported<br><br>Not reported | 1. Encourage to talk to staff for early detection<br><br>2. Press patient call bells if concerned.     | Not reported             | Communication Boards in patient rooms.           |   |
| Otway Health and Community Services (MPS) | Patient or carer escalation flowchart | Not reported       | Not reported                     | 1. Speak to nurse in charge about concern<br>2. Ask to speak to a doctor.                              | Not reported             | Not reported                                     |   |

| Health Service                                | Program name | Evaluation/review? | Phone number? | Steps  | Staff Education approach | Promotion approach | Other Quality Account notes   |
|---|--------------|--------------------|---------------|--|--------------------------|--------------------|---|
| Stawell Regional Health                       | No name      | Yes                | Not reported  | Not reported   | Not reported             | Not reported       | Past process was reviewed and found to be too confusing. New system being designed in collaboration with consumers. |
| Tallangatta Health Service                    | Speak Up     | Yes                | Not reported  | Not reported   | Not reported             | Posters            | Patient discharge phone survey indicated 100% were aware of system.   |
| Timboon and District Healthcare Service (MPS) | No name      | Not reported       | Not reported  | Inform nurse responsible for care who will inform nurse in charge of concerns. | Not reported             | Not reported       |   |

## APPENDIX 5 - RAPID REVIEW ADVISORY COMMITTEE COMMENTS AND RECOMMENDATIONS

Recommendations the Advisory Committee requested be reflected in the HEAR ME framework and report included:

| Theme   | Comments and recommendations  |
|---|---|
| <b>Communication messaging</b>                      | <ul style="list-style-type: none"> <li>• Emphasis on “All concerns are valid” as an important message to be communicated to patients, carers and family members and health services.</li> <li>• Ensure non-medical or non-academic language is used when communicating with consumers.</li> <li>• Utilise community networks and their partnerships with health services to promote escalation options.</li> <li>• Feedback loop needs to be complete for all calls. Consideration should be given to ensuring callers/initiators of escalation are responded to and followed up.</li> <li>• Importance that communication is standardised, consistent and simple to meet the needs of a mobile/transitory population that use multiple health services.</li> </ul>   |
| <b>Training and development</b>                     | <ul style="list-style-type: none"> <li>• Health services consider integrating within existing competency training requirements and initiatives modules about consumer participation in care, escalation and HEAR ME. Modules are recommended to include comprehensive communication skills training, familiarity with escalation steps/process and ability to respond to an escalation request or notification.</li> </ul>  |
| <b>Escalation process structure</b>                 | <ul style="list-style-type: none"> <li>• As the 3rd stage in a 3-step escalation process, HEAR ME supports health service to implement required criteria of the national standards while ushering in guidance that will support consistency in approach, expectations and opportunities for escalation for all Victorians at all health services. Ultimately, HEAR ME helps make safe systems safer.</li> <li>• Ensure HEAR ME provides consistency in expectations, process and understanding of actions for all Victorians regardless of how many different health services they may have or will attend.</li> <li>• Escalation processes will need to be sensitive to ensuring rapid response times are met and any obstacles that may slow down notification and response are identified and resolved quickly and efficiently.</li> </ul> |
| <b>Data collection and application</b>              | <ul style="list-style-type: none"> <li>• Ensure data and information are being collected and analysed to explore how HEAR ME could be adopted for other health sector services.</li> </ul>  |
| <b>Participation and partnership with consumers</b> | <ul style="list-style-type: none"> <li>• Co-design of local patient-initiated escalation response processes, and guidance for the messaging of promotion materials are critical and must be representative of the diverse background and identities of consumers (including CALD, ATSI and LGBTIQ+ as well as those with direct experiences of escalation and differing levels of health literacy).</li> </ul>  |
| <b>Champions for escalation</b>                     | <ul style="list-style-type: none"> <li>• Champions at all levels of a health service, including consumer champions will be critical to successful implementation and promotion.</li> </ul>  |