



REH PATIENTS COUNCIL

# Strengthening the Patient Voice:

Results Report:

*'I have a voice, hear me.'*

May 2019

No individual can be identified from the results in this report  
and no attempt should be made to do so.



YOUR HOSPITAL

YOUR VIEWS

YOUR VOICE

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## Introduction

This report captures what patients shared about their experiences in the Royal Edinburgh Hospital (REH) as part of a quality improvement project run by the REH Patients Council. A separate Quality Improvement Report sets out in detail the processes behind the project.

The information was gathered between January and March 2019 through a series of feedback events held on 7 mental health wards. (This project did not cover Forensic, IPCU and CAHMS wards). The events were based around a short survey and a group discussion. The first part of the survey had 9 questions on issues that had been found to be important to patients. People were asked to select 1 of 5 (1 question had 6) responses and could add comments. The second part of the survey had 3 qualitative questions. These 3 questions also formed the basis for the group discussions. (A copy of the survey is at Annex A).

The response levels for each ward are shown in the table below. 4 people also completed the survey just before discharge in one further ward. This report includes their responses.

	Total	Adult acute (F)	Adult acute (M)	Older acute (F)	Older acute (M)	Adult rehab (M)	Adult rehab (M)	Older rehab (mixed)
<b>Group participants</b>	40	4	4	7	6	6	9	4
<b>Survey responses</b>	46	8	8	7	1	4	10	8
<b>Combined no. of surveys completed and group participants</b>	86	12	12	14	7	10	19	12
<b>Patients given opportunity to participate</b>	101	16	16	15	11	17	17	9

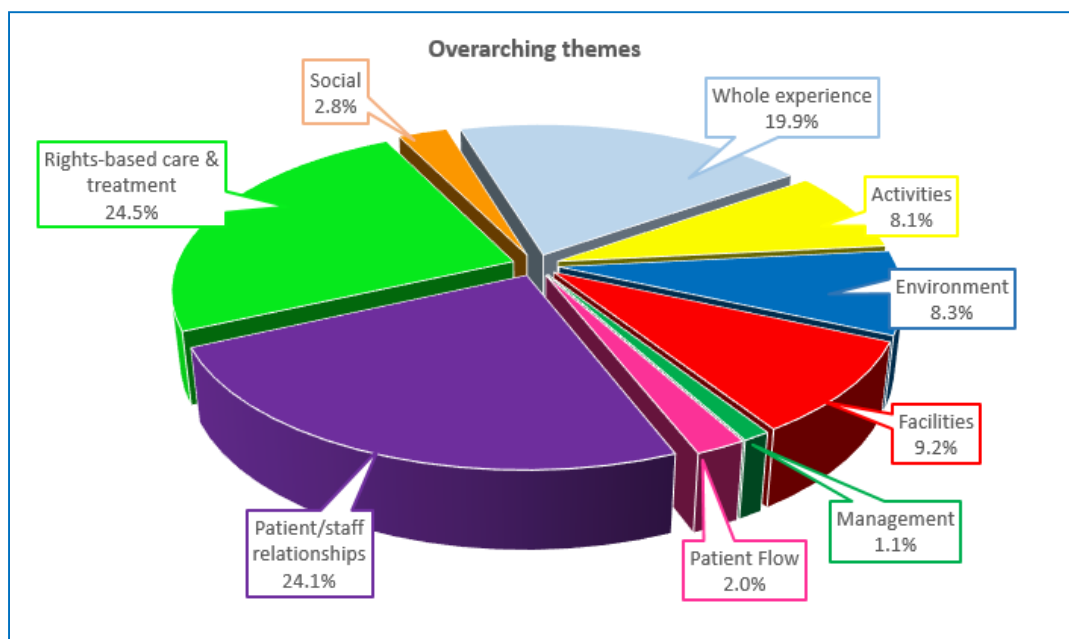
The 50 surveys responses and the 7 group discussions resulted in 543 comments from people and groups about how they felt and what they thought about being here. This qualitative data was coded and grouped under 9 themes. The quantitative data from the first 9 questions in the surveys was also collated and then linked to the most relevant theme.

The rest of this report is structured around these 9 themes, giving an overview of both the quantitative and qualitative feedback that people gave under each.



## The overarching themes

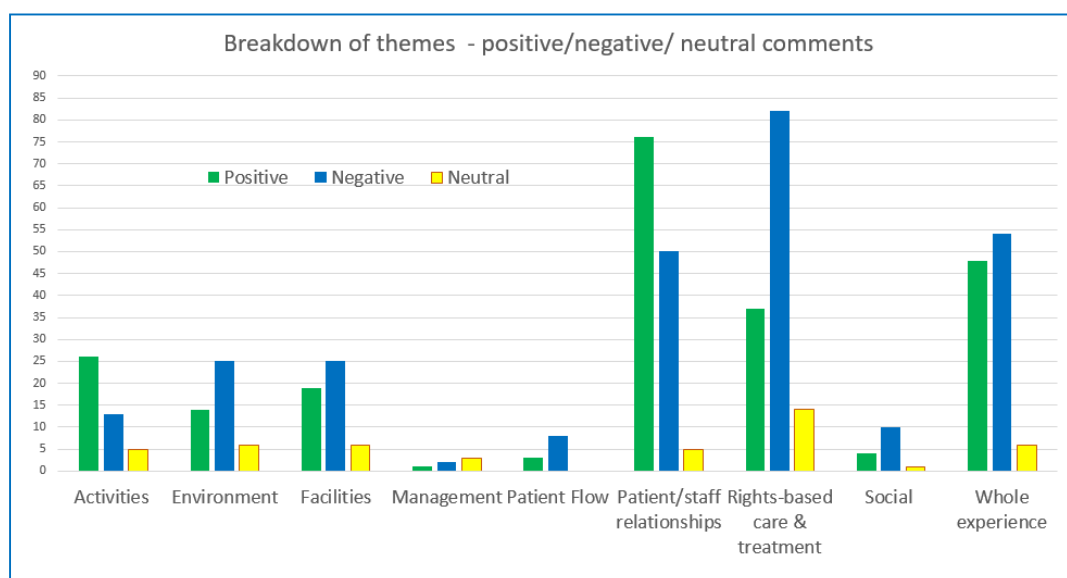
People made 543 comments about their experiences in the REH either in responses to the survey or as part of a group discussion. These comments were coded and grouped under 9 overarching themes. The chart below shows the themes - and the respective proportion of comments received for each.



The issues raised most often were about: the care and treatment people were receiving (24.5%); how people experienced the relationships they had with staff and/or patients (24.1%); and, comments that reflected their overall experience (19.9%).

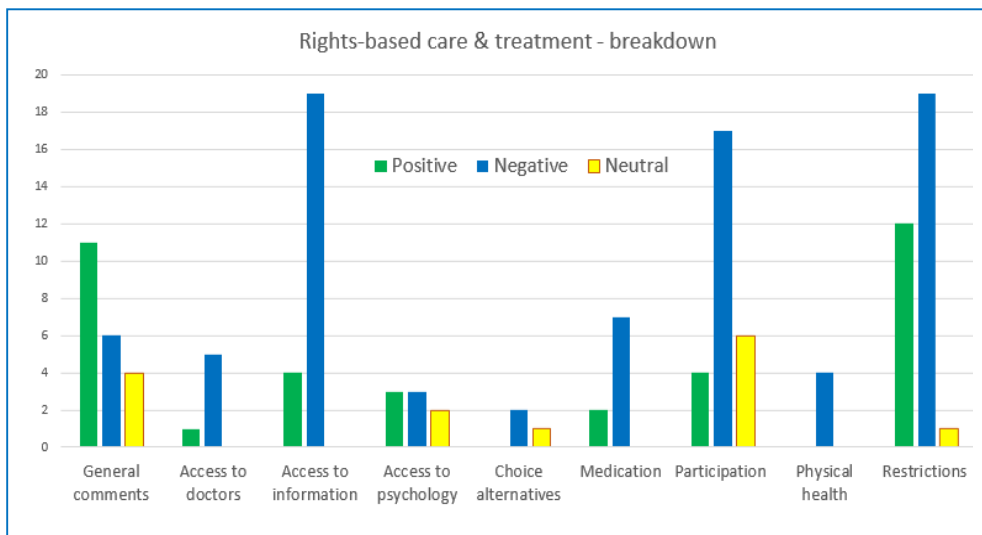
An analysis of the positive, negative and neutral comments found: 228 (42%) positive comments; 269 (50%) negative comments; and, 46 (8%) neutral comments. (Neutral comments include observation and suggestions).

The graph shows the positive, negative, neutral split for each theme.



## Theme 1: Rights-based care and treatment

The most comments (N=133; 24.5%) were received on the theme: **Rights-based care and treatment**. These comments were grouped into 9 sub-themes. There were also 4 questions in the survey that were to do with this theme.



The graph shows the breakdown of the sub-themes and the positive, negative, neutral split of comments within each.

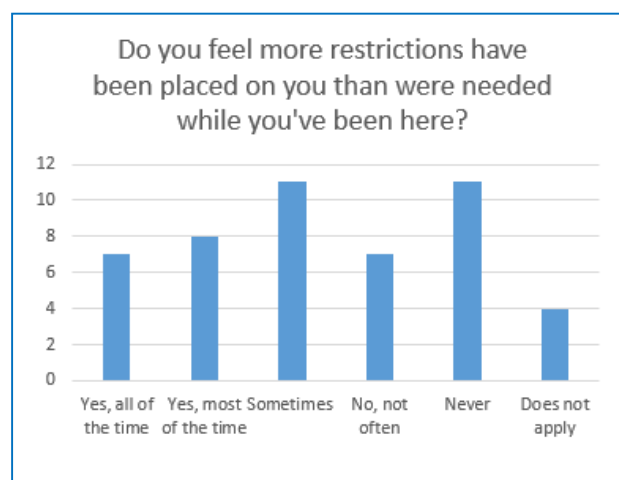
Overall, there were more than twice as many negative (61.7%) as positive (27.8%) comments about this issue. 10.5% of the comments were neutral.

As such, while a minority spoke positively about their care and treatment indicating, for example, that it was ‘helping’ or that they were ‘at the right staging point for the time being’, the majority spoke in more negative terms. They felt: that their ‘care and rights’ were ‘being judged’ by people who did not take their complex needs into account; that those treating them, ‘are just wasting my time and playing with my head’; and, that the psychiatric system was ‘defunct’.

### Restrictions

24.1% of comments (N=32) under this theme were about **Restrictions**. 37.5% were positive, 59.4% negative and 3.1% were neutral. There was 1 specific question about restrictions in the survey.

The graph shows the responses to the question in the survey on restrictions. It indicates a wide variance in experience, with some people never feeling that more restrictions than necessary have been placed on them (N=11) and others feeling this happens either most or all of the time (N=15).



\*4 people did not respond to this question.

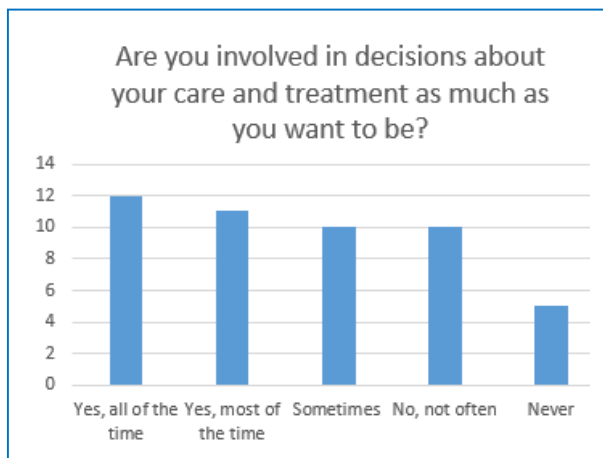
The 32 comments received about restrictions also reflected this diversity of experience with 37.5% (N=12) positive comments and 59.4% (N=19) negative. There were people who indicated that they were happy with the level of restrictions ‘given [their] current condition’. However, others described their restrictions as ‘Dickensian’ and of having ‘more restrictions than necessary’, and 1 person spoke of how the experience of being pinned down to be given medication left them feeling violated.

62.5% of the comments (N=12) about restrictions were about passes. 40% (N=8) of the comments about passes reflected positive aspects. People spoke of: passes making them feel less confined; especially valuing passes that allowed them to stay out into the evening or return home; and, about getting enough passes overall. 55% (N=11) of comments related to negative experiences. There were repeated calls for more passes. The time taken to get passes was criticised as being too long, during which time it was highlighted that people could ‘only get into the garden’. Losing passes was difficult and experienced as a punishment.

People who spoke of being detained found the experience unanimously negative: people did not want to be here; wanted to go home; and, found it difficult being held against their will.

### Participation

20.3% of comments (N=27) were about the extent to which people participated in decisions about their care and treatment plans. There was 1 question about **Participation** in the survey.



The responses to the question shown in the graph see more people selecting 1 of the 2 positive responses (N=23) than the 2 negative (N=15), with the remainder feeling involved sometimes (N=10).

In contrast, however, 63% (N=17) of the comments received on this issue were negative. The main message from these was that while people wanted to actively participate, they felt that they were, ‘not involved in decisions as much as [they] should be’.

\*2 people did not respond to this question.

People described: their ideas being ‘rarely taken into account by doctors’; ‘never getting a say in my needs’; and, having ‘no say in what’s happening’. They spoke of doctors’ manipulation and being made to feel ‘subservient’.

1 person explained, ‘I should not be ignored because I have a mental illness’, while another implored, ‘I have a voice, hear me.’ For another, it was important that their partner was also involved in decisions, while someone else reflected that they had been ‘too ill to be involved’.

14.8% (N=4) of comments were positive showing that some people do feel involved in the decision making process. 1 person had, for example, ‘devised my own plan with my own knowledge.’

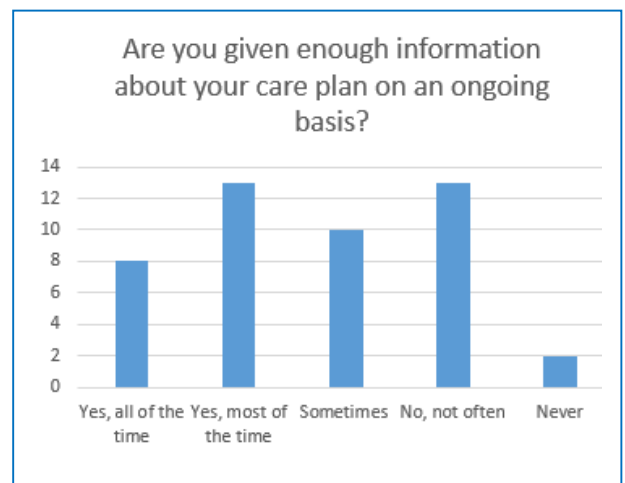
## Access to information and Access to doctors

17.3% of comments (N=23) were about **Access to information** in relation to care and treatment plans. 1 of the survey questions asked directly about this issue. The responses to the survey show a balance between those who felt they were given enough information ‘most of the time’ (N=13) and those who felt they were ‘not often’ given enough (N=13).

The comments did not reflect this balance as 82.6% (N=19) of them were negative.

People spoke of wanting more information about their treatment and finding it hard to get this information. They specifically mentioned not being told about: effects of medications; their rights and entitlements; when they will get home; and, what was discussed on the ward round.

The lack of information and communications left people having no clear idea ‘what is happening or when’ and was felt to ‘create anxiety’. And, even when information was shared, people explained that the very process of remembering could be ‘tiring’ and there were times when they remained confused.



\*4 people did not respond to this question.

Some people advised that they would prefer to hear the honest truth about their progress than be told nothing.

This lack of information linked not only to the previous *Participation* sub-theme, but also to the *Access to doctors* sub-theme. 5 of the 6 comments on this were about not getting enough contact with doctors. People spoke of being ‘rarely seen by doctors’ and that any time they did get with doctors was ‘limited’.

4 comments were from those who did feel they were given enough information. 1 person, for example, felt changes to their medication had been ‘well-explained’

## Medication, Choices/alternatives and Access to Psychology

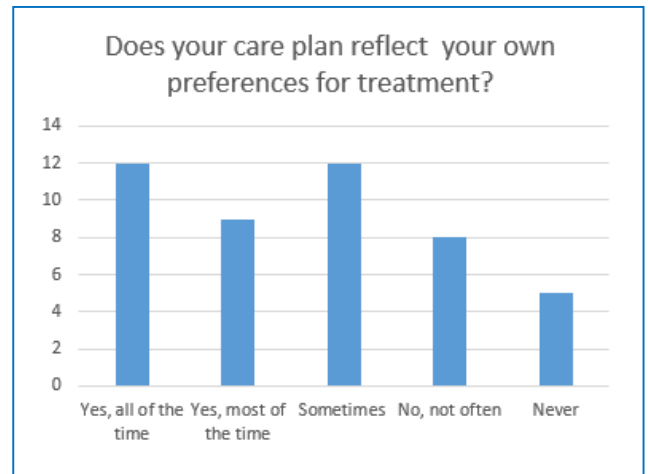
There was 1 question in the survey about the extent to which people’s care plan reflected their own preferences for treatment. The responses in the graph overleaf again indicate a variety of experiences. Most people felt their preferences were taken into account most or all of time (N=21), but others felt that it happened only sometimes (N=12), not often (N=8) or never (N=5).

Comments on this issue were grouped under 3 sub-themes: **Medication, Choices/alternatives** and **Access to psychology**.

6.8% of comments (N=9) under this theme were about **Medication**. 7 of the comments were negative. People felt they were given medications: that did not work; which may be harming them; and, that had side effects they did not like. People spoke of the ‘zombifying’ effects of medication and feeling like they were ‘guinea pigs’ on whom drugs were being tested. 2 comments demonstrated that medication was working for some and when this was the case it was viewed as helpful.

In terms of overall choice and access to alternative treatments, people spoke of how difficult it was when you are given a treatment that you do not want, with 1 person feeling that, ‘more freedom of choice would have suited [them] better’.

6% of comments (N=8) about care and treatment were about psychology. While there was a general feeling that psychology worked there was a variance in access to it. Those who had access felt it was more useful than medication. Others spoke of not getting psychological input when it was needed and there was uncertainty among some people as to whether or not it was available on their wards. Despite the positivity felt for psychology, people were clear that it should not be forced on anyone.



\*4 people did not respond to this question.

### Physical health

A small number of issues that people highlighted as making things more difficult for them were to do with **Physical health** issues. Feelings of dizziness, in particular, were raised.

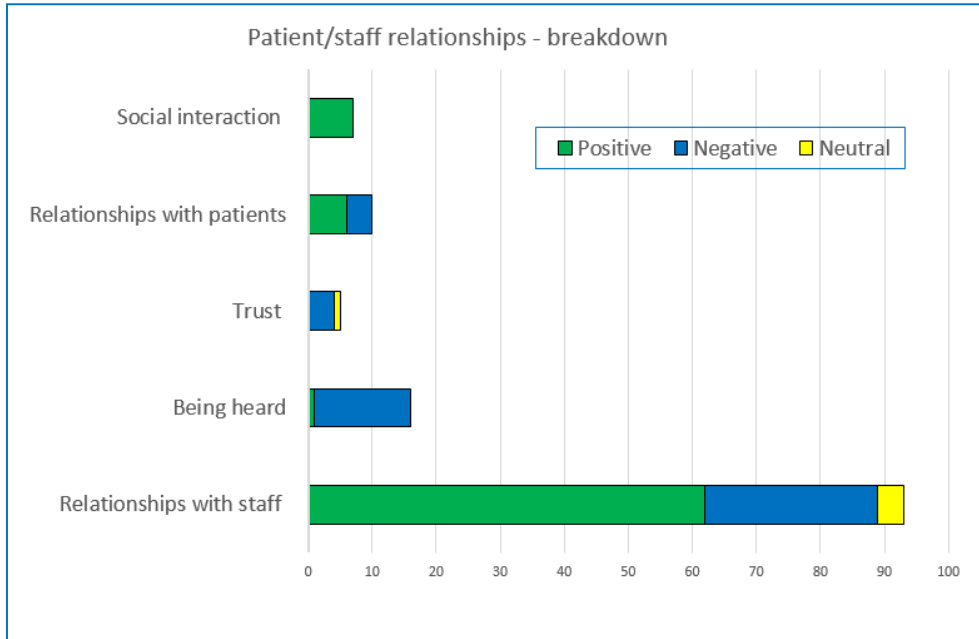
## Theme 2: Patient/staff relationships

131 (24.1%) of the comments received were about **Patient/staff relationships**, a theme which includes relationships formed with either staff or patients.

This is 1 of only 2 themes for which more positive (58%, N=76) than negative (38.2%, N=50) comments were received.

The graph overleaf shows the breakdown of the theme into 5 sub-themes and the positive, negative, neutral split for each.





### Relationships with staff

Most comments (71.0%, N=93) in this theme related to *Relationships with staff* and the majority of those comments were positive (66.7%). The key words used in the 62 positive comments to describe staff are shown in the Wordle© below where the size of the word reflects how often it was used, i.e. words that appear larger below were said more often.



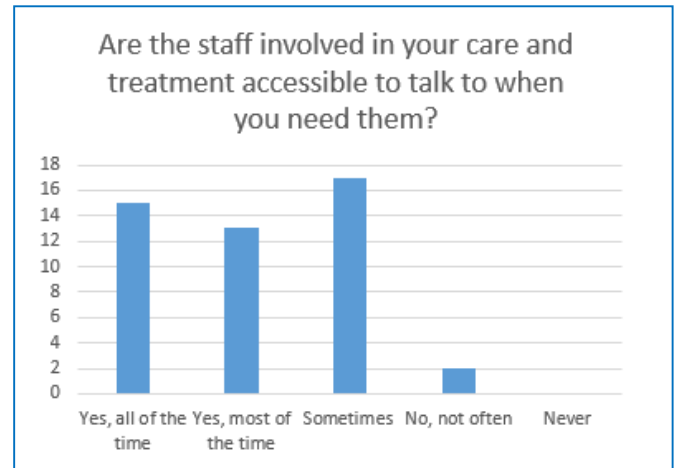
Wordle © 1: Positive responses about staff.

People having positive relationships felt the staff, ‘could not be better’ and were ‘good at combining things and making people feel wanted’. The impact that such positive relationships can have was summed up by 1 person who spoke of the nurses on their ward as being, ‘totally responsive’ to their needs and without whom they would, ‘have lain in bed not moving until I died’.

This positive experience of staff was also reflected in the responses to the 2 questions on this issue in the survey. These are shown in the graphs below.



\*2 people did not respond to this question.



\*3 people did not respond to this question.

29% of comments (N=27) about staff were negative. These reflected people who: did not like the staff; felt ‘terrified’ of them; had been humiliated by them; or, felt hostility from them. The unprofessionalism of staff was spoken about, as were staff who did not have enough patience or show people enough respect. People felt staff held all power and 1 person said they had been pushed into their room by a member of staff.

Other comments recognised that not all staff are the same and that people get on better with some staff members more than others. It was highlighted that some staff interpreted rules differently for different patients, or interpreted rules differently from other staff. Pragmatism over rules was appreciated, especially around the smoking policy, however, the lack of consistency of when rules were applied made it difficult for people to know where they stood. It was felt that quieter patients were valued more by staff, but equally that if you did not cause trouble, you would be ignored.

The final negative comments related to the sense that nurses were too busy and wards understaffed. This chimes with the option ‘sometimes’ being the most popular response to the question in the survey about whether staff are accessible when needed.

## *Being heard and Trust*

Despite the predominantly positive comments about relationships with staff, there was a sub-theme which indicated that this did not necessarily result in people feeling that they were **Being heard**. 12.2% of comments (N=16) under the patient/staff relationships theme dealt with this.

People described feeling ignored or not listened to. They spoke of a ‘lack of understanding’ about how they were feeling and of it being arrogant of professionals to assume that they did. People said that they found it hard to share how things really were with others and there was a plea to be listened to ‘more closely’.

**Trust** in staff had also broken down for some people. Comments about trust made up 3.8% of the overall comments under this theme. For some this was a blanket distrust of all staff, for example, 1 person had been ‘fobbed off’ with ‘false hope’ so often, they no longer expected doctors to keep their word. Others just found some staff more trustworthy than others.

## *Relationships with patients*

7.6% of comments (N=10) about patient/staff relationships were about **Relationships with patients**. 60% of the comments reflected the positive relationships that can form with other patients. People spoke of finding other patients to be friendly, and the rapport that can build between patients on the ward. The peer support of other patients was valued not only because, ‘speaking to other patients [can] really help’, but also because fellow patients can be skilled at de-escalating situations on the ward.

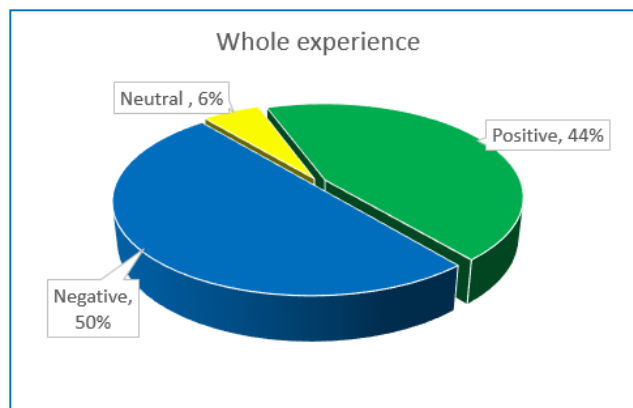
The negative comments (N=4) reflected ways in which the behaviour of patients, or not liking other patients, can make the experience on the ward more difficult for people.

## *Social interaction*

Issues on the value of **Social interaction** itself made up 5.3% of the comments (N=7) under this theme. All comments raised reflected positively on the benefit that some people find simply from being among other people. Having other people around made people ‘feel less isolated’. People spoke positively about ‘not being on their own’, the ‘camaraderie’ among patients on the ward and the ‘good company’ of the staff’.

### Theme 3: Whole experience

19.9% of comments (N=108) fell under the theme: **Whole experience**. The chart shows the split between positive and negative responses. The survey and the discussion groups asked people to try to sum up in 2 or 3 words how it felt to be here. In responses to other questions, people also described their overall experience.



The first Wordle© below shows the key words used in the 48 positive comments people made about their experience. The second shows the words used in the 54 negative responses.

As before, the size of each word reflects how often it was used.



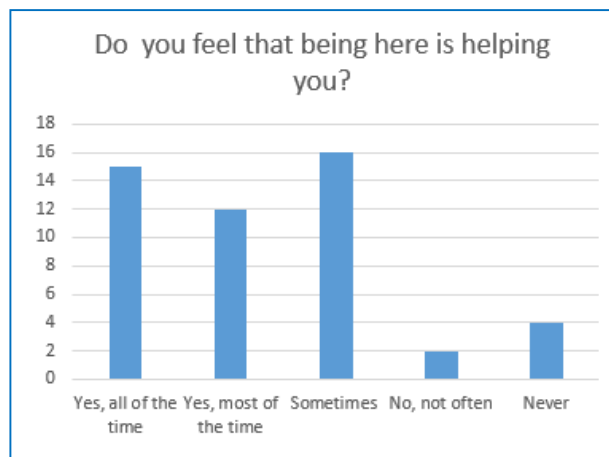
Wordle © 2: Positive responses about experience



Wordle © 3: Negative responses about experience

The Wordles© suggest that the degree to which a person feels that being in hospital is helping (or not helping) influences their overall experience. The issue of whether being here is felt to be helpful was also addressed directly by a question in the survey.

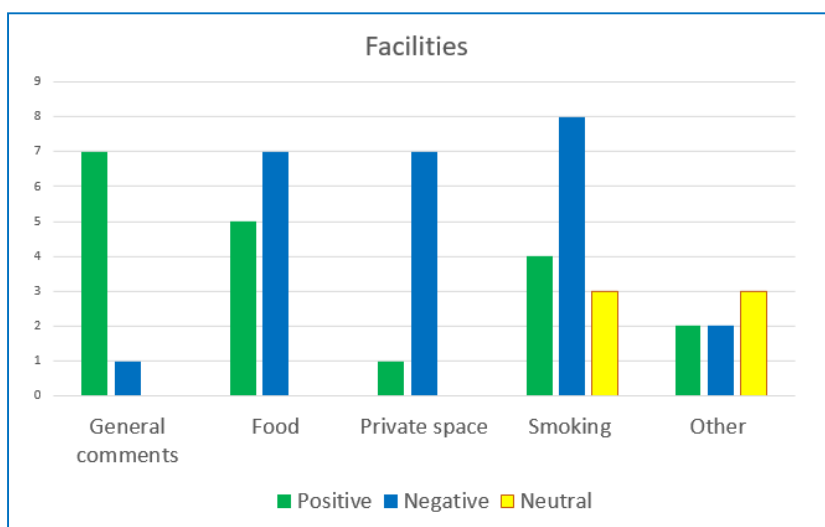
The graph shows that nearly everyone felt that being here was helping them at least some of the time, with the majority of people (N=27/49) choosing the 2 most positive options.



\*1 person did not respond to this question.

## Theme 4: Facilities

9.2% of comments (N=50) made were about the theme: **Facilities**. The comments received were grouped into 5 sub-themes.



The graph shows the breakdown of the sub-themes and the positive, negative, neutral split within each.

Overall, 38% of comments were positive, 50% were negative and 12% neutral.

### General comments

There were 8 comments about the hospital facilities in general, all but 1 of which were positive. The Royal Edinburgh Building was felt to be ‘much better than the old’ hospital, with comments about having ‘very good rooms’, being like a 5\* hotel and having good accessibility. The only complaint was that there was no identified place where people could exercise easily.

Discussion in 1 of the wards in the Andrew Duncan Clinic described the ward as ‘comfortable’.

## Smoking

The sub-theme with the most comments was **Smoking**. 30% of comments (N=15) were about this. 53.3% of these comments negative. For these people the smoking policy is ‘hell’ as the inability to smoke on the ward removes one of their strategies for dealing with stress and anxiety. People highlighted that they had not come here to stop smoking and the restrictions in place made the experience of being in hospital harder, especially for smokers who did not have passes.

Pragmatism shown by staff around the enforcement of the non-smoking policy was therefore welcomed. 1 person felt the policy had helped them stop smoking which they viewed as a ‘bonus’.

## Food

24% of the comments (N=12) about facilities were grouped around the sub-theme of **Food**. There were conflicting experiences with 58.3% negative comments and 41.7% positive.

The food was identified as one of the positive things about being here by a number of people. For them the standard of food was ‘very good’.

Others’ experience of the food was not good. People spoke of: not liking the food; not always getting what they had ordered; it not looking attractive; and, the portions being too large, leading to food waste.

## Private space

The issue of **Private space** accounted for 16% of the comments (N=8) under this theme. All but 1 of the comments were negative.

People spoke of not being able to have other people in their rooms without staff harassment. This policy was felt to impair social integration on the ward. Equally, however, the policy did not prevent others from feeling paranoid about people going into their rooms and being worried about the security of their personal belongings as a result.

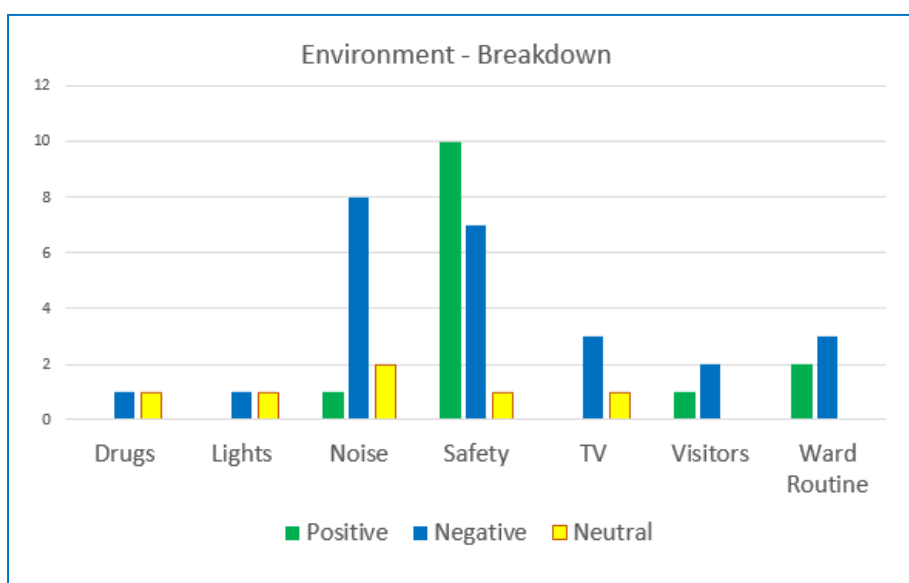
1 person spoke of their ward having a nice room where people could have private conversations. However, others highlighted that there is only one such room making it difficult to find a private space if it was in use – and people advised that doctors did use this room to chat with patients. People explained that there was nowhere private to take visitors and nowhere, more generally, to have a conversation on the ward without the feeling of being overheard or observed.

## Other

In the Royal Edinburgh Building, en-suite shower facilities were very welcome, but people in 1 ward felt the pressure of the water could be improved. The provision of WiFi would be appreciated.

## Theme 5: Environment

8.3% of the comments (N=45) were about theme: **Environment**. This theme seeks to capture the extent to which the ward and hospital environment is conducive to mental wellbeing and recovery. The comments received were grouped into 7 sub-themes.



The graph shows the breakdown of the sub-themes and the positive, negative, neutral split within each.

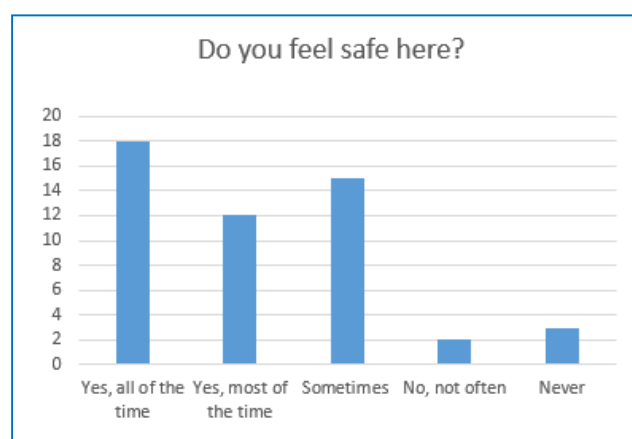
Overall, 31.1% of comments were positive, 55.6% were negative and 13.3% neutral.

There was 1 survey question linked to this theme which asked whether people felt safe.

## Safety

40% of comments (N=18) under this theme related to the extent to which people felt safe.

There was a specific question in the survey on this. The graph shows that the majority of people selected 1 of the 2 positive options (N=30/50). Only 5 people selected the negative options, with the remainder (N=15) indicating that they felt safe at least some of the time.



55.6% of comments (N=10) were also positive. People felt safer in hospital than they had in the community and spoke of feeling ‘safe at last’ and being well monitored by staff for their own safety. There was also an acknowledgment by some that they could not currently live safely at home.

Alongside these feelings of security however was the recognition that coming into hospital can be ‘scary’, especially if it is your first time and you don’t know anyone.

There were also reflections about how the behaviours of others, both staff and patients, can create feelings of unease: ‘it can be scary when people kick off’; and, there are ‘more vocal and intimidating staff which for me is a very scary environment’. People spoke of altering their own routines to avoid specific people.

### Noise

24.4% of the comments (N=11) under this theme were about **Noise**. 72.2% (N=8) of these reflected the negative impact of noise. At its worst, people had experienced ‘horrendous’ and ‘continuous, unbroken noise’ coming from people’s rooms and pled for ‘at least 1 hour in the day when I could have a quiet coffee’. Other negative comments related more to the practicalities of sharing space with other people, with complaints of the TV being too loud and about people snoring and banging doors. There was an appreciation for being on ‘quieter’ wards, although 1 person complained their ward could be ‘too quiet’.

### Ward routines

4 comments related to **Ward routines**. The inflexibility of routines was difficult and meant that while some people wished breakfast could start earlier others hated that the hoovering of the ward started their day so early.

The ability and requirement to take more responsibility was viewed positively on the rehab wards (e.g. having facilities to cook for yourself and rotas for setting dining tables).

### Visitors

Being in hospital left some people feeling ‘cut off from the world’, and having **Visitors** was said to make a positive difference. It was suggested, however, that it was still not an environment that people would want to have children come into.



## Drugs, Lights and TV

Issues to do with **drugs, lights and the TV** were each brought up on a few occasions. While some argued that cannabis should be allowed on the ward, others had experienced the presence of people dealing drugs on the ward and felt that they preyed on the most vulnerable patients.

People wished that the bright lights in their ward could be changed to dimmer switches. The fact that the TV was constantly on was annoying for some people and a call was made for guidelines for it, at least, to be switched off at mealtimes. It was also suggested that TVs in the bedrooms would be nice.

## Theme 6: Activities



\*1 person did not respond to this question.

One question in the survey related to the theme, **Activities** and whether they met people's needs. Only 3 out of 49 people who responded felt their needs were never or not often met.

8.1% of comments (N=44) received were about activities. This is 1 of only 2 themes where more positive (59.1%) comments were received than negative (29.5%).

Activities are highly valued by people. They are 'useful in passing the time' and making people 'feel good'. Activity nurses, occupational therapists, therapists and music and art groups were all praised. Activities in the Hive and the library, as well as educational and employability opportunities were also commended. For some, group activities were positive, while others highlighted that people of a more solitary nature need to be in the mood to take part.

While some said that there were enough activities, other spoke of having 'nothing to do on the wards' and that the 'weekend is incredibly long' as there are no activities on the ward or in the Hive. Another criticism was the lack of opportunity for physical exercise.

## Theme 7: Social

This theme reflects that aspects of people's lives outside of the hospital continue to impact on their experience within it. 2.8% of comments (N=15) related to this theme.

People were worried about how things would work once they were back in the community and until these worries were addressed they did not feel they would be able to leave. There were doubts voiced about whether they would be able to cope and a lack of knowledge about what supports would be available in the community once they left.

People spoke of the lack of resources in the community, with stories of people asking for help prior to admission and not getting it. It was felt that a 10 minute GP appointment was not long enough to deal with complex mental health issues.

Support in the hospital to deal with issues in the community was valued. People spoke of their appreciation for staff helping them to clear up problems they had had with their house prior to admission and of good discharge planning to ensure enough support was in the community to allow them to return home.

People worry about the impact their being in hospital is having on the ones they care about in the community – this can be family, friends or pets.

A lack of money can make the hospital experience more difficult as everything is felt to be expensive here.

## Theme 8: Patient flow

**Patient flow** refers to the length of time a person may stay in hospital. 2.0% of comments (N=11) were about how people felt about this. The majority of comments (72.7%, N=8) about this reflected that people felt their progress was too slow.

On adult acute wards, people spoke: of wishing for their care-plan to be reviewed frequently, but it taking 'a lifetime' to happen; of making progress but 'it's very slow'; and, about how in general, everything takes a long time here.

In adult rehab wards, the overriding sense was that any initial benefits that people felt they had gained from being in hospital were undermined by being kept in too long. People said being here was 'good for a spell when you need it for, no longer', that 'rehabilitation had been good, but too long' and that they were now ready to move on. 1 person explained that they had been waiting for accommodation in the community for over a year.

A few people indicated that they were satisfied with their rate of progress even if it was slow. They linked this gradual approach - where 'recovery wasn't rushed' - to a hope for better longer-term outcomes.

## Theme 9: Management

1.1% of comments (N=6) concerned the overarching **Management** of the hospital. People recognised that it cost a lot to run a hospital and that there were limited resources, however, it was felt that patients should be involved in decisions about how the finite funding for wards should be divided up. There was an impression that there was a high turnover of staff and a feeling that staff deserved a pay rise.

Finally, there was a concern that issues in the ward were merely symptoms of systematic problems and that those higher up the hospital hierarchy simply do not care.

## Key messages

The Patients Council want to thank all the people who took the time to share their experiences and the staff who supported the events on the wards. The results in this report provide a wealth of information about the experience of patients in the REH. We hope this will be used by the hospital to stimulate discussion with patients to identify not only areas for improvement but also ways to sustain and spread good practice.

The Patients Council has taken the following key messages from the experiences that people have shared.

## Prioritising rights

A human-rights approach to care and treatment increasingly prioritises the rights, will and preferences of patients. This requires a movement away from ‘substituted’ towards ‘supported decision-making’, with decisions being taken *with* patients rather than *imposed upon* them. The results support this approach with patients indicating that they wish their voice to be heard in decisions about their care and treatment.

As a starting point, the Patients Council considers that decision making requires access to all relevant information and opportunities to meaningfully engage and participate. The results here suggest that this is the experience of some patients, reflecting that such an approach is possible. However, the comments received demonstrates that many patients still feel uninformed about their care and treatment. This leaves them feeling confused, disempowered and increases their levels of anxiety. Without information, people cannot meaningfully participate in decisions about their care and treatment and our results show that many people do indeed feel they are not involved in these decisions as much as they wish to be - or feel they should be. The results suggest that decisions about medication and passes are of particular importance to people.

## The social patient

The results confirm that relationships with both staff and patients are vitally important and influence how people feel about their experience here. Humans are social beings and the social interaction people experience on the ward is appreciated, especially for those who feel it in stark contrast to a sense of isolation they have felt in the community.

While the results indicate predominantly positive relationships with staff, some people continue to feel they are not being heard and many cite loneliness as a key part of their experience here. This appears, in part, to be linked to the experiential gap that patients perceive in staff and the consequent limited understanding staff can have about what is really going on for people while they are here. The results suggest that this gap may be alleviated, in part at least, by recognising the value of peer support within the ward or by staff listening ‘more closely’.

It follows, therefore, that the responsiveness of staff is highly valued among patients. However, experience of this is variable. On a practical level, staff are simply not always accessible to patients at the time they need them. And, the negative experiences of personal interactions are ones that often leave the impression on patients that the staff base these on their authority as staff members, rather than on the understanding, as 1 person put it that, ‘at the end of the day, we are all humans’.

## Final thoughts

These final thoughts combine the results in this report with information that the Patients Council have also gathered through their collective advocacy meetings which took place over the same timescale as the project:

- Health and social care integration is not yet working for everyone. Those without support in the community seem to enter a hospital ‘vacuum’ where their worries about how they will cope when they return to the community and the practical preparations for community living are not always met either by the hospital or the community. This can result in delays to discharge, traumatic discharges and ultimately re-admissions.
- There seems to be an optimal time for people to be in hospital and any positive experiences of recovery can be undermined if a person is kept in too long.
- Activities and passes are important to people. Getting these right improves the experiences of people.
- Issues around facilities consistently represent a much larger proportion of the concerns raised by people during collective advocacy meetings than was borne out by this exercise.

**REH PATIENTS COUNCIL**  
**MAY 2019**



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