

## PROCESS AND SYSTEMS When patients (and families) raise the alarm: Patient and family activated rapid response as a safety strategy for hospitals

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### ABSTRACT

Patients and those close to them often have an intimate understanding of their condition and can participate in a broad range of clinical processes. During times of deterioration, their concerns might go unheard. Advocacy of family and friends can fulfil an important safety function and can support patients and healthcare professionals looking after them. If concerns by patients are not heard by the patient's primary team in hospital, patient and family activated rapid response systems allow patients and family members to alert critical care outreach teams directly. These types of systems are stipulated by regulators in Australia and in parts of the USA, and there are examples in the UK built around the 'Call for Concern' model championed by the Royal Berkshire Hospital. Implementation is not without its problems and requires a deep understanding of barriers and enablers. Empowering patients to escalate directly might help to change safety culture and have protective effects for patients and staff. Policy makers are urged to consider standardised regulation to aid implementation.

**KEYWORDS:** patient centred, patient safety, advocacy

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### Introduction

Partnering with patients and families in care and care decisions was founded upon the notion that patients have a legitimate right to be involved in their own care and care decisions. Although patient and family roles in promoting patient safety have been

advocated internationally, the understanding of interventions and strategies to achieve meaningful engagement and successful implementation is poorly understood. Patient and family participation has been studied in bedside handover, ward rounds, medication management, pressure injury prevention and recognition of clinical deterioration.<sup>1–6</sup> Other research has focused on patient and family involvement in patient safety activities, transitions of care and clinical communication.<sup>7–9</sup> Notably this body of evidence demonstrates that a continuum of participation, from passive to active engagement, exists. Preferences for participation involves a complex interplay between factors such as personal characteristics, knowledge, understanding of care, health status and expectations. Importantly, preferences and needs are dynamic and may vary depending on a patient's health status or their family being present. Family member engagement is especially valued by health professionals when caring for vulnerable, elderly, critically ill, or cognitively- or hearing-impaired patients. Although research highlights both benefits and challenges associated with patient and family participation, embedding effective strategies remains a frontier to be crossed.

Here, we review the argument for patient and family participation in care and care decisions of acutely unwell patients in hospital with a focus on two systems: the role of advocacy and the functioning of patient and family activated escalation systems.

### Advocacy as a driver for patient safety

Advocacy in healthcare is everyone's responsibility. But in order to truly represent the patient, the advocate is required to know the patient's wishes and needs, and who better to do this than family and friends? Not only do those closest to the patient know them best, but they are also most invested in ensuring that the patient gets the best possible outcome. Family and friends might not be familiar with hospital and professional culture, hierarchy, conflicting priorities and professional boundaries that may influence clinical decision making of healthcare workers but might be still affected by them. The importance of the involvement of family and friends in patient care and planning is evidenced in the literature and has been recognised as a crucial resource for protecting vulnerable patient populations in acute healthcare environments in Australia.<sup>10–12</sup> The importance of this resource has been additionally highlighted by its absence during the COVID-19

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pandemic with restriction of visiting having a detrimental effect on the ability of families to adequately advocate for the patient. In addition, the separation of family from loved ones in stressful circumstances can have a negative effect on the ability of the family to cope.<sup>13</sup>

### What is a patient and family activated rapid response system?

Rapid response systems consist of two parts: an afferent limb and an efferent limb.<sup>14</sup> The function of the afferent limb is to monitor patients in hospital using physiological parameters such as vital signs through a tool such as the National Early Warning Score and escalate care to the efferent limb, a critical care outreach type of team, where there is concern about signs of deterioration.<sup>15</sup>

Given these insights into the ability of patients and families to recognise deterioration, a number of initiatives have explored the ability of patients to escalate care beyond their own clinical team and without the team's mediation. Critically ill and deteriorating patients, however, are often unable to express concerns, whereas families and friends are much more likely to raise awareness of possible deterioration.<sup>16,17</sup>

In Australia, the National Safety and Quality Health Service (NSQHS) standards are required for hospital accreditation and include standard 8: Recognising and responding to acute deterioration.<sup>18</sup> This standard, updated in 2017, specifies the duty of hospitals to ensure that 'a person's acute deterioration is recognised promptly and appropriate action is taken'. Deterioration is defined as changes in physiology, cognition and mental state.<sup>18</sup>

Following widely publicised adverse events, when children died after delayed escalation despite parents' concerns, three of the seven Australian states have embedded the intent of this legislation in consumer activated rapid response systems: 'Ryan's rule' in Queensland, Call for Help (C4H) in Western Australia and REACH in New South Wales.<sup>19,20</sup> Ryan's rule stipulates that patients, families and friends can request an urgent independent review if they are not satisfied by the response of the patient's own care team to their concern.<sup>19</sup> Other states (such as Victoria) were unable to navigate the political landscape.<sup>21</sup> Consequently, hospitals and healthcare facilities have implemented local policies and procedures to meet accreditation standards independently.

The fragmented approach in Australia presents a number of risks, including a failure of the programme to be triggered due to the consumer being unaware of its existence or how to access it, as well as inappropriate use of the system and a subsequent waste of resources and time.

In the USA, individual states have enshrined the right of patients to escalate to senior staff in legislation.<sup>22</sup> In the UK, no universally accepted model of care exists for patient and family escalation but the Royal Berkshire Hospital's 'Call for Concern' (C4C) has been adopted by a number of other institutions.<sup>16,17</sup>

While the evidence is only just building, the International Consensus Conference for Rapid Response Systems recommended in 2018 that the option for patients and their friends and families to escalate their concerns directly to a critical care outreach team (CCOT) is a quality indicator for the patient-centred care of deteriorating patients.<sup>23-25</sup> Involving patients and families in the co-design of patient activated rapid response and similar resources

can help ensure that their voice is heard and is reflected in the developed resource to ensure their needs are addressed.<sup>26</sup>

### Opportunities and barriers for implementation of patient and family activated rapid response

The contribution that patients and/or families can make to the detection of and response to hospital deterioration is increasingly being recognised. However, calling for help can be challenging for patients and/or relatives. Factors have been identified that act as both barriers and facilitators to being heard, including personal factors (such as previous experience or knowledge of illness) and personality traits determining how confident patients and families will feel about responding to changes and raising concerns.<sup>27</sup> Perceptions of the patient–healthcare professional's role, including the notion that the healthcare professional 'knows best', also contribute to a reluctance to voice concerns and to the adoption of a passive role. In addition, the quality of relationships between patients/families and healthcare professionals can promote or inhibit the ability to speak up. Finally, organisational factors (such as reduced staffing levels / resources) can act as further barriers to patient and/or family involvement in the escalation of care.<sup>28</sup> Given these challenges, there is a need to further consider the processes and interventions that will influence patient and relative empowerment in this area and help patients and families to move more confidently towards feeling that they have 'permission to participate'.<sup>27,29</sup> Systematic review evidence recommended that, given the paucity of robust research in this area, further research was required that utilised a structured approach and included consumer involvement in the development of an escalation of care intervention.<sup>30,31</sup> To further explore these and other contextual factors that may impact on their role, and to address some of the identified challenges, a Health Service Executive funded project in Belfast co-designed a patient and family escalation of care prototype resource based on the experiences of patients, relatives and healthcare professionals to improve patient and family engagement across Ireland. This aimed to further examine the extent to which patient and/or relative intuition can be used to complement clinician judgement and preferences for involvement as well as identifying strategies to enhance future implementation.<sup>28</sup>

The difficulties of implementing a patient and family activated rapid response system are illustrated by the implementation of a C4C service following a recent trust merger between Ipswich and Colchester to form East Suffolk and North Essex NHS Foundation Trust: prior to the merger, Ipswich hospital had a well-established patient activated service run by the local CCOT. This patient safety initiative enabled patients to call for help if they were concerned about a noticeable change or deterioration in their condition, or if they experienced emotional stress after discharge from intensive care. The service was well received by patients and their families as well as clinical staff.

Following the merger, the patient activated service was relaunched with permission from the Royal Berkshire Hospital to rename it 'Call for Concern' on both sites.

Understandably, there were initial reservations about the impact of the new service on the clinical team and patients. The CCOT team was concerned about how C4C would be embedded into the CCOT service: would there be an increase in CCOT workload, how would medical and ward-based teams respond to the idea that

patients and families could independently activate a call to CCOT over their own care, and would the service create a 'them and us' mentality resulting in conflict between the CCOT and ward-based teams.

There were anxieties about inappropriate calls by patients and families who didn't fully understand when or when not to activate the service, and would expectancies of the patients be disappointed if a call could not be responded to immediately, and would patients and families actually use C4C or would they feel anxious that they may be treated differently as a result.

Engagement across the organisation achieved an understanding that C4C was an additional safety net with the patient at the centre and not something that would overshadow or undermine other services. Using a collaborative approach and close links with the trust's communications team, detailed and concise communications about the service were sent out cross site and presented to senior teams. Data about the comparatively small number of calls generated by existing services was shared with staff. However, the most powerful message came from the patient and families who reported that the service had positively impacted their experience and that they felt listened to when at their most vulnerable. Today, C4C has now been successfully embedded across the two hospitals and continues to have a positive impact on patient and family experience.

## Discussion

Patient safety remains a reactive process in many parts of the health service rather than a co-designed, collaborative, proactive process to reduce risk and improve care. Patients and families can play a significant role in patient safety, however, navigating the healthcare system and obtaining help for concerns regarding deterioration will remain challenging unless greater efforts are made to enable and normalise their involvement in the recognition and escalation of deterioration. Taking an active role, when possible, has shown benefits for patient safety and satisfaction with care in other areas.

While sentinel events might be rare, the effects are devastating for patients, families and affected healthcare professionals. For healthcare providers, patient and family activated rapid response might, therefore, be a key intervention to create a hospital culture that truly embraces patient/family empowerment and partnership in the detection and escalation of deterioration in hospitals. More often than not, poor communication is at the heart of failed escalation.<sup>32</sup> Clinical decision making is prone to bias, and error in a complex system is common and should not be routinely labelled as failure.<sup>33,34</sup> Patient and family activated rapid response offers a safety-net of escalation past healthcare professionals but might protect patients and overstretched healthcare professionals alike.

Initiation of a broader policy discussion that provides a platform to develop a coordinated and consistent national approach to patient and family activated rapid response systems is required. In the USA and Australia, patient safety has been driven by accreditation standards for hospitals whereas, in the UK, standards are being developed and published by the National Institute for Health and Care Excellence.<sup>35</sup> A standardised approach would use the same process in all healthcare facilities in much the same way that we use a national approach for calling an emergency through 999. For a system like patient and family activated rapid response to succeed,

it is essential to ensure the support and buy-in from decision makers at a local and national level. In this context, the recent launch of a task-and-finish-group by NHS England on 'worry and concern' chaired by the deputy chief nursing officer for safety and innovation is encouraging.

## Conclusion

Patient and family activated rapid response systems can be an important tool to enhance safety for patients in hospital in situations where communication breakdown with a patient's primary clinical team has occurred. They might also positively influence the culture of patient and family involvement and increase confidence in care. A consistent national approach supported by a coordinated public education programme should be explored. ■

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