



## Research article

## Patient and/or family activated rapid response service: Patients' perceptions of deterioration and need for a service

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## ABSTRACT

**Background:** Patient and/or family activated escalation may improve care to deteriorating patients. However, limited literature describes patients' and families' experience of deterioration and what barriers might restrict call activation.

**Objective:** This study explored patients' and families' experiences of acute ward deterioration, their perception of a need for a patient and/or family activated escalation service and barriers that may prevent them from using it.

**Design:** Using a qualitative cross sectional research design and a co-design approach, data were collected using face-to-face semi-structured interviews, field notes and reflective journaling. Between December 2015 and February 2016, purposeful sampling recruited 41 adult ward patients and family who either experienced a recent Medical Emergency team (MET) or Patient at Risk team (PART) escalation, or no recent MET or PART escalation.

**Findings:** Themes included: (1) patient awareness of their illness and deterioration, (2) the importance of returning to their normal lives, (3) reassurance on arrival of the PART and MET, (4) beliefs held to prevent use of such a service, and (5) support for a patient and/or family activated escalation service.

**Conclusion:** Most participants supported a patient and/or family activated escalation service, however barriers may prevent some patients from using it.

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## Implications for clinical practice

- Patients are aware of their illness and their deterioration.
- Patients and families perceive that concerns related to their deterioration are not being heard.
- Patients should be informed when their care has been escalated.
- Most patients and families support a patient and/or family activated escalation system however cultural and personal beliefs may prevent some from using it.

## Introduction

Patients in hospital wards may experience potentially avoidable physiological deterioration which can result in unplanned admissions to intensive care, cardiac arrest and/or death (Beaumont et al., 2008). Internationally and nationally this has led to the

implementation of track and trigger systems, such as early warning scores (EWS), in conjunction with the activation of appropriately trained responders, such as a rapid response team (RRT) (Barrett et al., 2018; Smith et al., 2013). Although deterioration can often be predicted by close observation of vital signs, these are not always recognised or appropriately acted upon (Currey et al., 2018; Gill et al., 2016a; Quirke et al., 2011). This has led to an increasing emphasis on enabling patients and families to escalate their concerns to reduce adverse events (Dean et al., 2008;

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Gerdick et al., 2010; Greenhouse et al., 2006; Odell et al., 2010). This is based on the premise that patients and relatives often recognise changes in their condition before medical and nursing staff (Rainey et al., 2013; Vorwerk and King, 2015).

Internationally, initiatives providing patients or their families with a mechanism to seek assistance if they are concerned about deterioration of themselves or a family member have been introduced initially, in the paediatric setting (Brady et al., 2014; Dean et al., 2008; Greenhouse et al., 2006; Hueckel et al., 2012; Ray et al., 2009) and later, in adult wards (Gerdick et al., 2010; McCawley et al., 2013). These include patients or family members mobilising a rapid response team (RRT) (Brady et al., 2014; Vorwerk and King, 2015) or having direct access to a critical care outreach service (CCOS) or similar services (Brady et al., 2014; Odell et al., 2010; Vorwerk and King, 2015). Evaluation of these strategies has occurred predominantly post-implementation, with some described as having poor post implementation data analysis (Gill et al., 2016a) and others focusing on the appropriateness of calls made, rather than why calls were not made (Berger et al., 2014). Currently there is insufficient evidence demonstrating a patient and/or family activated escalation service (PFAES) is the most effective way patients and relatives can prevent patient deterioration (Albutt et al., 2016; Gill et al., 2016b).

Studies found that PFAESs, although valued by patients and their families, were not heavily utilised and had little impact on overall emergency calls, admissions into intensive care (Bogert et al., 2010; Brady et al., 2014; Gerdick et al., 2010; Vorwerk and King, 2015) or patient safety (Berger et al., 2014; Gill et al., 2016b).

Under-utilisation of PFAES may be due to barriers preventing patient and/or families initiating calls (Ray et al., 2009). Barriers identified include: illness severity, with the patient being too ill to notice and/or report or remember acute deterioration (Guinane et al., 2018; Rainey et al., 2013); self-perception of being subordinate to clinicians and an unwillingness to challenge staff (Albutt et al., 2016); unwillingness to either overburden busy staff or bypass known/trusted staff (Gerdick et al., 2010; Guinane et al., 2018; Vorwerk and King, 2015) and lack of resources to expedite effective care (Berger et al., 2014; Rainey et al., 2013). More recently, Guinane et al. (2018) identified that although patients identified a change in their condition, they felt they did not have the knowledge to trigger a RRT call and would be reluctant to over-ride nurses' decisions by activating a call.

Recent research identifies families often activated calls that were unrelated to deterioration, such as communication issues (Albutt et al., 2016; Gill et al., 2016b) or about how care was being given (Bogert et al., 2010). Gill et al. (2016b) emphasise that it is critical to determine the reason for the call; if the call is not related to deterioration, a RRT may not be the most appropriate response.

This paper shares the results of a study investigating adult patients' and families' experiences of acute ward deterioration, their perception of a need for a PFAES. The rationale for the study was to identify patients' and families' perceived need for a PFAES and any barriers to them using it prior to designing and implementing a service in our hospital.

## Method

### Study design

This study used a qualitative cross sectional design incorporating a co-design approach to explore ward patient and family perspectives of: 1) recognising their acute illness and deterioration, 2) the need for a PFAES and 3) barriers that may prevent them from activating the service.

Co-design, also known as co-production, is described as an approach to "actively involve patients and staff in a process to ensure the results meets their needs and is usable" (Clarke et al., 2017, p. 2). It involves firstly capturing and understanding the patient experience, choosing what improvements to make and turning improvement ideas into action (Boyd et al., 2012). This study followed a pilot quality improvement project conducted on two wards that investigated nursing staffs' opinions on a PFAES. Following positive feedback from staff during this pilot, the patients and families perspectives for the need for a PFAES were sought.

Face to face interviews using a semi-structured questionnaire, field notes and reflective journaling collected qualitative data.

### Setting

The study was undertaken in a New Zealand 990 bed tertiary metropolitan hospital which has a 18-bed critical care complex; an established early warning score EWS; a 24 h a day, seven days a week (24/7) RRT known locally as the Medical Emergency Team (MET); and a 24/7 nurse led CCOS, known locally as the Patient at Risk Team (PART). The PART has a minimum of two nurses on duty each shift and respond to lower threshold Early Warning Scores (EWSs) than the MET; the PART are also members of the MET. The PART reviews adult ward patients over 18 years of age. Our hospital serves a population of 512,000, which is ethnically diverse; by 2020 our population is predicted to be 15% Maori, 22% Pacific, 26% Asian and 37% European.

### Participant selection

In line with the PART patient population, purposeful sampling recruited ward patients over 18 years of age who met the following inclusion criteria in one of three contexts: 1) ward patients referred to and reviewed by the PART, 2) ward patients who received a MET call and 3) patients who were currently in one of two pilot wards and were clinically progressing toward discharge. This latter group served as the control group to identify if there were differences between those progressing towards discharge and patients who had recently experienced deterioration necessitating a MET call and or PART review.

The exclusion criteria for participants were those who were confused and/or unable to provide informed consent and paediatric patients and their families. Because the study was confined to two pilot wards (one medical and one surgical), obstetric patients were also excluded. The PART notified the researchers of potential participants who met the inclusion criteria. These patients were then invited by the research team to participate in the study.

### Ethical considerations

Using the National Health and Disability Human Ethics Committee (HDEC) screening criteria, the study did not require their approval. The study was registered and approved by the hospital research office (Approval number 222) who agreed HDEC review was not required. This approval enabled collection of demographic data from patients' medical records.

All participants were given an information sheet about the study, which also included access to information about patient and/or family support, cultural support services, advocacy services and complaint processes. Patients and/or family members were asked whether they would like a support person present during interviews and interpreter or cultural support services were offered and provided where required. Patients' requests for family members to speak with them in the interviews were supported.

Participants provided verbal consent prior to data collection and were given the opportunity to withdraw from the study up to the time of data analysis. Patient/family confidentiality and anonymity was maintained throughout the study.

#### Data collection

Data were collected between December 2015 and February 2016 (inclusive). Patients and families were interviewed in a private or secluded site or in a place selected by them. Participants were asked questions from a semi-structured questionnaire dependent on their inclusion category. Data were recorded using handwritten notes; this method was used in preference to audiotaping to encourage patients of ethnicities (who may not have agreed to audiotaping) to participate in the research and enable the results to better represent our hospital population. To ensure internal validity, the researchers checked with the participant during and at the end of the interview that the interview transcript was accurate; Bengtsson (2016) describes this process as respondent validation. Following the interview, the researchers wrote field notes using reflective journaling to enable a richer description of the individual patients' and families' responses.

#### Data analysis

Responses from the interviews were coded into three identifying groups: 1) those that experienced a MET call were coded 'MET', 2) those that received a PART review were coded 'PART', and 3) participants from the ward control group were coded 'WARD'. Demographic data were described using count and percentages. Descriptive data were analysed using mean (M) and standard deviation ( $\pm$ ) for normally distributed continuous variables.

Data from the face to face interviews, field notes and reflective journaling were subjected to content analysis as described by Bengtsson (2016). Two researchers who did not participate in data collection separately read the interview transcripts several times to gain an understanding of the content prior to coding the data into subcategories. Three researchers discussed the transcript content and the two researchers' subcategories prior to gaining consensus on the categories. Finally, the three researchers reviewed the transcripts again to ensure the meaning within the transcripts accurately reflected the categories. We utilised manifest analysis when participant quotes were available by using participants' words to enable us to "stay closer to the original meanings and context" (Bengtsson, 2016, p. 12). Latent analysis was used for summarised data, which allowed the researchers to identify hidden meanings in the text (Bengtsson, 2016).

#### Findings

A total of 41 participants were recruited into the study; 14 participants were referred to and reviewed by the PART, 14 participants triggered a MET escalation and 13 participants were in the ward control group (see Table 1). Participants had a mean age of 59.3 years ( $\pm 17.8$ ) and were of ethnicities reflective of our hospital population (see Table 1). As shown in Table 1, more ( $n = 6$ , 42.9%) families of patients who had a MET call participated in the study at the patient's request. Data of all participants were included in the analysis. The time for each interview ranged between 30 and 60 min.

Content analysis identified five categories: 1) patients aware of their illness and deterioration, (2) recovering and returning to their normal lives, 3) relief on arrival of the PART and MET team, 4) barriers to a PFAES, and 5) support for a PFAES.

**Table 1**  
Participant demographics (N = 41).

Variable	MET n = 14	PART n = 14	Ward n = 13
Participants – n (%)			
Patient	8.0 (57.1)	12 (85.7)	13.0 (100.0)
Family	6.0 (42.9)	2.0 (14.3)	0
Gender – n (%)			
Male	8.0 (57.1)	6.0 (42.9)	10.0 (76.9)
Female	6.0 (42.9)	8.0 (57.1)	3.0 (23.1)
Age – M ( $\pm$ )	54.6 (19.9)	62.8 (18.8)	61.6 (14.4)
Ethnicity – n (%)			
New Zealand	7.0 (50.0)	5.0 (35.7)	7.0 (53.9)
European			
NZ Maori/Pacifica	7.0 (50.0)	4.0 (28.6)	4.0 (30.8)
Asian	0	5.0 (35.7)	2.0 (15.4)

#### Patients aware of their illness and deterioration

Across the three participant groups, 85.0% ( $n = 35$ ) of patients understood their current illness and were able to articulate, in varying detail, what they perceived was wrong with them. This was based on what they had been told by doctors and nurses, including tests and scan results, and where they felt they were placed on the wellness continuum progressing towards discharge from hospital.

The degree to which patient recognised deterioration varied from total awareness by patient to a vague sense that something was not quite right as described in the following comments:

*"I knew I was unwell and my wife was concerned"* (MET-12)

*"I think I had a fever, so was not thinking clearly. My family were concerned. They did not want to leave"* (PART-9)

There was, however, also surprise by some participants when informed by nursing staff of physiological deterioration.

*"I felt ok; I didn't think I was that unwell"* (PART-14)

*"I actually didn't feel too bad, I was surprised when the nurse told me I had a temperature of 39.0"* (MET-10)

Notably half of the ward group participants had experienced deterioration in their condition at some stage in their current admission with 100.0% ( $n = 13$ ) of this group being aware of deterioration and able to report how they felt; this was in contrast to 92.9% ( $n = 13$ ) of the MET group and 79.0% ( $n = 11$ ) of the PART group being similarly aware of their deterioration.

#### Fearing death

In the MET and PART groups, one-third of the participants interviewed were fearful that they were going to die. This is illuminated in the following patients' comments:

*"I told my husband I think I might die"* (PART-8)

*"I was frightened I was dying, I knew straight away what was happening. I knew I was bleeding"* (MET-3)

*"I couldn't breathe; I thought it was the end"* (MET-7)

This fear was exacerbated when the patient was alone or without family present.

*"They [nursing staff] knew how unwell I was but I don't think they knew how scared I was"* (PART-10)

*"I was not sure if I would survive; my family were not here at the time, so I felt quite alone"* (PART-6)

*"I thought it might be the end and felt I had a good run but was concerned about leaving my wife"* (PART-11).

### Concerns not heard

It was noted that patients who were intimately aware of why they were in hospital and noticed a change or deterioration in their condition were also concerned about being heard and not dismissed when they expressed concern. This is illustrated in the following patient comments:

*“I told them several times that I was thirsty and needed to drink. This was before my blood pressure dropped. I think I knew before them that I was dehydrated. They should have listened to me straight away”* (PART-13)

*“I knew I had gone into SVT because I could feel it. There were four nurses around me; I told them that they needed to call a doctor. They just looked at me. Then they got the emergency trolley. The people around me didn't know what to do. I had to tell them. . . I knew it was benign but it was frightening”* (MET-5)

There were also expressions of concern, particularly from family members, at delays in treatment when the potential for deterioration had been noticed and reported by them but not acted upon by staff.

*“I knew there was something wrong. I came in the morning; she [participant's mother] wasn't as responsive as usual. I felt I needed to come back and check on her. Why didn't they come in and say something wasn't right? I came back at 6 pm and asked a nurse to look at her”.* (PART-1)

### Recovering and returning to their normal lives

When asked “what matters to them right now” the majority of patients verbalised the importance of recovering and returning to their normal lives. This included returning to independence, family, jobs and pets although the expected length of time to return to normalcy varied. Examples of what matters were:

*“Getting well and going home to my wife and dog. . .not necessarily in that order”* (PART-10)

*“That she gets back to the way she was before she got to hospital. She is usually really active, probably the most active in the house, so it is really difficult seeing her like this”* (PART-3)

*“Getting better, returning to life as normal. Before this happened I was fit, playing bowls and living independently. Getting back to that feels like it may be a long way away”* (MET-12)

The data highlighted the wider impact of hospitalisation and illness on patients and their families from financial issues to provision of care and support for those family members who are vulnerable or have health issues.

*“[What matters to me] is getting home. My wife is in a private hospital. She has Parkinson's. I visit her regularly”* (PART-11)

*“Family; supporting my family. I am the person who is the financial support for my family. I need to get better to help them”* (MET-7)

*“My animals, also my job. I have to be here. My boss has not been supportive”* (PART-14)

### Having basic needs met

Aside from the primary concern of recovery and returning to normalcy, what mattered most to participants were food and dietary needs, managing pain, confidence in care, care and compassion from ward staff, getting good information, enabling family support and maintaining everyday activities including personal dignity. The importance of these needs is highlighted in the following comments:

*“...to make sure she gets fed and enough to drink. Sometimes they [the nurses] just pop in. I don't want her to be neglected”* (PART-1)

*“Mum staying alive. She has been unwell since Sunday and is exhausted. She worries about personal dignity; she is worried about people having to wipe her bottom. She is stoic and won't complain. . .the nursing staff should have called us to explain she was unwell”* (MET-8)

### Relief at the arrival of the PART and MET

It was noted that 64.0% (n = 18) of patients and families from both the PART and MET groups felt reassured, relieved and safe once their care had been escalated and the PART or the MET team arrived. They felt informed, comforted and had confidence in the attending teams. These feelings are illuminated in the following comments:

*“I felt a lot happier, a lot more reassured [when the MET team arrived]”* (MET-3)

*“She [the PART nurse] was very comforting. She explained what was wrong with her (the participant's mother) very well. She came back several times to check on her”* (PART-3)

Although many patients and their families felt relief when the PART or MET attended, six reported initial anxiety at their arrival. This is portrayed in the following comments:

*“My husband told me not to worry. . . these people are really good and will help you”* (PART-8).

*“I knew something was really wrong but I also felt safe as I knew people were now looking after her”* (MET-6)

*“[The arrival of the emergency team made me feel] awesome, [name of the PART nurse] told me factually what was happening. When your family is unwell having all the facts is important. So is good communication”* (MET-8)

### Not informed of escalation

Among those patients who experienced deterioration and whose care was escalated to a PART or MET call, 64.0% of the PART group and 57.0% of the MET group had no knowledge of escalation until the team arrived. In some instances the sudden arrival of an emergency team left the participants feeling overwhelmed and fearful. This is seen in the following patient's comments:

*“It was confusing because I didn't know who half the people were, they kept coming in and out, doctors and nurses”* (PART-14)

*“I can't really remember too much prior to them coming. . .It made me feel silly because I didn't know why everyone was here”* (MET-11)

### Barriers to using a patient and/or family activated escalation system

Cultural, spiritual and personal beliefs were found to impact on patients and families experiencing deterioration. Participants in the MET group relied strongly on seeking immediate help from nursing staff, however not all patients relied solely on hospital staff. A small number (n = 5) of participants utilised prayer or sought support from their churches as a priority. This theme emerged predominantly from participants in the PART and ward control groups who reported a reliance on such things as prayer, priests/pastors, family and self.

*"I talked to my family. We are a close family. I also didn't want to worry them any more than necessary. I don't think I would talk to nurses and doctors in front of my family"* (PART-10)

*"I just rely on myself"* (PART-5)

*"I prayed, read the bible and saw the chaplain"* (WARD-9)

While recovery was important to them, 46.0% (n = 6) of participants in the control group highlighted the importance of achieving this by doing what doctors and nurses asked of them. Their responses indicated a faith and trust in the staff caring for them and included:

*"...getting better, listening and following instructions from the doctors and nurses"* (WARD-12)

*"...getting well by trusting in the healthcare"* (WARD-11)

### Support for patient and/or family activated escalation service

Overall the support for a PFAES was positive with 100.0% of the MET, 86.0% of PART and 76.9% of the control group participants expressing support for the idea of introducing a service; the same numbers identified that they would utilise such a service if one were introduced. The MET group participants had no reservations and felt that families would benefit from the service.

*"I think it is a good idea especially for families"* (MET-4)

*"Yes an excellent idea. I think it would reassure family to be able to voice concerns"* (MET-6)

Other respondents from both the MET and PART groups based their support on prior experience.

*"It sounds good. If I could've pushed a button and got the professionals here I would've"* (PART-3)

*"I wish I had known about your team earlier. I would have come to you a week ago"* (PART-1)

Although the support for a PFAES was predominantly positive there were a small number (n = 2) who felt it might be subject to misuse.

*"It's a good idea; I hope people would not ring for silly reasons"* (PART-13)

Others (n = 7) qualified their response by saying they would speak to their families or home ward staff first if they were concerned. The reasons for this were multiple and included: shyness about expressing concern particularly to medical staff, concerns that bypassing the home team would imply a lack of confidence in their care and concerns about imposing on an already busy service.

*"I still think I would talk to my family first"* (PART-10)

*"I am not sure I would call the team straight away as they may be busy. I would talk to my nurse first"* (PART-6)

*"It sounds like a good idea [but] I would just rely on the ward"* (PART-2)

*"I think it would be good to be listened to by someone who knows what they are doing [but] I think I would talk to my family first"* (PART-12)

### Barriers to support

Those who felt that the proposed service was unnecessary were participants from the control group who had confidence in the ward doctors and nurses and participants who appeared to be influenced by such things as culture, religion or a hesitation to insult the ward staff.

*"No, don't think we would use it [we are] happy to talk with the nursing staff and doctors."*

*"We feel more comfortable talking to our Pastor for ongoing support and don't wish to insult nursing staff, they do a good job"* (WARD-1)

### Implementation suggestions

There were many suggestions from the study participants about the best way to be informed about a PFAES. The highest number of responses (n = 19) suggested some form of communication on the wall in the ward and more specifically in the patient's room, such as posters, signs or whiteboards. The second most common suggestion was a card (n = 12) with phone number or contact details while the next most common was face-to-face information from ward staff on admission (n = 10) or via pamphlets or brochures (n = 9). Unanimously the participants felt that the best way to contact the service would be by phone or text.

### Discussion

This study identified most participants had a good knowledge of their patient illness and were aware when they were deteriorating. Communication of their concerns about deterioration was predominantly with healthcare professionals. Of those patients whose deterioration was escalated to a PART or MET call by the bedside nurse, most had no knowledge of escalation until the team arrived. For some participants, the sudden arrival of an emergency team left them feeling overwhelmed and fearful. This indicates that although staff recognised patient deterioration and escalated care, the escalation was not always communicated to patients and their families. These findings resonate with those of other studies which found concerns that 'something is wrong', and lack of communication about these concerns (including the proposed plan of care), among the main reasons consumers escalated calls directly to the RRT (Albutt et al., 2016; Dunning et al., 2010; Vorwerk and King, 2015). This is in contrast to the findings of Guinane et al. (2018) who highlighted MET patients felt their bedside nurses effectively communicated with them and escalated accordingly.

Patients' and families' awareness of their deterioration is not unique to our study. It is reported that patients and their families' use "a sense of knowing" related to a perceived change in common behaviour to identify clinical deterioration. This is purported to occur before clinicians utilise quantifiable changes, such as alteration in vital signs, to recognise deterioration (Brady et al., 2014; Vorwerk and King, 2015). A surprising finding in our study, however, is how fearful patients were once they were aware of their deterioration. Although this fear was evident in patients who had triggered MET calls, it was also evident in patients who triggered lower threshold PART reviews.

Our findings identified that patients experiencing deterioration, recognised their symptoms from a previous experience, yet they perceived their concerns were not heard. Rainey et al. (2013) highlighted this same issue in their United Kingdom study in which they identified how frequently important patient subjective measures of acute illness are outweighed by staffs' objective measures.

Despite the fact that most patients escalated to the PART or MET expressed confidence in the escalation team once they arrived, some were overwhelmed by the number of personnel associated with a MET call and feared the worst. This reinforces the importance of clear and compassionate communication, particularly to those patients whose fearful reactions may exacerbate already exaggerated physiological responses. Failure to communicate in

these situations can inadvertently cause patient harm (Dean et al., 2008).

Our results showed all patients who had a MET call and most patients who were escalated to the PART, supported implementing a PFAES. Although we identified that patients were relieved when the MET and PART arrived, we also identified they felt previously ignored when they raised their concerns with staff earlier. This experience likely contributes to their support for a patient and family escalation service. Studies have identified that dissatisfaction with staff response to deterioration has motivated many consumer activated escalation services (Bogert et al., 2010; Dunning et al., 2010; Hueckel et al., 2012; Odell et al., 2010; Rainey et al., 2013; Vorwerk and King, 2015). Others identify dissatisfaction with plan of care and communication failures related to systemic issues rather than patient deterioration as the reason for consumer escalation (Albutt et al., 2016). As stated earlier, Gill et al. (2016b) emphasises the importance of determining whether escalation is for clinical deterioration or concern about general care as this has implications for how hospitals implement a PFAES and who are the best people to respond.

For many patients in our study, the sense of relief associated with the arrival of the MET and PART suggests that more than communication issues were addressed once the escalation team arrived. When evaluating PFAES, Bogert et al. (2010) demonstrated that patients and families felt empowered by being able to activate a RRT; they felt their concerns could be addressed in a timely manner and felt included in a partnership of care.

Vorwerk and King (2015) identified that in all 11 studies reviewed, patients' and families had concerns about bypassing trusted staff and felt fearful of offending health care professionals. This is a common barrier to consumers activating a rapid response call. Whilst this is similarly found in our study, we also identified religious and cultural reasons for why patients and family might not use a call for concern service. This implies that whilst we may implement a service for patients and their families, there will always be a group of them who may not utilise the service.

### Limitations

The study has a number of limitations. Not audiotaping patient and family interviews may have encouraged participation; however it also may have meant a lost opportunity for richer data. Although the accuracy of the data transcript was checked with participants during and at the end of interviews, the use of field notes and reflective journaling by interviewers, may have introduced some bias into the data. Confirming the final study findings with participants might have further enhanced validation of the study findings. While an attempt was made to recruit participants reflective of the hospital's ethnic population, the qualitative design of the study limited sample size. This meant only small numbers of specific ethnicities were included in the study, which may influence the transferability of results to ethnic groups.

### Conclusion

The findings of this study indicate that patients and their families are very aware of their health condition, are sufficiently aware of deterioration and are concerned when their deterioration is not recognised or acted upon in a timely manner.

Findings indicate overwhelming support for a PFAES at our hospital and that consumers have very firm ideas about how this could be implemented. Consumer participation in planning and implementing such a service is highly recommended. Once established further research is needed on how the service is used, including the type of calls made.

### Ethical statement

The authors have ensured that this research has been carried out in accordance with The Code of Ethics of the World Medical Association (Declaration of Helsinki).

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### Conflict of interest

None to declare.

### References

- Albutt, A., O'Hara, J., Conner, M., Fletcher, S., Lawton, R., 2016. Is there a role for patients and their relatives in escalating clinical deterioration in hospital? A systematic review. *Health Expectations* 1–8. <https://doi.org/10.1111/hex.12496>.
- Barrett, J., Hawdon, G., Wade, J., Reeves, J., 2018. Measuring the success of medical emergency teams; potentially preventable deaths versus total cardiac arrest death: a single centre observational study. *Int. Med. J.* 48 (3), 264–269. <https://doi.org/10.1111/imj.13676>.
- Beaumont, K., Luettel, D., Thomson, R., 2008. Deterioration in hospital patients: early signs and appropriate actions. *Nurs. Stand.* 23 (1), 43–48.
- Bengtsson, M., 2016. How to plan and perform a qualitative study using content analysis. *Nurs. Plus Open* 2, 8–14. <https://doi.org/10.1016/j.npls.2016.01.001>.
- Berger, Z., Flickinger, T., Pfoh, E., Martinez, K., Dy, S., 2014. Promoting engagement by patients and families to reduce adverse events in acute care settings: a systematic review. *Br. Med. J. Qual. Safety* 1–8. <https://doi.org/10.1136/bmjqs-2012-001769>.
- Bogert, S., Ferrel, C., Rutledge, D., 2010. Experience with family activation of rapid response teams. *MEDSURG Nurs.* 19 (4), 215–222.
- Boyd, H., McKernon, S., Mullin, B., Old, A., 2012. Improving healthcare through the use of co-design. *New Zealand Med. J.* 125 (1357), 76–86.
- Brady, P., Zix, J., Brilli, R., Wheeler, D., Griffith, K., Giaccone, M., Tegtmeyer, K., 2014. Developing and evaluating the success of a family activated medical emergency team: a quality improvement report. *Br. Med. J. Qual. Safety* 1–9. <https://doi.org/10.1136/bmjqs-2014-003001>.
- Clarke, D., Jones, F., Harris, R., Robert, G. on behalf of the Collaborative Rehabilitation Environments in Acute Stroke (CREATE) team, 2017. What outcomes are associated with developing and implementing co-produced interventions in acute health settings? A rapid evidence synthesis. *BMJ Open.* <https://doi.org/10.1136/bmjopen-2016-01-4650> E014650.
- Currey, J., Allen, J., Hones, D., 2018. Critical care clinician perceptions of factors leading to medical emergency team review. *Aust. Crit. Care* 31, 87–92.
- Dean, B.S., Decker, M.J., Hupp, D., Urbach, A.H., Lewis, E., Bennes-Stickle, J., 2008. Condition HELP: a pediatric rapid response team triggered by patients and parents. *J. Healthcare Qual.* 30, 28–31.
- Dunning, E., Brzozowicz, K., Noel, E., O'Keefe, S., Ponischil, R., Sherman, S., Wentworth, J., Westsly, M., 2010. Fast track beyond RRTs. Follow how one facility moved from code team, to rapid response team to family-activated safety team. *Nurs. Manage.* 41 (5), 38–41. <https://doi.org/10.1097/01.NUMA.0000372032.52605.ef>.
- Gerdyck, C., Vallish, R., Miles, K., Godwin, S., Wludyka, P., Panni, M., 2010. Successful implementation of a family and patient activated rapid response team in an adult level 1 trauma center. *Resuscitation* 81 (12), 1676–1681.
- Gill, F.J., Leslie, G.D., Marshall, A.P., 2016b. The impact of implementation of family-initiated escalation of care for the deteriorating patient in hospital: a systematic review. *Worldviews Evid.-Based Nurs.* 13 (4), 303–314.
- Gill, F.J., Leslie, G.D., Marshall, A.P., 2016a. Family initiated escalation of care for the deteriorating patient in hospital: family centered care or just "box ticking". *Aust. Crit. Care* 29, 195–200.
- Greenhouse, K., Kuzminsky, B., Martin, S.C., Merryman, T., 2006. Calling a condition H(elp). *Am. J. Nurs.* 106 (11), 63–66.

- Guinane, J., Hutchinson, A.M., Bucknall, T.K., 2018. Patient perceptions of deterioration and patient and family activated escalation systems: a qualitative study. *J. Clin. Nurs.* 27, 1621–1631.
- Hueckel, R.M., Mericle, J.M., Martin, P.L., Champagne, M.T., 2012. Implementation of condition help: family teaching and evaluation of family understanding. *J. Nurs. Care Qual.* 27 (4), 176–181.
- McCawley, B., Gannotta, R.J., Champagne, M.T., Wood, K.A., 2013. Calling a condition H. *Nurs. Manage.*, 30–35 <https://doi.org/10.1097/01.NUMA.0000437770.71392.8d>.
- Odell, M., Gerber, K., Gager, M., 2010. Call 4 Concern: patient and relative activated critical care outreach. *Br. J. Nurs.* 19, 599–602.
- Quirke, S., Coombs, M., McEldowney, R., 2011. Suboptimal care of the acutely unwell ward patient: a concept analysis. *J. Adv. Nurs.* 67 (8), 1834–1845. <https://doi.org/10.1111/j.1365-2648.2011.05664.x>.
- Rainey, H., Ehrich, K., Mackintosh, N., Sandall, J., 2013. The role of patients and their relatives in 'speaking up' about their own safety: a qualitative study of acute illness. *Health Expectations*. <https://doi.org/10.1111/hex.12044>.
- Ray, E.M., Smith, R., Massie, S., Erickson, J., Hanson, C., Harris, B., Willis, T.S., 2009. Family alert: implementing direct family activation of a pediatric rapid response team. *Joint Commiss. J. Qual. Patient Safety* 35 (11), 575–580.
- Smith, G.B., Prytherch, D.R., Meredith, P., Schmidt, P.E., Featherstone, P.L., 2013. The ability of the national early warning Score (NEWS) to discriminate patients at risk of early cardiac arrest, unanticipated intensive care unit admission, and death. *Resuscitation* 84 (4), 465–470. <https://doi.org/10.1016/j.resuscitation.2012.12.016>.
- Vorwerk, J., King, L., 2015. Consumer participation in early detection of the deteriorating patient and call activation to rapid response systems: a literature review. *J. Clin. Nurs.* 25, 38–52. <https://doi.org/10.1111/jocn.12977>.