



**10,000 More Voices**  
**Interim Report of Experience of Delirium**

**June 2018**



## 1.0 Introduction

The 10,000 More Voices initiative is commissioned and funded by the Health and Social Care Board (HSCB) and Public Health Agency (PHA) to introduce a more patient focused approach to improving the way health and social care services are shaped and delivered. This initiative asks people to tell us what was important to them in their experience and to describe their overall feelings by “telling their story”, using Sensemaker® methodology. This approach blends together qualitative and quantitative data, with patient stories providing a rich source of information from which we can identify themes and trends.

It was agreed by the regional patient and client experience steering group that a specific project which would capture stories in relation to experience of an episode of delirium would be included in the 2017/2018 workplan. This could also be integrated into the evaluation of the regional delirium improvement work stream, which was taken forward as part of the Dementia Together NI work.

Following a pilot phase it was agreed that the story collection in relation to experience of delirium would be extended to include any ward in which patients presented with an episode of delirium and would not be restricted to the pilot wards which participated in the regional delirium improvement work stream.

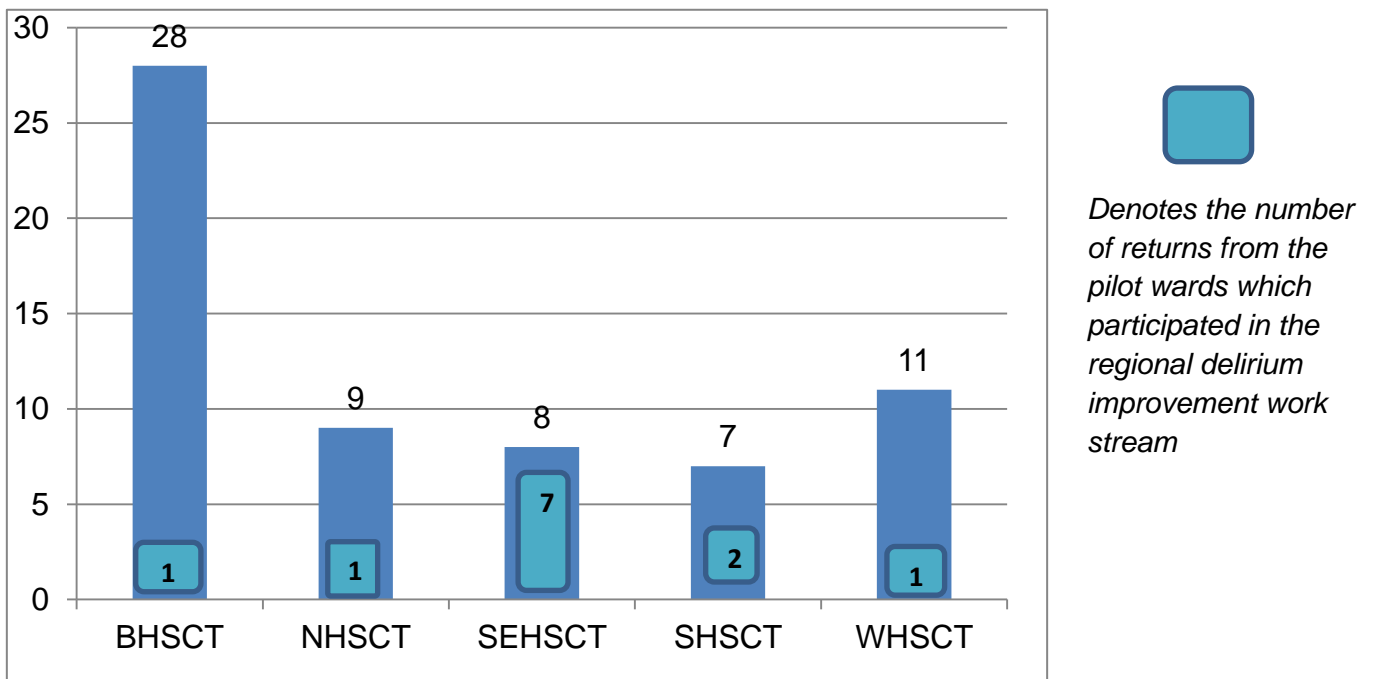
This report presents the findings from the 63\* stories which have been received as part of the 10,000 More Voices experience of delirium project, from December 2017 until 29 March 2018. The project will remain live with an end date to be agreed.

*(\*12 stories related to experience within pilot wards for the regional delirium improvement work stream).*

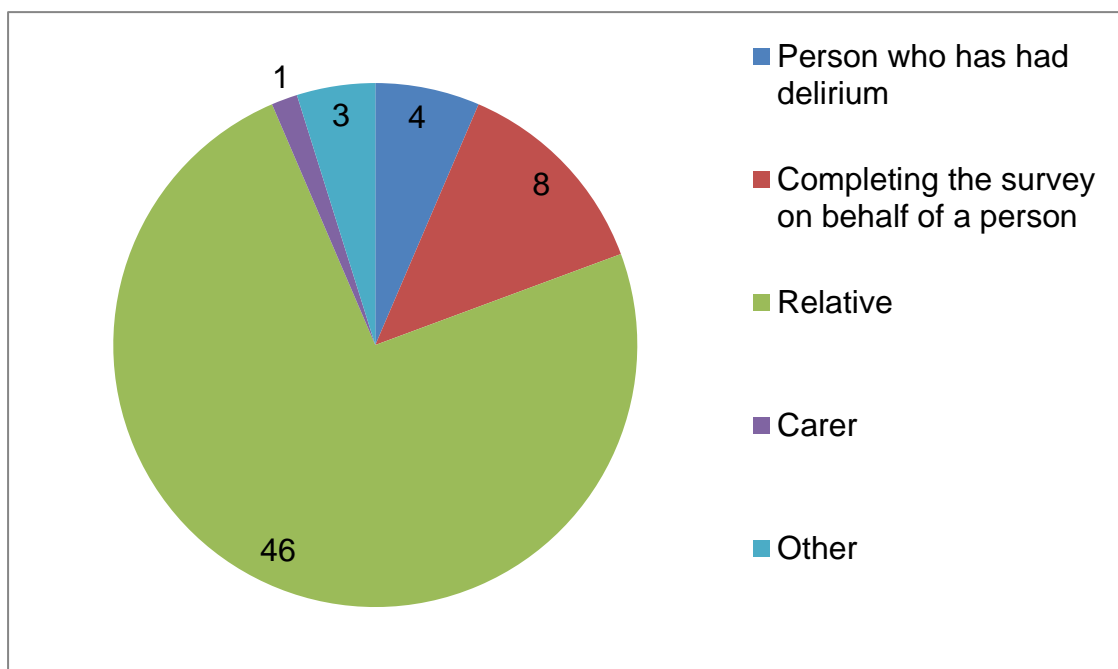
The engagement process to capture stories in relation to an episode of delirium has to date, focused primarily on collecting stories from carers/relatives or someone acting on behalf of the patient. This has provided some challenges in the practical arrangements of identifying a suitable time for the Trust facilitators to meet with family members/carers. There are 4 stories which have been submitted by a person who has an episode of delirium themselves. Although the number of stories is relatively low, the narratives provide very useful and thought provoking insights into the effects of delirium for both the patient and the family members and carers.

## 2.0 Results

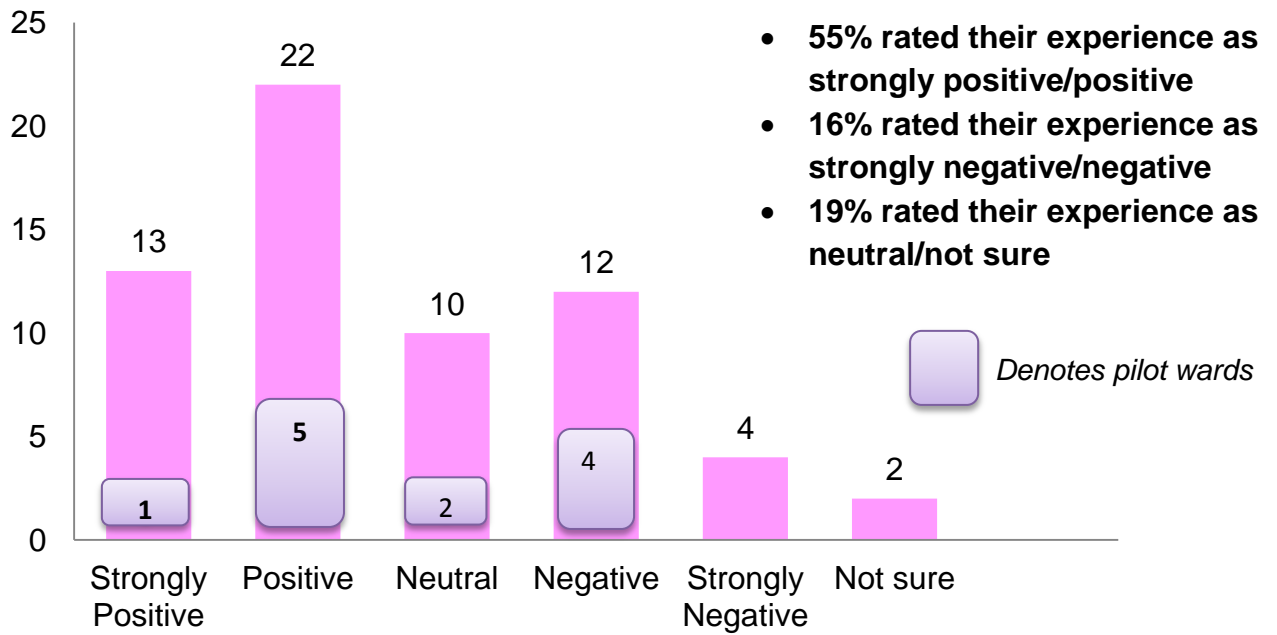
Returns per Trust area are shown below:



Returns by who participated in the survey



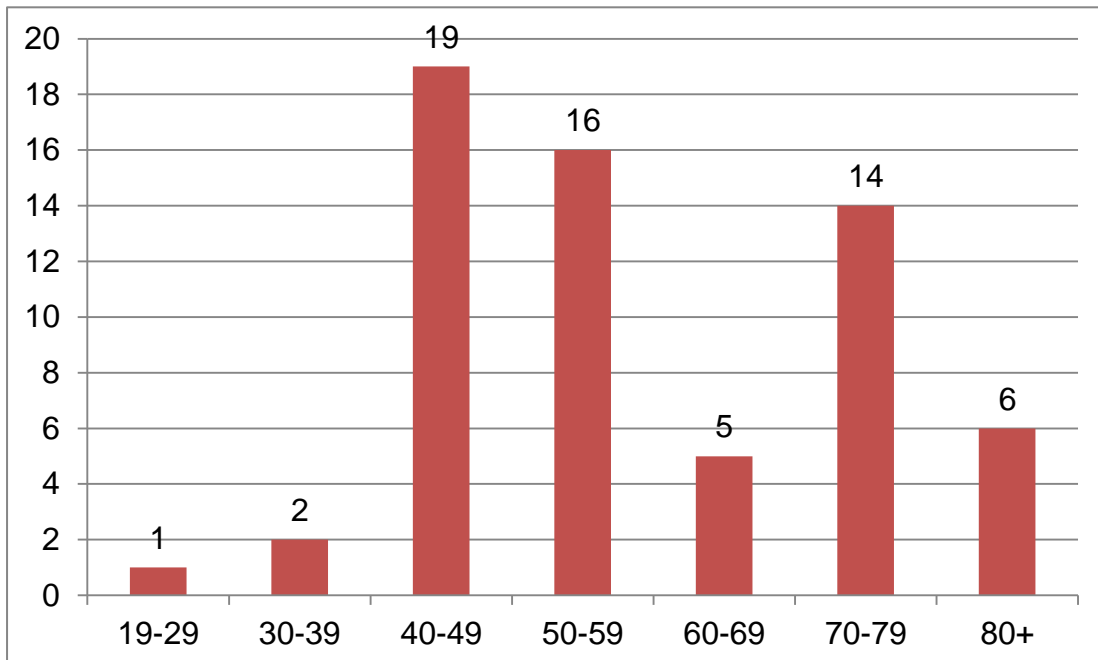
### Overall feelings about experience



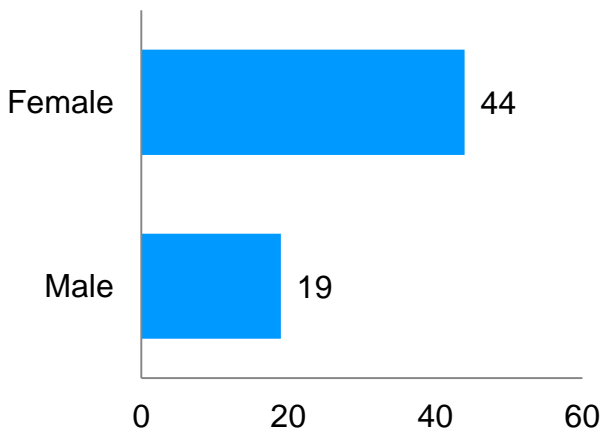
### Demographic information:

This section presents the demographic information in relation to the 63 respondents

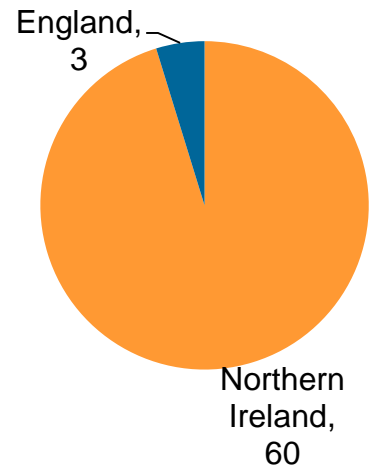
### Returns by age group



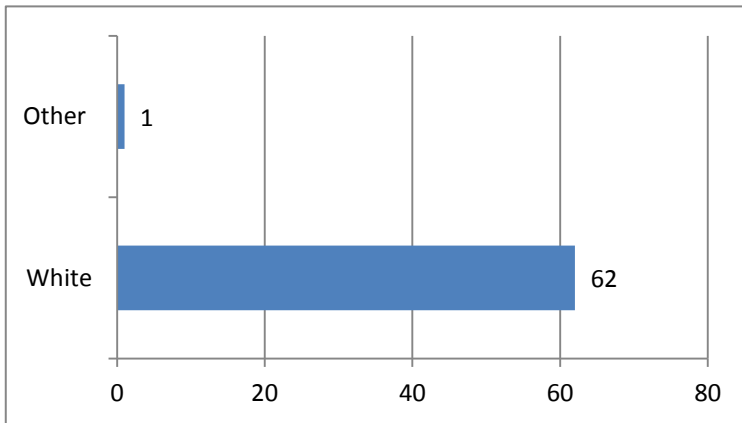
**Returns by Gender**



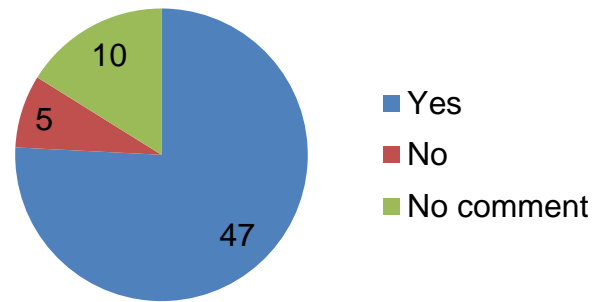
**Returns by place of birth**



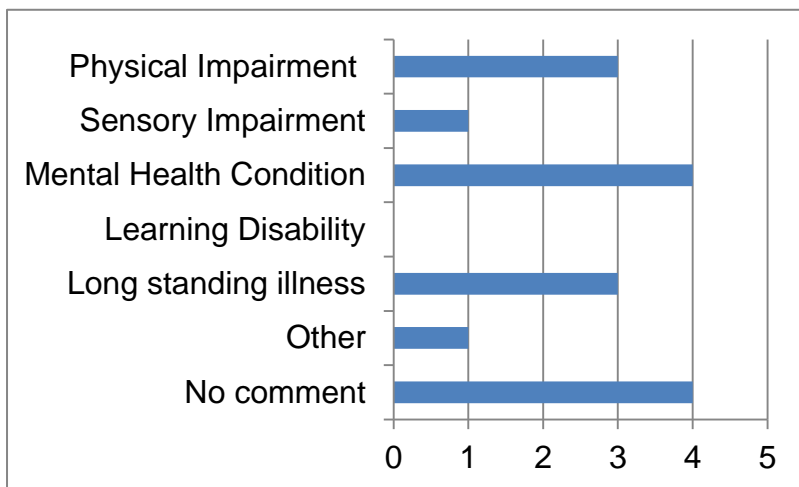
**Returns by Ethnic Group**



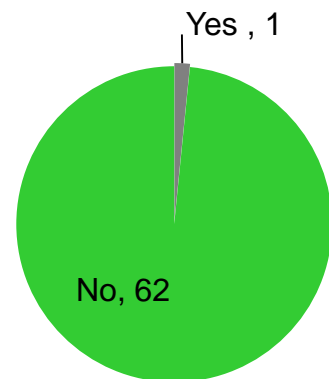
**Returns by Disability**



**Returns by Nature of Disability**



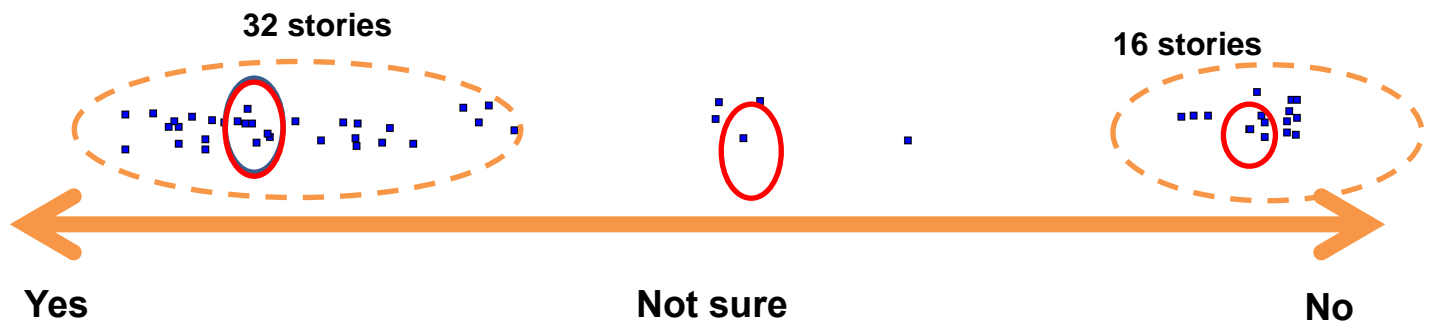
**Returns by: Do you have a rare disease?**



### 3.0 Response to signifiers

 Denotes stories from pilot wards

Q1. Were you told that your relative had a diagnosis of Delirium?



#### Discussion/interpretation

There were 53 responses to this question, of which 32 were told that their relative had a diagnosis of delirium. For the people who were told that their relative had a diagnosis of delirium, this appeared to be very helpful and reduced their anxiety.

#### Extracts from stories:

*I was told about the delirium and about how a high temperature affects people of a certain age which was a relief to me because I understood what was going on*

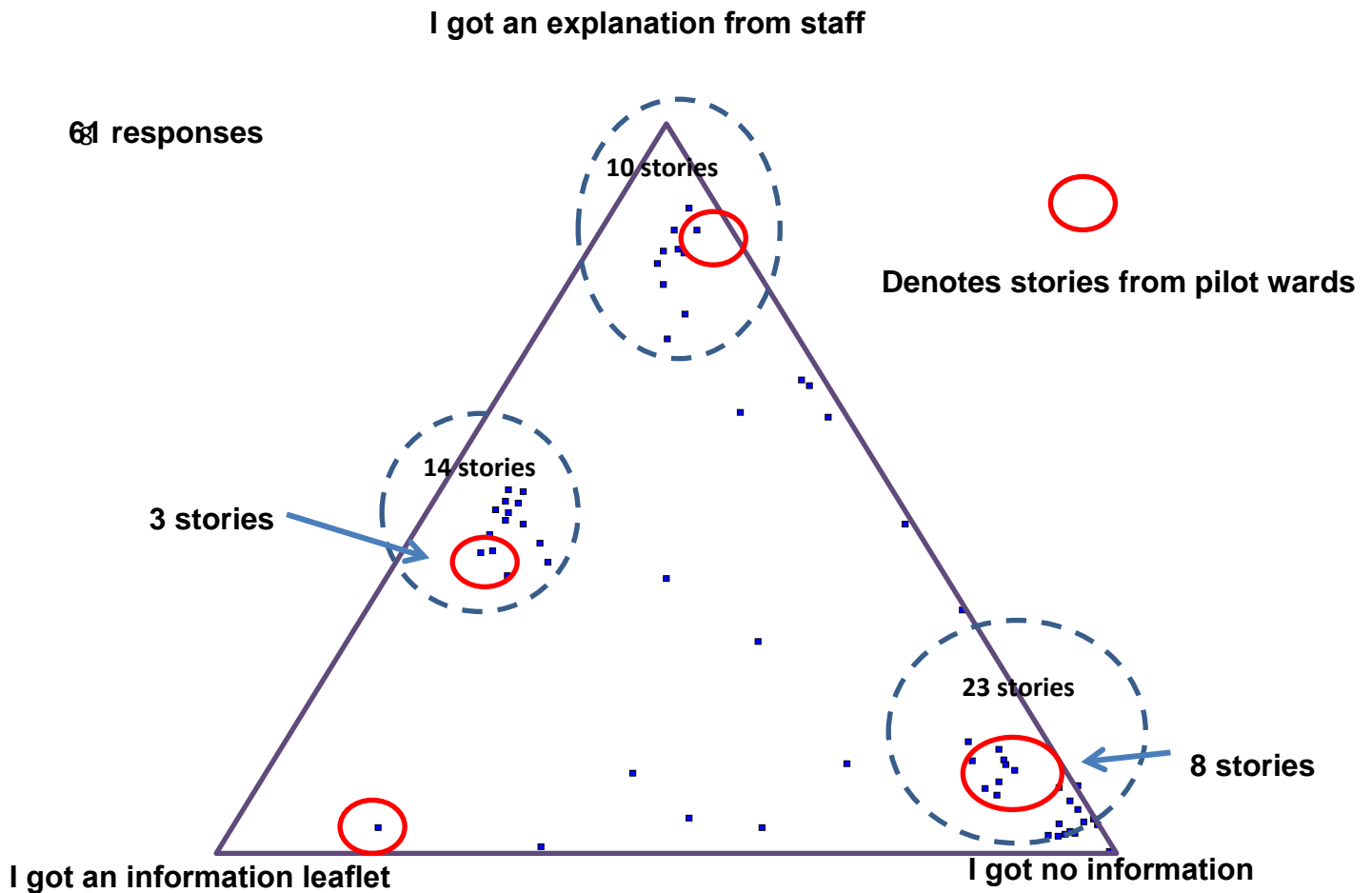
*(Pilot ward)*

*The doctor told me it was delirium and it was due to an infection.*

*(Pilot ward)*

*I only found it my mum had been diagnosed with delirium during a recent hospital admission, a few days before she was discharged*

## Q2. What information did you receive about Delirium?



### Discussion/interpretation

In total there were 61 responses to this question. It appears that in 25 of the stories people received explanation from staff about delirium and/or got an information leaflet. In almost a third of cases (23) no information was provided.

It is clear from the detail in the stories that during an episode of delirium anxiety levels of family members and carers are heightened and having access to the right information at the right time provides reassurance and advice on what to do during the episode or if the delirium recurs. The provision of the delirium information leaflet appears to help reinforce the explanations provided by staff and it seems that patients/family members/carers find that the leaflet is well designed and very beneficial.



## Extracts from stories

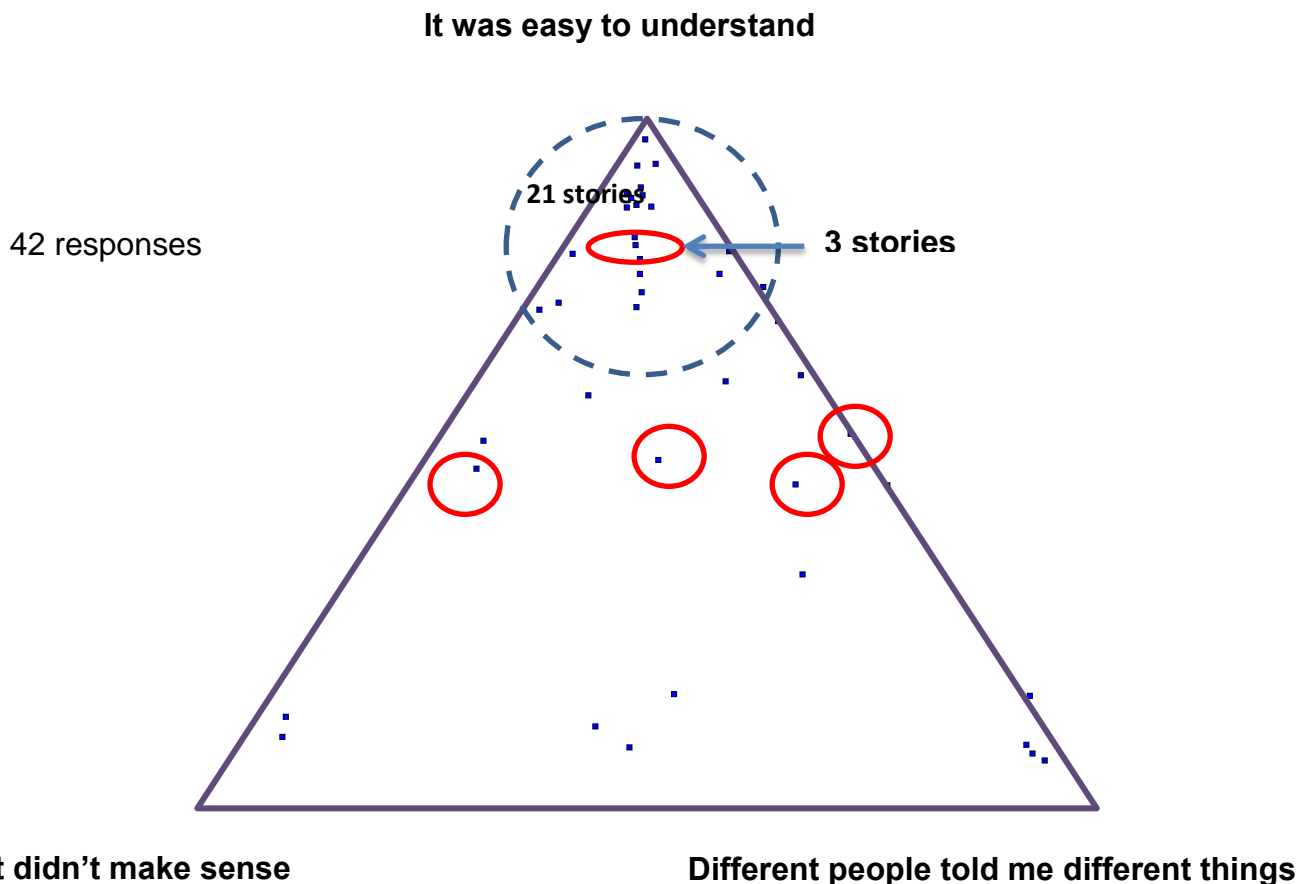
*They were able to reassure me about what was going on and that I was totally safe. I know now that I had a thing or condition called delirium. Someone came while my family were there and explained to me what had happened. I'm not sure who it was a lady maybe a doctor. She gave me this leaflet. It's only a short leaflet but it explains everything clearly. I've looked at it a few times.*

*Nobody explained why. They certainly didn't mention delirium*

*It has happened again but I knew the signs of delirium and it was an infection. I was worried but knew more about it and wasn't as worried I was so ignorant the first time. I got a leaflet about delirium it was great and explained it well.*

*It was only at another visit to the hospital outpatients department that I lifted a leaflet on delirium and I read with interest. I was in one way reassured that now I knew what the episode was but it would have been helpful to have known that at the time.*

### Q3. What best describes what you were told about Delirium?



#### Discussion and interpretation

In total there were 43 responses to this question, of which half indicated that what they were told about delirium was easy to understand. A small amount of responses indicate that different people told them different things and for two people the information did not make sense. It is clear from the stories that having clear explanations and consistency in the information provided is a key element of the care provided during an episode of delirium.

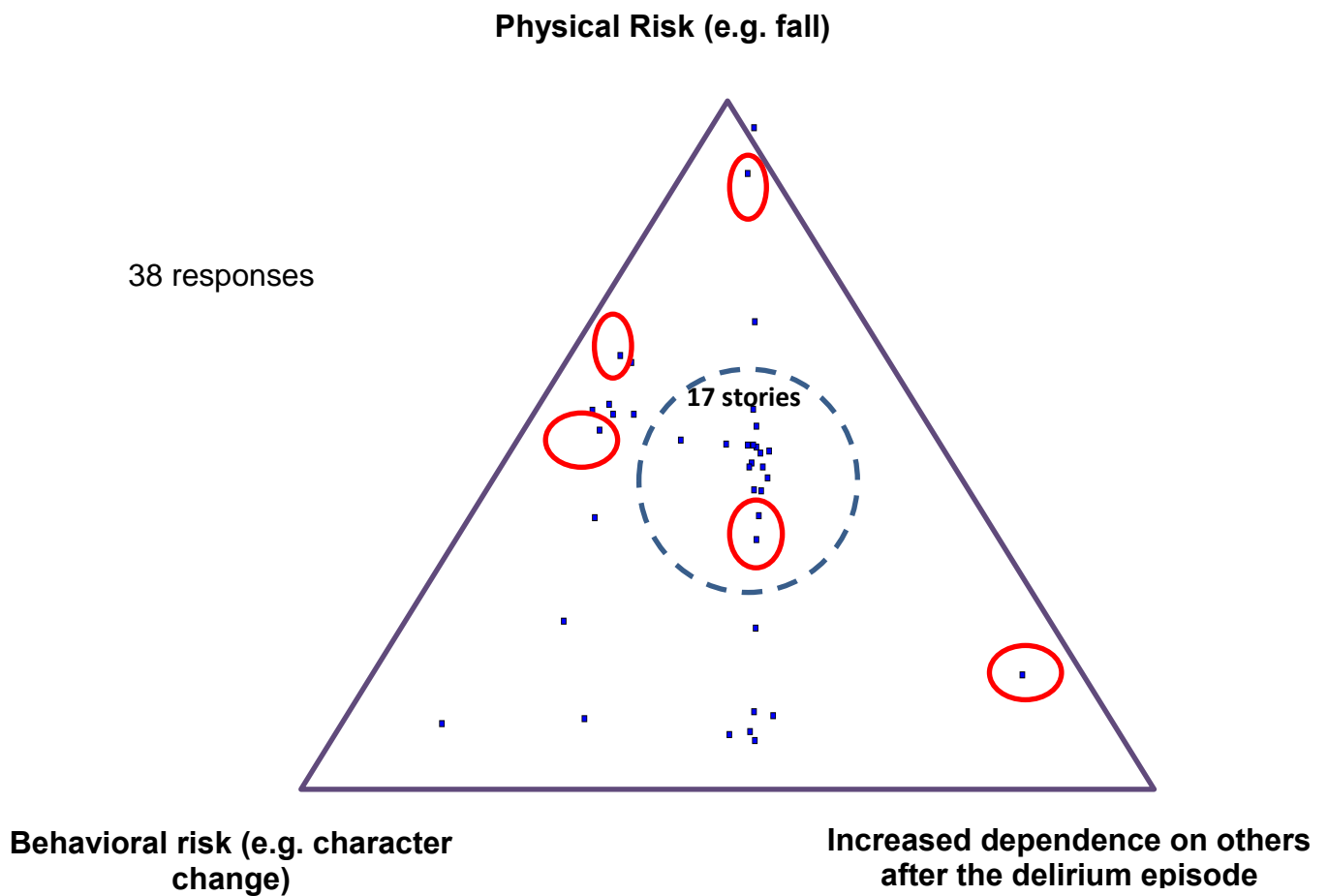
#### Extracts from stories

*Doctors don't take much time to explain things, always in a hurry so the nurse kept us up to date.*

*The doctor explained all about delirium to my brother, who then explained it to me*

*She took the time to listen and genuinely seemed to understand. She explained to me about delirium and she really appeared to sympathise with what I'd been through. She left me a leaflet about it too. Everyone else just thought I was a lunatic or a mad aggressive old man.*

#### Q4. Were you advised of possible risks associated with Delirium?



#### Discussion and interpretation

There were 38 responses to this question, of which half were indexed at the centre of the signifier meaning that people were advised of physical risk, behavioural risk and increased dependence on others after the delirium episode.

Being advised of possible risks helps to prepare the patient/family member/carer in relation to keeping safe and providing ongoing care.

## Extracts from stories

*Had operation and whilst in recovery ward developed confusion/delirium. Transferred to Trauma ward still with acute delirium. Constantly trying to get out of bed (at risk of falling) trying to grab things off the ceiling and talking nonsense.*

*Pilot ward*

*....but I am so worried about my husband and what will happen when he comes home. I couldn't say a bad word about the staff I'm sure they are worried looking after all these confused people.*

*When my brother was so confused and being violent it was terrible for them but they never complained or got annoyed. They were always reassuring us that they knew it was the illness and not his normal behaviour*

*When I visited that evening I was very concerned and he was was trying to take his clothes off. He was very agitated and there was no reasoning with him so I spoke to the nursing staff again. They reassured me that this was not unusual behaviour after this type of operation and that it was due to the medication.*

**Q5. In relation to Delirium did you find the staff's knowledge to be?**



There were 50 responses in total to this question; these are fairly evenly spread across the dyad, indicating that the respondents felt that staff knowledge in relation was variable

## Q6. How did you feel staff responded to your needs regarding Delirium?



### Discussion/interpretation:

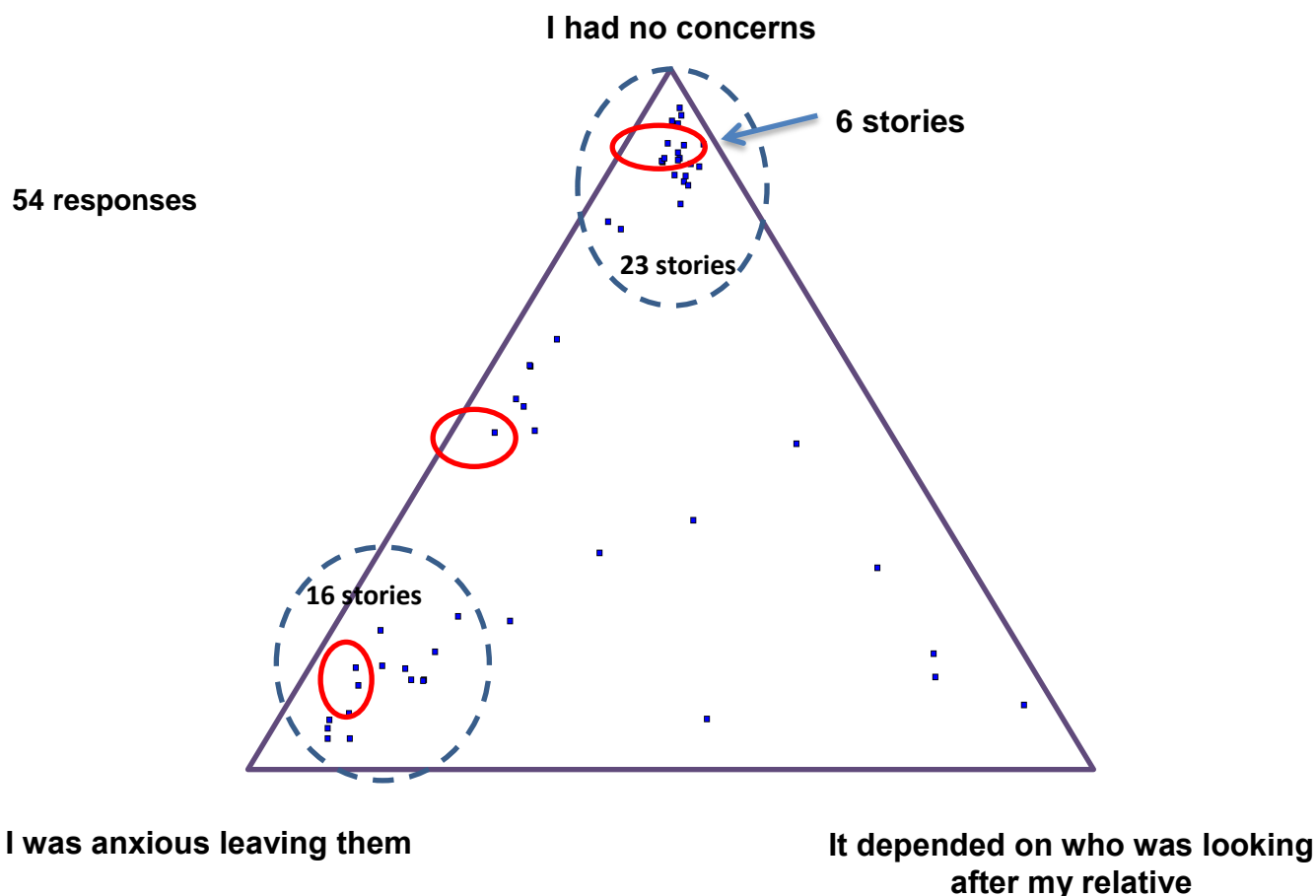
In total there were 52 responses to this question. For 25 people they felt that at the staff knew what mattered to them/involved them in decisions. 15 people felt that no-one listened to them. From the stories it is clear that people want to feel listened to, particularly when they know that the behaviour of the person having the episode of delirium is not in keeping with their usual pattern.

### Extracts from stories

*This behaviour was totally out of character for my mother. I spoke to the nurses and doctors and actually told them that in my opinion she was completely delirious. I actually used that word. No one listened. No one took notice of what we were saying.*

*The nurses were great very caring and compassionate on admission there was no waiting around Mum was taken more or less straight away into a private room and monitored. The environment was calm I have to say that Mum had an experience anyone attending hospital would want to have*

**Q7. How safe did you feel leaving your relative in the care of our staff when you went home?**



### Discussion/interpretation

In total there were 54 responses to this question, with 23 people indicating that they had no concerns when leaving their relative in the care of staff. 16 people indicated that they were anxious leaving their relative and only a few indicated that it depended on who was looking after their relative. Feeling safe and having confidence in the staff is an integral of person centred care.

### Extracts from stories

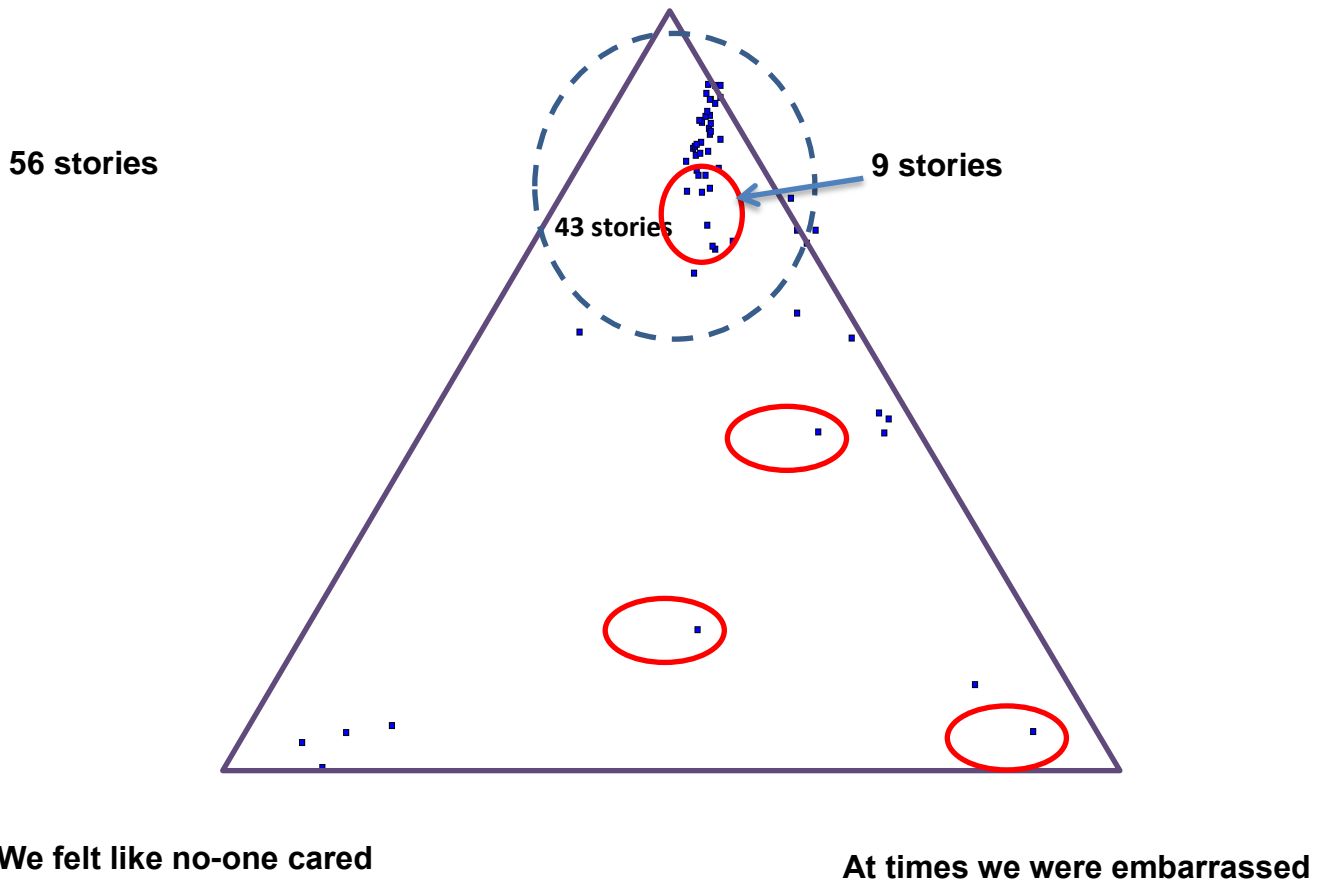
*I was very worried and anxious but I just had to keep telling myself I'd get him back to normal when I got him home.*

*They were able to reassure me about what was going on and that I was totally safe. I know now that I had a thing or condition called delirium.*

*A few days after admission, he became very, very confused and agitated. I was quite shocked and found it all very distressing. The nursing staff were all extremely kind and very considerate. It was the more senior nursing staff who were able to explain to us that this was a condition called delirium and they were hopeful it would resolve. They allowed the family to come in and out of the ward as much as we could manage and they kept us informed*

## Q8. Did staff ensure privacy and dignity were protected?

Staff did their best to protect the privacy & dignity of my relative



### Discussion and interpretation

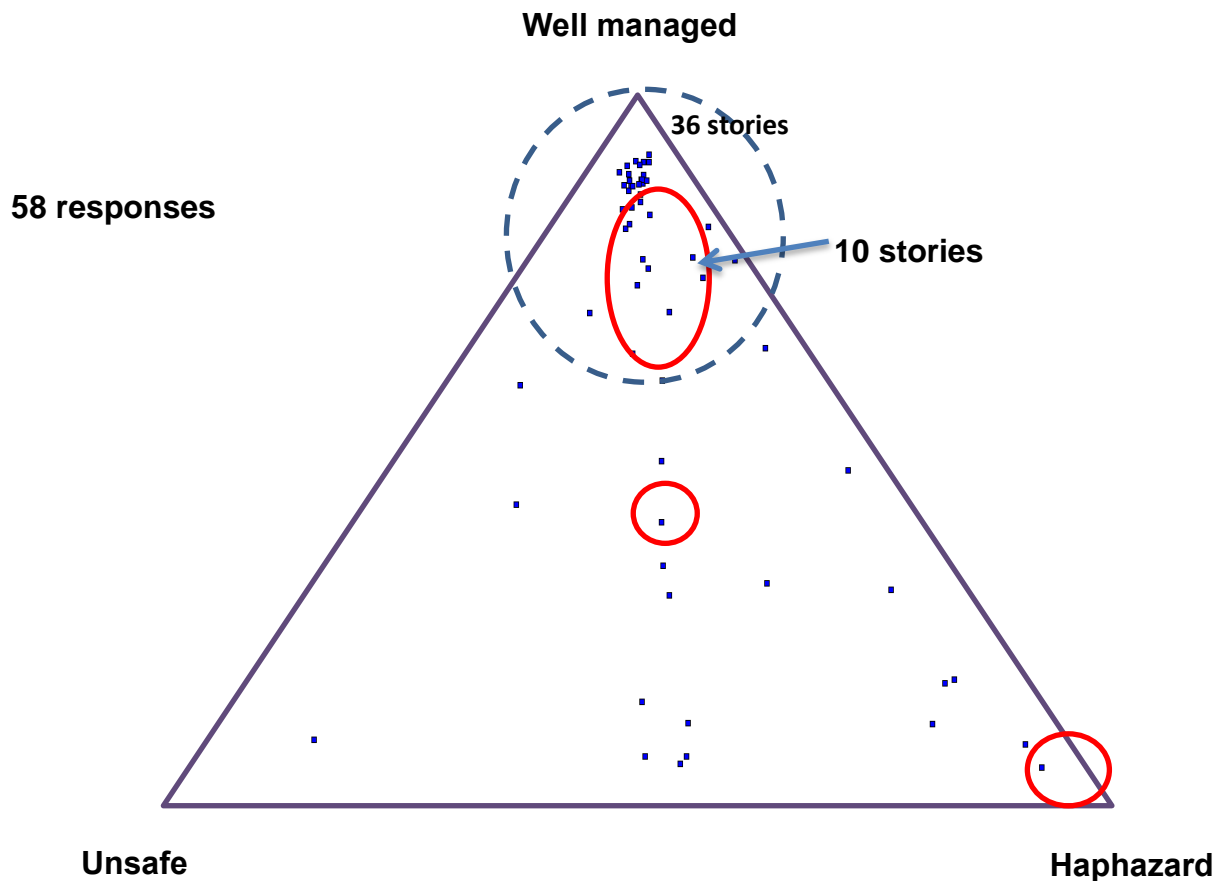
In total there were 56 responses to this question, with the majority (43 people) indicating that the staff did their best to protect the privacy and dignity of their relative. In two cases people appeared to feel embarrassed and in four cases people felt like no-one cared.

### Extracts from stories

*The nurses were great very caring and compassionate on admission there was no waiting around Mum was taken more or less straight away into a private room and monitored.*

*Sometimes some nurses ask us to leave the ward when they are busy this causes mum and her family great distress as we know how quickly she deteriorates especially if she can't see us*

## Q9. Did you feel the service was?



### Discussion/interpretation

In total there were 58 responses to this question with 36 indicating that they found the service to be well managed, and 11 people indicating that they found the service to be unsafe and /or haphazard. In some of the responses outside the main cluster, reference is made to the business of the wards and the numbers of staff present.

### Extracts from stories

*.....but I do have concerns for other families who do not have my knowledge and have a relative in a similar situation being told they are ready for discharged home yet have this confusion without a diagnosis or understanding of delirium - this is not acceptable!*

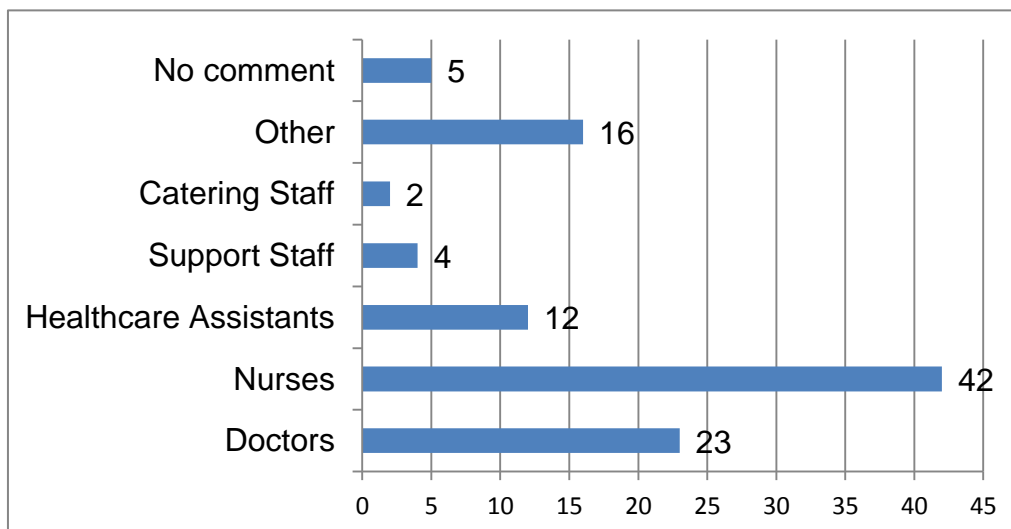
*I understand they are busy. I explained how worried I was about the confusion I thought she was a wee bit dismissive but she did say it was the infection that was causing the confusion.*

*The staff do work extremely hard and are clearly under extreme pressures but I just can't understand why this is not being recognised and more staff put in place.*

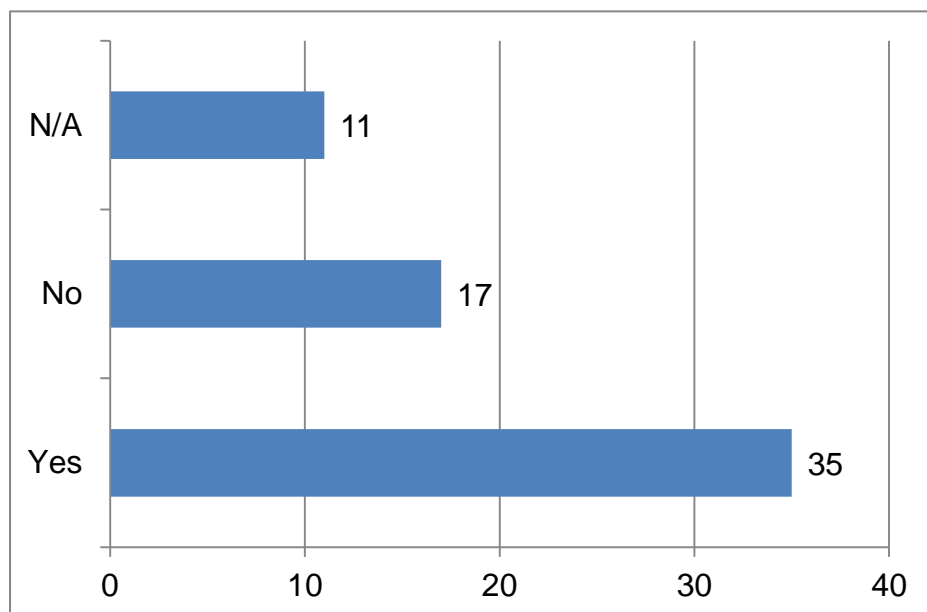


#### 4.0 Responses to multiple choice questions

##### Who did you feel was able to provide you with the most support?



##### Were you allowed to visit whenever you wanted?



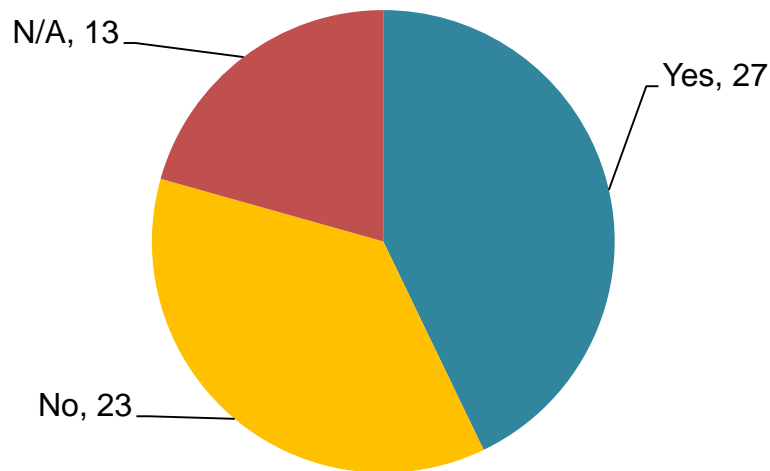
*They allowed the family to come in and out of the ward as much as we could manage*

*I asked the staff if I could stay just for that first night but I was not allowed to do so. I was informed that I should tell my mum I was going to the bathroom and then sneak out just not come back*

*The staff were very attentive and caring and I was allowed to stay as long as I wanted*

*As a family we try to stay with him as much as we can so he has familiar faces around him this helps him settle and he appears more content. When we are here we have time to encourage him to eat and take his meals his appetite is terrible and he needs a lot of encouragement as well as this when we are here we can go and get him a cup of tea or a glass of water if he needs it. In the ward I was free to come and go as needed I was able to help other patients too as the nurses were so busy and over stretched and over worked they had no time I was eyes and ears for the nurses*

**Were you contacted at home to return to the hospital to supervise your relative?**



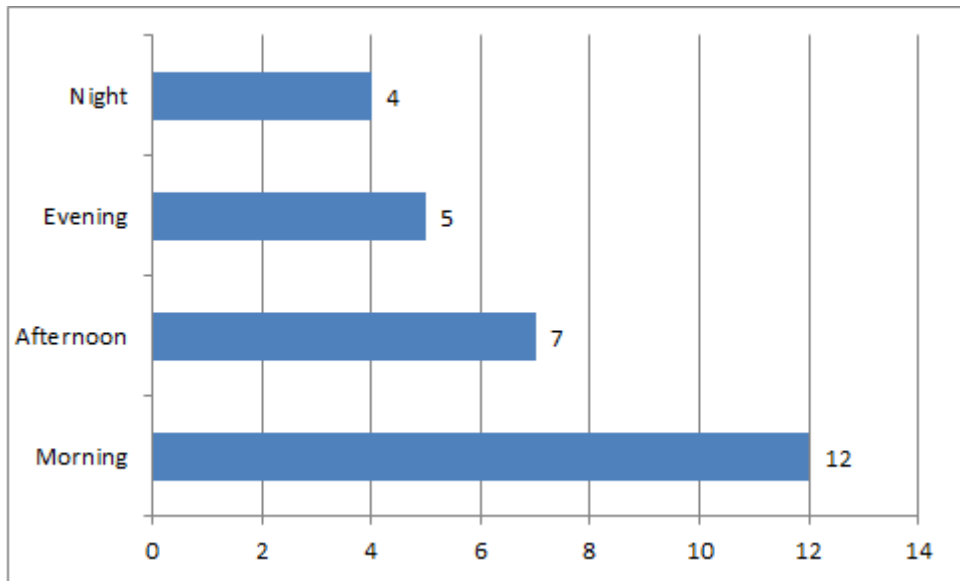
**If you answered 'Yes' how did this make you feel?**

*She was only in a couple of days when I got a phone call one afternoon to say she was very upset and confused and being aggressive with the staff. They said they were struggling to control her and it might help if I came up earlier than usual. My wife and I went as soon as we could but when we got there we were shocked. A nurse tried to console us and asked my wife's name. When we told them they said it might be better if my wife didn't go in as my sister had been shouting about her and might harm her. We were very upset - my wife is very good to my sister and my sister has no one else but us. The nurse explained that she didn't know what she was doing or saying. When I went in there was security men there and she was completely mad. Screaming and kicking and hurling abuse. It was terrible to see. For the next few days I tried to be there as much as I could to try to settle her*

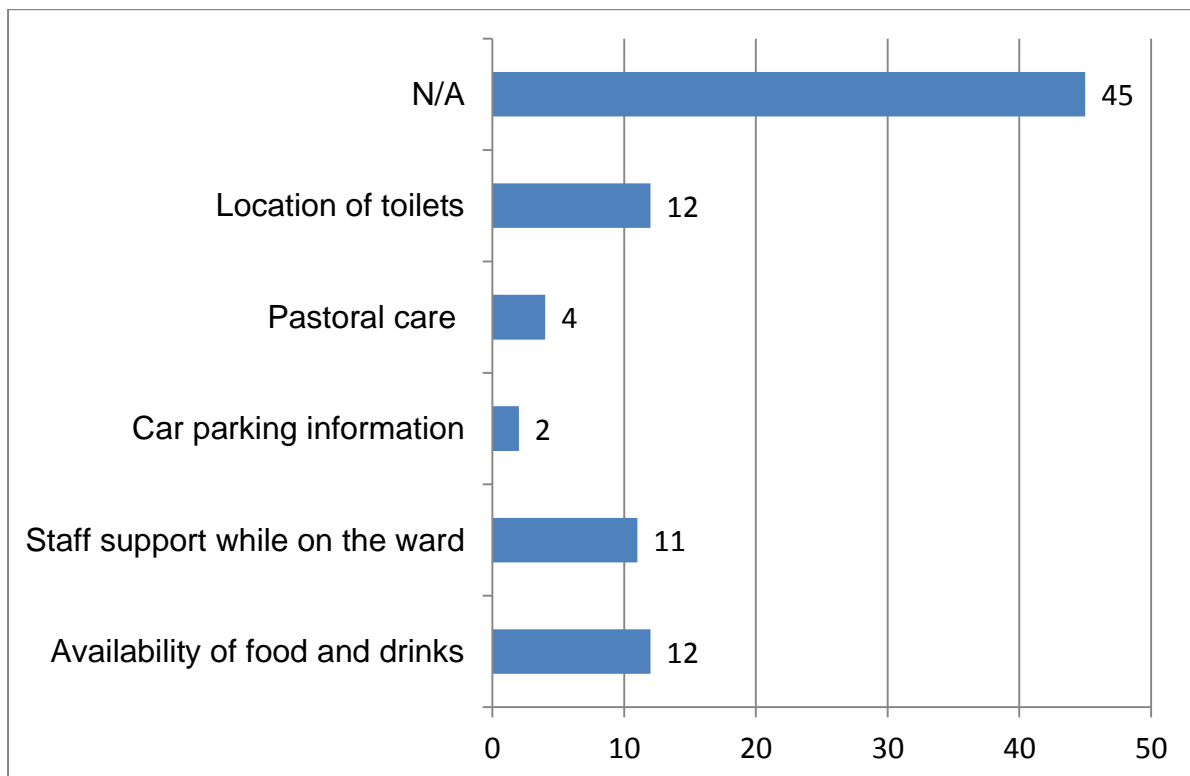
*That night my phone went about 2 in the morning. It was the staff on the ward saying that dad was very agitated and they couldn't settle him. They asked if I could come up to sit with him and try to settle him*

*Eventually my family arrived. I later was told by my son and daughter that they were sent for before visiting to try to reassure me. As soon as my family came everything started to come back to normal. They were able to reassure me about what was going on and that I was totally safe.*

**If you answered Yes what time were you contacted at?**



**If you have utilised extended visiting hours or were called to return and support your relative were you advised of?**



## What could have improved your experience?

*One person who had overall knowledge of the patient. Also the same person to take time to spend 15 minutes with the family to explain the process and what to expect.*

*More toilets in the hospital for patients and visitors.*

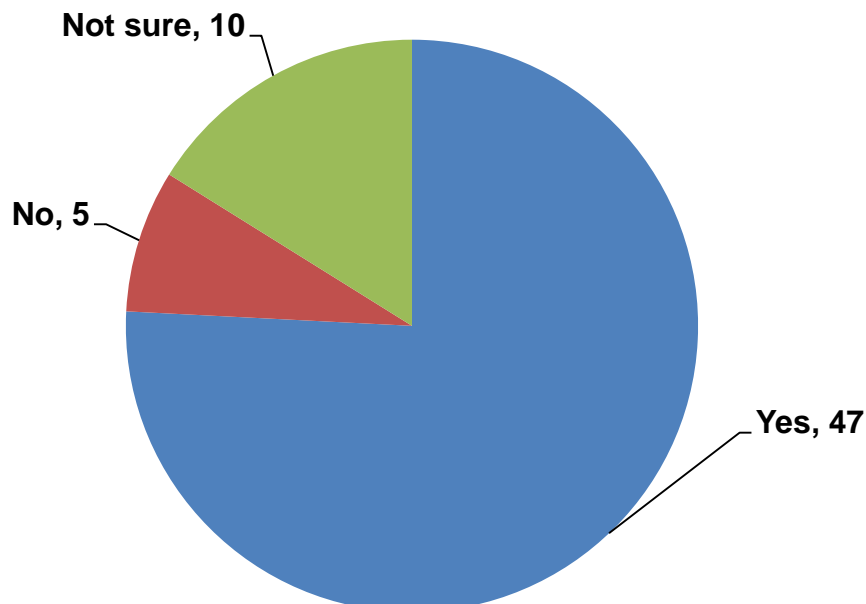
*Yes getting more information on the ward about the delirium*

*Communication with family members is so important the nurses showed great care towards my mum but in 7 days of being in hospital I never once got to talk to a Doctor.*

*When he was delirious being able to come in outside of visiting and be with him more. We could have got him to eat and drink more and would have been happier*

*More staff who understood what was happening.*

## Would you recommend for a friend or family member to received treatment and care in this facility?



## 5.0 Key messages from stories:

A number of key messages were evident in the individual stories, which help to identify “**what matters**” to patients/family members and carers during and after an episode of delirium.

### Key message 1: Providing information and explanations

From the detail in the stories it is very clear that for many people the onset of an episode of delirium can be unexpected, unexplained and can contribute to high levels of anxiety and distress for both the patient and their family /carers. A positive patient experience is enhanced by explanations and information about diagnosis, ongoing care, and advice on discharge and follow up care. Information and explanations need to be provided in a timely manner and in a consistent manner. The provision of written information through the delirium advice leaflet appears to be very beneficial.

### Key message 2: Importance of family presence

Knowing **what matters** can be extended to knowing “**who matters**” as many stories describe the importance of having close family members and friends present, particularly if the patient becomes very agitated and unsettled during the episode of delirium. Some stories from family members also describe how they feel that the staff are under pressure and by being present with their relative can also be helpful for the staff.

### Key message 3: Appreciating the effects that an episode of delirium can have on patients/family members and carers

From the information in many of the stories, an episode of delirium can have profound effects on patients/family members and carers. Many describe how the sudden change and out of character behaviour of the patient can cause high levels of anxiety and distress. This can have an impact in a number of ways, including, how the patient can communicate, the feeling of safety which the patient may have and the degree of uncertainty about the outcome and possible recurrence.

## 6.0 Areas for reflection, learning and action:

- Continue to embed the work from the regional delirium improvement work stream
- Ensuring consistency in explanations and checking that it has been understood
- Ensure that patients and their families receive information about delirium in a timely way and that this is also supplemented by providing the information leaflet
- Work with Trusts to ensure person centred approaches to visiting are in place.
- Continue with the collection of stories from patients/family members/carers
- Consider collection of stories from staff in relation to their experience of caring for patients with delirium episode

## 7.0 Conclusion

Whilst it is recognised that the number of stories to date is relatively low there is some evidence to suggest that the regional delirium improvement work is making improvements in delirium care and engagement for patients, family/carer and staff members. The collection of stories will be ongoing in order to further evaluate this work. The stories provide a rich source of information and insights into the care of patients and their families during an episode of delirium, and it is clear that this opportunity is welcomed, as summarised below:

***When I heard about 10,000 More Voices I felt it was important to tell our story, I hope that by doing so other families will be listened to or receive better explanations in these circumstances..... If as you say our story is used to shape future healthcare, improve services and educate staff then I am content that this opportunity is available***

## **References**

Sensemaker® software produced by Cognitive Edge Pte