REH PATIENTS COUNCIL

Strengthening the Patient Voice:

Quality Improvement Report

May 2019

YOUR HOSPITAL YOUR VIEWS YOUR VOICE

Contents

Strengthening the Patient Voice

Background

The Royal Edinburgh Hospital (REH) Patients Council is an independent advocacy project providing independent collective advocacy to patients in the hospital. In 2018, the NHS gave the Patients Council funding to do additional work on patient experience. This allowed for a Development Worker to join the Patients Council staff on a part-time basis from October 2018 – May 2019.

The NHS had no influence over the way in which the funding was used, but provided training for the development worker in the NHS Quality Improvement (QI) model. The patient experience work was run as a QI project and this report provides information on what was done, how it went and what can be learned.

The information on patient experience that was gathered as a result of the project is presented in a separate report.

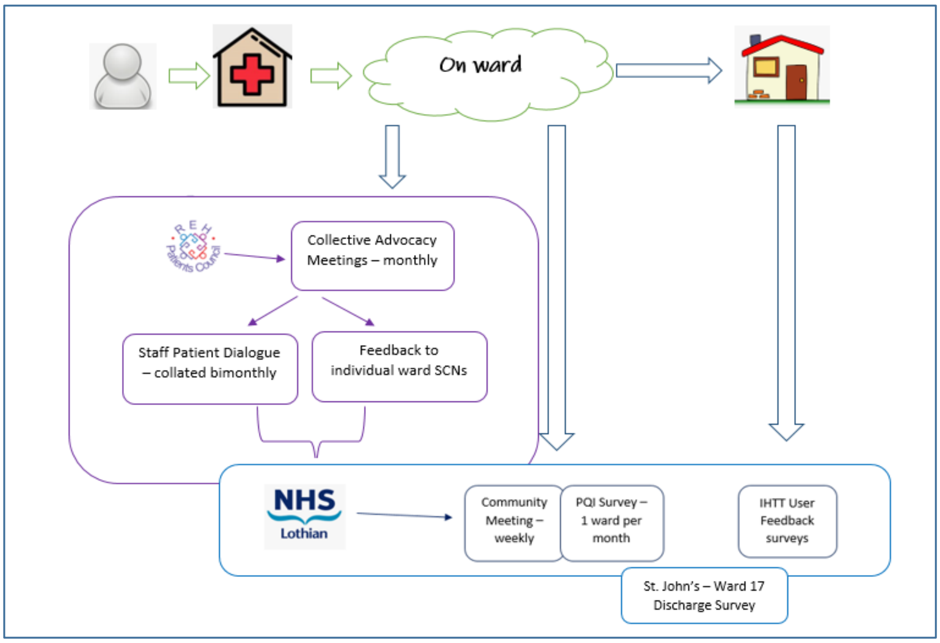
Confirming the need for the project

The Patients Council wanted to run a QI project aimed at strengthening the patient voice by finding effective ways to collect and report patient experience. There are underlying ethical, moral and legal reasons why the patient voice needs to be heard. A short review of literature on patient experience also confirmed additional reasons why such a project would be of value:

- Patient perspectives are critical for the evaluation and improvement of services. Insights from those with lived-experience can identify positive and negative aspects of care which cannot be detected by service providers alone.
- The views that patients hold about their care and treatment can be linked to patient outcomes. For example, higher satisfaction levels are linked to less likelihood of re-admission and poorer views to longer admissions.
- Improving the patient experience on the ward can also improve staff outcomes.

Dodds, P. & Bowles, N. (2001). Dismantling formal observation and refocusing nursing activity in acute inpatient psychiatry: a case study. *Journal of Psychiatric and Mental Health Nursing, 8*(2), 183-188.
Edwards, K. (2000). Service users and mental health nursing. *Journal of Psychiatric and Mental Health Nursing, 7*(6), 555-565.
Gilbert, D. (2015). Seven things that patients bring: The benefits of patients as partners for change. *Future Patient.* Retrieved from https://futurepatientblog.com/
van der Post, L., Peen, J. & Dekker, J. (2014). A prediction model for the incidence of civil detention for crisis patients with psychiatric illnesses; the Amsterdam study of acute psychiatry VII. *The International Journal for Research in Social and Genetic Epidemiology and Mental Health Services, 49*(2), 283-290.
van Der Post, L. F. et al. (2014). Patient perspectives and the risk of compulsory admission: The Amsterdam Study of Acute Psychiatry V. *International Journal of Social Psychiatry, 60*(2), 125-133.

To add value and to strengthen the patient voice, the project would have to bring something new to the table. The Patients Council did not want to replicate or repeat existing processes that were in place to gather patient views. Conversations were held with REH staff and management to gain an understanding of existing NHS methods of collecting patient experience. These were placed alongside the methods used by the Patients Council to create the process map below.



This exercise suggested that a more systematic collection of patient experience could bolster work already being done by the Patients Council and the NHS.

Establishing a patient mandate

As an advocacy organisation, the Patients Council is led by the views of patients. The project could only proceed if patients agreed it was of value. It was also critical that the design of any method of gathering feedback and experiences was underpinned by the views and wishes of patients.

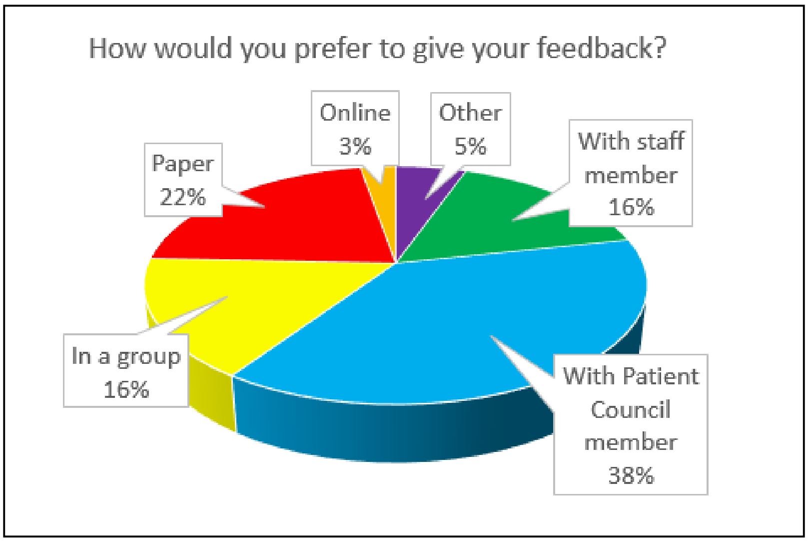
A short, '*What makes a good patient exercise*?' survey was designed to find out:

- Whether patients felt it was important that they were asked for feedback on their experience here; and,
- What a good feedback exercise would look like.

The survey was taken to 11 Patients Council advocacy meetings in November. It was also offered to any patient or former patient who visited the Patients Council offices during that month. At least 1 survey was completed on 8 wards. 17 patients and 5 former patients completed it.

The findings of the survey were:

- Only 1 person did not agree that it was important patients were asked for their feedback on their experience.
- 37.5% of people wanted to be asked regularly. 25% felt the best time was at discharge; 21.9% within the first weeks of their stay. 12.5% wanted to be asked after they had left the hospital.
- 36% would be willing to spend 5-10 minutes on a feedback exercise and 36% would give up 10-20 minutes of their time.
- The pie chart shows the ways in which people said they would prefer to give their feedback having been given the following options: online survey; paper survey; in a group; with a staff member; with a member of the Patients Council. The selection bias inherent in the surveys only being offered to patients who attended the advocacy meetings may have influenced, 'with member of the Patients Council' being the most favoured option (38%).
- 9 people ticked more than 1 method. A separate breakdown of the 13 who selected only 1 option showed preferences for all options other than, 'online'.



The table below shows what people said would make them more or less likely to take part in a patient feedback event.

Barriers	Incentives
• If it was too much hassle. • If I'd left the hospital. • Fear of repercussions for self or staff. • Survey fatigue. • None.	• Having private space to complete it. • To be able to talk and discuss it. • If I knew it would make a difference. • Drinks/chocolate
• Depends on who is carrying out the exercise. • Depends on when you ask me.	

These results provided a patient mandate to do a project aimed at gathering patient feedback and guidelines for how to design a way to do this.

The design of the patient feedback exercise

The '*What makes a good patient feedback exercise?*' survey suggested that any feedback exercise had to:

- Be able to be completed within 10 minutes, with scope to spend more time on it.
- Ensure the anonymity of respondents.
- Give multiple ways to participate.
- Provide feedback to patients and staff.

This meant that any exercise needed to cater both for people who preferred to give their feedback verbally and those who felt more comfortable submitting it in writing. This led to the design of a 'Patient Feedback Event' designed around a short paper survey and a group discussion on the ward.

Using the experiences that the Patients Council had of working through the NHS Patient Quality Indicators (PQI) surveys with patients on the wards, it was felt important that any paper survey:

- Allowed respondents multiple responses (not simply, Yes or No).
- Sought qualitative as well as quantitative responses.
- Gave respondents advance notice of the questions and time to complete it when and how they wanted.

The design of the survey is considered in more detail in the next section.

Optimal times for the events on individual wards were agreed with Senior Charge Nurses to ensure they would not clash with other activities or clinical routines. The Development Worker attended patient meetings on the ward in the two weeks leading up to the event to let people know about the event and to leave surveys to be handed to each patient by staff.

On the day of the event, Patient Council Members led a group discussion on the ward around the 3 qualitative questions in the paper survey. The group discussions were informal. They took place over coffee, cake and fruit – all of which was on offer whether or not patients chose to take part in the discussion. People could pop in and out of the discussion.

Comments from the group discussion were recorded on post-it notes on flip chart paper that the group could see. Any completed surveys were also collected during the event and patient Council Members were available to support anyone who wanted to complete a survey on the day.

The data from the surveys and the group discussions on each ward was analysed together and individual ward reports produced and presented to patients and staff. The data from all the wards was combined and analysed. The results were presented to patients and staff in the REH on 8 May 2019. The written report on the results - ***Strengthening the Patient Voice****: 'I have a voice, hear me'* – is on the Patients Council website (www.rehpatientcouncil.org.uk).

Designing the survey

The survey was designed with two aspects in mind:

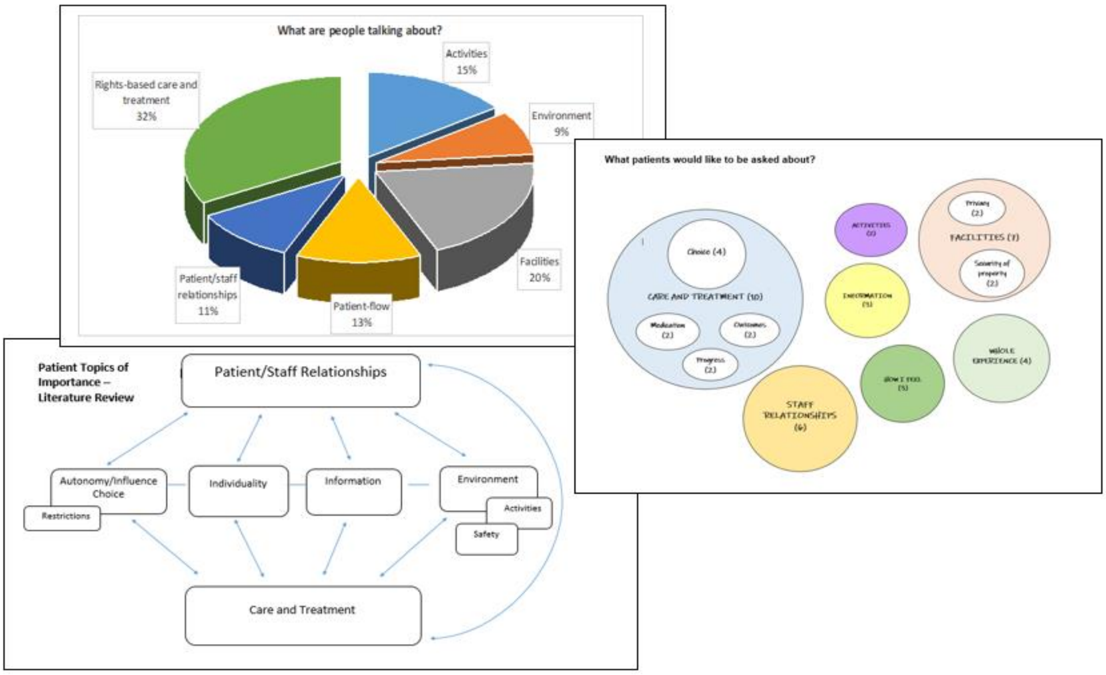
- that the credibility of any feedback exercise relies on its ability to reflect issues that are important to the respondents; and,
- that, nevertheless, it is critical that sufficient opportunity is given to allow people to share whatever experiences they want to.

Given that over 1/3 of people indicated they only wanted to spend 5-10 minutes giving feedback, there was a limit on how many questions could be asked and a 12 questions limit was set. 3 exercises were done to try to identify the key issues of importance to patients.

The first exercise looked at the issues that people were bringing up in advocacy meetings. All the comments from November's meetings were coded and grouped into themes.

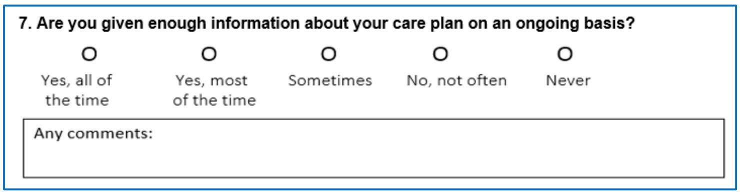
The second exercise was an analysis of the responses to the final question in the '*What makes a good feedback exercise*?' survey. This question asked what people would want to be asked about. Again, the answers were analysed and presented under key themes.

The final exercise was a short literature review to see what academic research had found was important to people in psychiatric hospitals, in general. The results of this were compared with the themes found in the earlier exercises to check that no major issues had been missed in the November analyses. The thematic maps of the three exercises are below.



The degree of overlap between the results provided sufficient confidence to draft 9 questions that reflected key areas of importance.

A spreadsheet of questions was collated from other surveys used in the NHS, in the REH and in research to inform the drafting of the questions. Rating scale questions were used with 5 options (and an additional N/A option for the question on restrictions), with space for additional comments. The copy of the survey is provided at Annex A but an example of 1 of the ratings scale questions is reproduced below.



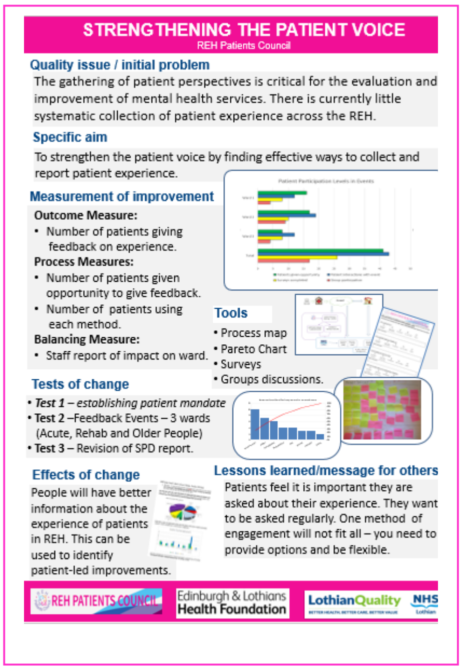
7. Are you given enough information about your care plan on an ongoing basis?

○ Yes, all of the time
○ Yes, most of the time
○ Sometimes
○ No, not often
○ Never

Any comments:

The rating scale questions were followed by 3 qualitative questions asking people to say what was difficult, what was good and what it felt like to be here. The group discussions were also based on these questions. Space was left at the end of the survey for additional comments. The survey was translated into Spanish, German and Hungarian to meet the needs of patients on the wards at the time. 1 ward provided a German translator for the group discussion.

How did we measure success?



STRENGTHENING THE PATIENT VOICE

REH Patients Council

Quality issue / initial problem

The gathering of patient perspectives is critical for the evaluation and improvement of mental health services. There is currently little systematic collection of patient experience across the REH.

Specific aim

To strengthen the patient voice by finding effective ways to collect and report patient experience.

Measurement of improvement

Outcome Measure:

- Number of patients giving feedback on experience.

Process Measures:

- Number of patients given opportunity to give feedback.
- Number of patients using each method.

Balancing Measure:

- Staff report of impact on ward.

Tools

- Process map
- Pareto Chart
- Surveys
- Groups discussions.

Tests of change

- ***Test 1** – establishing patient mandate*
- **Test 2** –Feedback Events – 3 wards (Acute, Rehab and Older People)
- **Test 3** – Revision of SPD report.

Effects of change

People will have better information about the experience of patients in REH. This can be used to identify patient-led improvements.

Lessons learned/message for others

Patients feel it is important they are asked about their experience. They want to be asked regularly. One method of engagement will not fit all – you need to provide options and be flexible.

The project ran a pilot phase of 3 feedback events in January. To pilot events with different populations, 1 adult acute (male) ward, 1 adult (mixed) rehab ward and 1 older person's rehab ward were chosen. By the time of the event, the adult rehab ward had been changed to all male which made the pilot exercise more biased towards male experience than had initially been planned.

The following measures were chosen prior to the pilot to assess how it went:

Outcome measure: to assess the extent to which the events were strengthening the patient voice, the number of people giving feedback as part of the events was collected.

Process measures: to see which methods of collection were effective, the following was collected:

- Number of patients given the opportunity to give feedback as part of the event.
- Number of patients using each method of feedback.

Balancing measure: to check for any unintended consequences of the events, an online survey was sent to staff after the event to assess any impact it had on the routine running of the ward.

The initial results from the 3 pilot events were analysed. In general, the events appeared to have been well attended and resulted in meaningful information on patient experience being gathered. It was agreed to continue to run events on further wards, with the following adaptions:

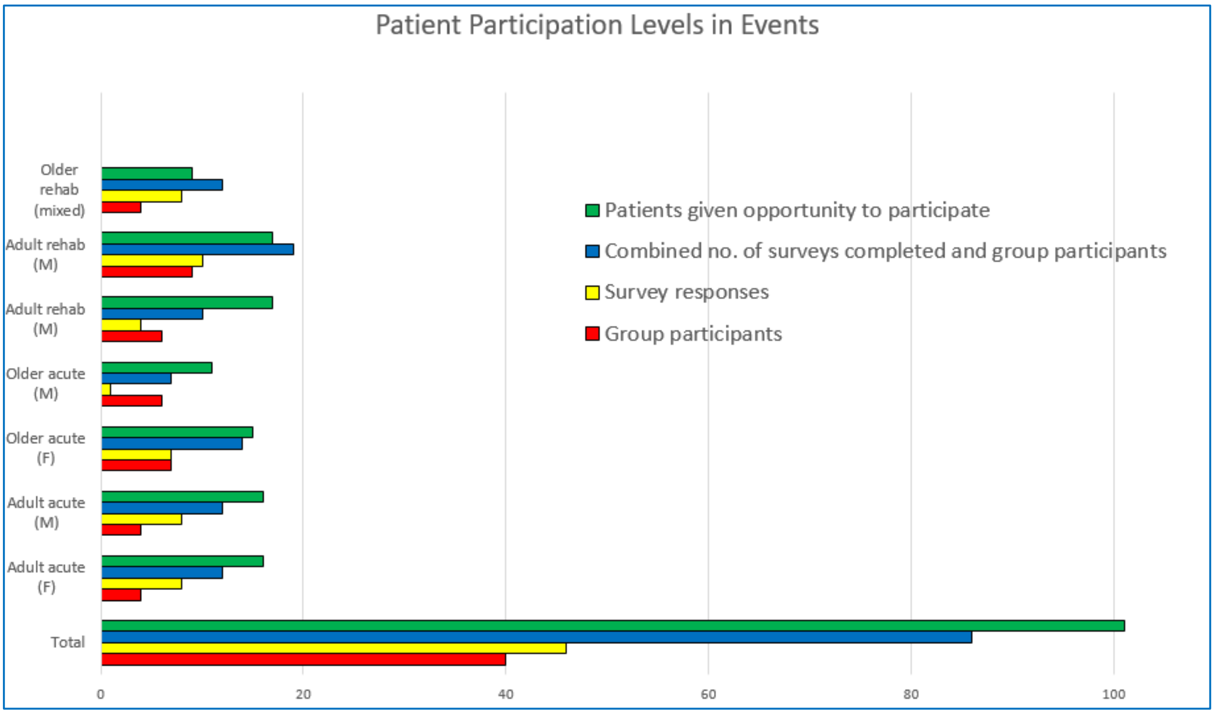
- 1 question in the survey was re-drafted to remove confusion based on feedback from patients completing the survey.
- The event time was reduced from 2.5 hours as experience suggested the optimal time was 1 - 1.5 hours.
- Test the effectiveness of running an event at the weekend.
- Test whether people would fill out the survey in the lead up to their discharge.

During the lifecycle of the project, four further events were run, one on a Sunday. The survey was also offered to patients at time of discharge on 1 female acute ward as a trial. The results of that trial are still being analysed. Forensic, ICPU and CAHMS wards were not included in the project.

How did the events go?

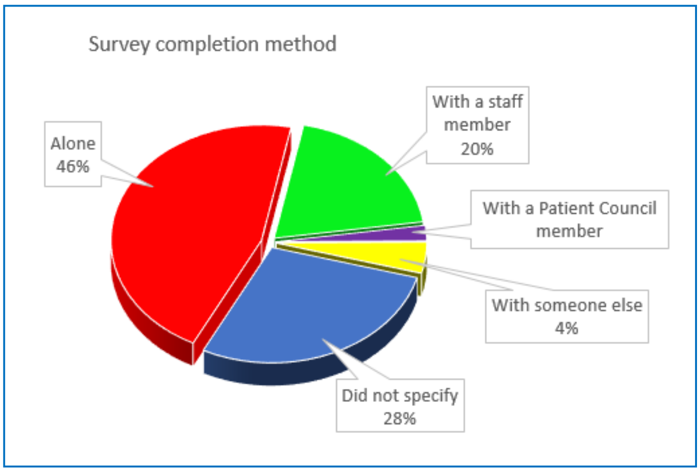
Feedback events were held on 7 wards between January and March 2019.

The graph below shows the overall levels of participation broken down by ward and participation method.



Outcome and Process measures

- There were 101 people on the wards during the time of the events. All were given 2 opportunities to feedback on their experience by either completing a survey and/or taking part in a group discussion.
- Of the people who chose to participate, 46 people (45.5%) completed the survey. 40 people (39.9%) took part in a group discussion.
- The participation rate falls between 45.5% and 86.1%. Only a range can be given because – to preserve anonymity - people in groups were not asked whether they had also completed a survey. Information volunteered by people during the feedback events did indicate, however, that some people chose to only complete the survey or to only take part in the group discussion, and that some people chose to do both.
- Of the 101 people given the opportunity, 62 were men (61.4%). 23 (37.1%) of them chose to complete the survey. 26 (41.9%) took part in a group discussion.
- 39 (39.6%) of those given the opportunity were women. 23 (59%) of women who participated chose to complete the survey. 14 (35.9%) took part in a group discussion.
- The pie chart shows how people chose to complete the survey.
- 15 people (32.6%) who filled in the survey chose only to answer the quantitative (rating scale) questions.
- 7 people (15.2%) chose not to respond to all of the quantitative questions.
- Only 1 person appeared to abandon the survey – completing only the first 5 questions.
- Nearly 543 qualitative comments were collated from the surveys and group discussions.
- These comments were coded and grouped into 9 overarching themes: Rights-based care & treatment; Patient/staff relationships; Whole experience; Environment; Facilities; Activities; Social; Patient-flow; and, Management.



Balancing measures

- A 4 question survey was created on SurveyMonkey® for staff who supported the events (see Annex B). The link to the survey was sent to 16 staff; 5 (31.3%) completed it.
- 3 of the respondents (60%) felt that the event had had no impact on the running of their ward. 2 (40%) felt it had had a positive impact.

- 4 people (80%) felt that the report of feedback was useful, with comments suggesting that the feedback was 'interesting' and 'definitely opened up good discussions and suggestions between staff and patients'. 1 person, however, felt the report was not useful; they felt the results were biased 'due to the cohort of patients on the ward at the time' of the event.
- All respondents said they had, or planned to use the results.
- It was felt by 1 person that the event was, 'well organised and executed' and that it was an 'important opportunity for patients to get their voices heard'. 1 person also noted that the copies of the reports left on the wards were being read by patients.

Lessons learned/message for others

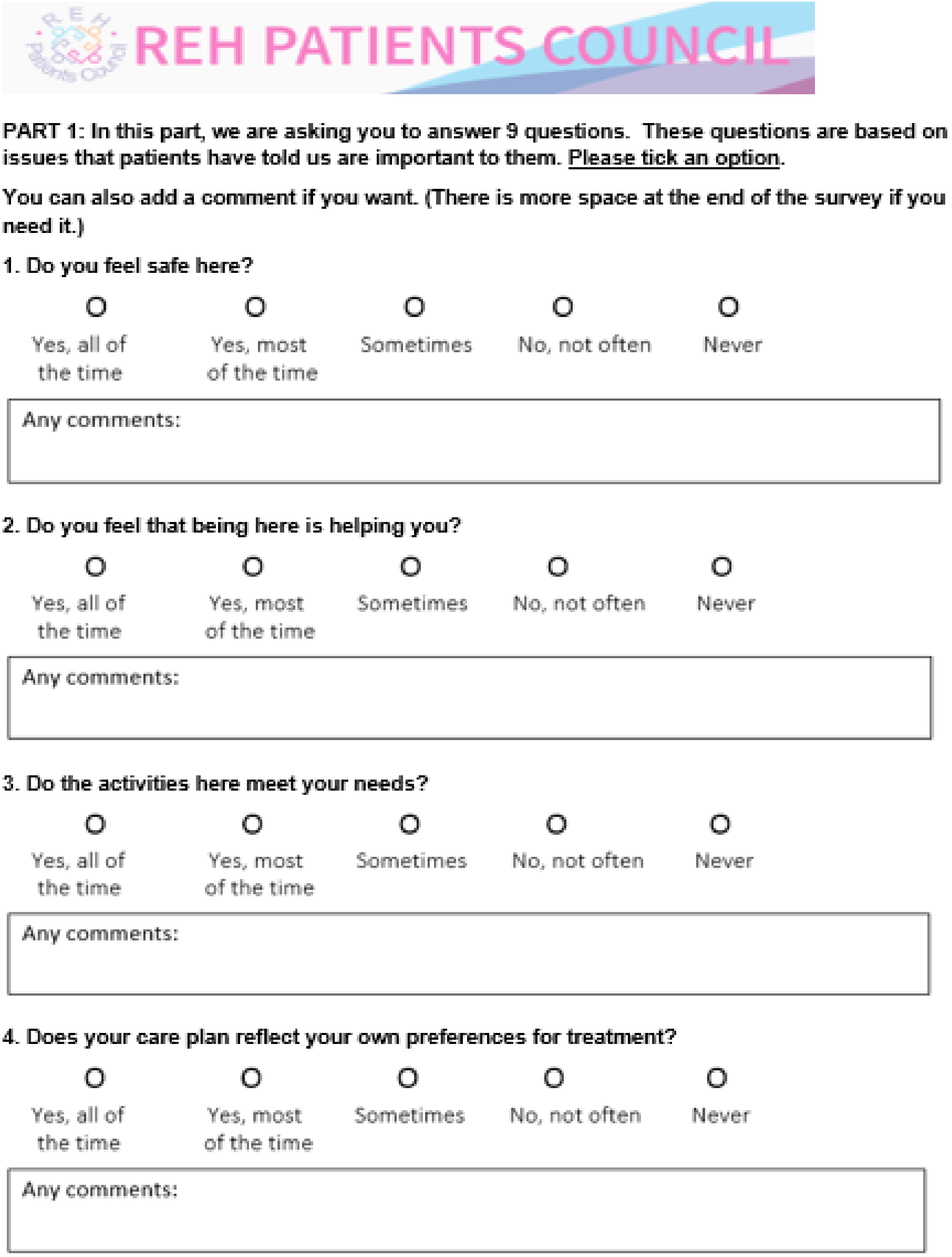
The lessons learned from this project for others wishing to gather patient feedback are:

- Patients on mental health wards are willing to give feedback on their experience and think that it is important it is collected.
- They are able to reflect and give feedback on their experiences, providing insights that can be used to sustain good practice and inform improvements.
- Most people felt that feedback should be collected regularly and this project was, therefore, designed around a process that could be used to capture the overall experience of patients at any time during their stay.
- 'Soon after admission' or 'at discharge' were, however, also felt to be good times to ask for feedback. Our survey was offered to people at discharge as a trial in 1 ward, but only 1 question was added to reflect the discharge stage. Additional research and design work would need to be done if feedback exercises at these times wanted to collect information about the specific experience of admission or discharge.
- While some people were clear that they would not be interested in giving their feedback after leaving hospital, there was some support for this approach and there are ethical advantages to it. This, however, is not an option for the Patients Council as it does not gather personal data about patients.
- 1 method of engagement will not suit everyone – different options need to be provided and a flexible approach taken:
    - Choosing from a list of responses to a question is enough for some people. 9 such questions appeared manageable for all but 1 person.
    - 1/3 of people chose not to provide any written comments in the survey.
    - Some people feel more comfortable giving their feedback verbally.
    - The group environment works best for some people.
- An exercise that can be completed within 10 minutes, with the opportunity for people to take longer if they wish to appears to work for the majority of people.

- Quantitative questions alone cannot capture patient experience. Qualitative responses provide context and depth behind numbers and allow patients to drive the feedback.
- Success of any feedback event is dependent on leadership and ownership on the ward. For this project it was clear that, in particular, staff holding the roles of the Recreation Nurse (alternatively called Activities Co-ordinator, Mental Health Assistant) made a great impact in degree of engagement with the events. They did this by providing support to patients to complete surveys, driving interest in the event and, in 1 instance, arranging a time for patients to complete the surveys together.
- It is critical to bear in mind the legitimacy of any patient experience feedback as reflecting the experience, feelings and thoughts of the person at that time. The natural tendency to try to ‘explain away’ negative experiences rather than engage with them should be guarded against.
- This project has benefitted from having the Patient Council Members, who are volunteers with lived-experience, trained in independent collective advocacy to facilitate group discussions.
- Not participating in feedback must always be a valid choice.

REH PATIENTS COUNCIL
MAY 2019

Annex A: The REH Patients Council Survey



REH PATIENTS COUNCIL

PART 1: In this part, we are asking you to answer 9 questions. These questions are based on issues that patients have told us are important to them. Please tick an option.

You can also add a comment if you want. (There is more space at the end of the survey if you need it.)

1. Do you feel safe here?

○	○	○	○	○
Yes, all of the time	Yes, most of the time	Sometimes	No, not often	Never

Any comments:

2. Do you feel that being here is helping you?

○	○	○	○	○
Yes, all of the time	Yes, most of the time	Sometimes	No, not often	Never

Any comments:

3. Do the activities here meet your needs?

○	○	○	○	○
Yes, all of the time	Yes, most of the time	Sometimes	No, not often	Never

Any comments:

4. Does your care plan reflect your own preferences for treatment?

○	○	○	○	○
Yes, all of the time	Yes, most of the time	Sometimes	No, not often	Never

Any comments:

5. Are you involved in decisions about your care and treatment as much as you want to be?

○ Yes, all of the time ○ Yes, most of the time ○ Sometimes ○ No, not often ○ Never

Any comments:

6. Do you feel that more restrictions have been placed on you than were needed while you've been here?

○ Yes, all of the time ○ Yes, most of the time ○ Sometimes ○ No, not often ○ Never ○ Does not apply

Any comments:

7. Are you given enough information about your care plan on an ongoing basis?

○ Yes, all of the time ○ Yes, most of the time ○ Sometimes ○ No, not often ○ Never

Any comments:

8. Are you treated with kindness, compassion and respect by staff here?

○ Yes, all of the time ○ Yes, most of the time ○ Sometimes ○ No, not often ○ Never

Any comments:

9. Are the staff involved in your care and treatment accessible to talk to when you need them?

○ Yes, all of the time ○ Yes, most of the time ○ Sometimes ○ No, not often ○ Never

Any comments:

PART 2: In this part, we are interested in your thoughts about your overall experience. There are 3 questions.

10. What things, if any, are making it more difficult for you here?

11. What aspects, if any, of your care and treatment are particularly good?

12. What 2-3 words would you use to describe how it feels to be here?

PART 3: These are two final questions about you and how you did the survey. <u>Please tick an option</u>.

13. Are you: Male ○ Female ○ Rather not say ○

14. Did you fill in the survey:

Alone ○ With a member of the Patients Council ○

With a member of staff ○ With someone else ○

Please say who (friend, family)

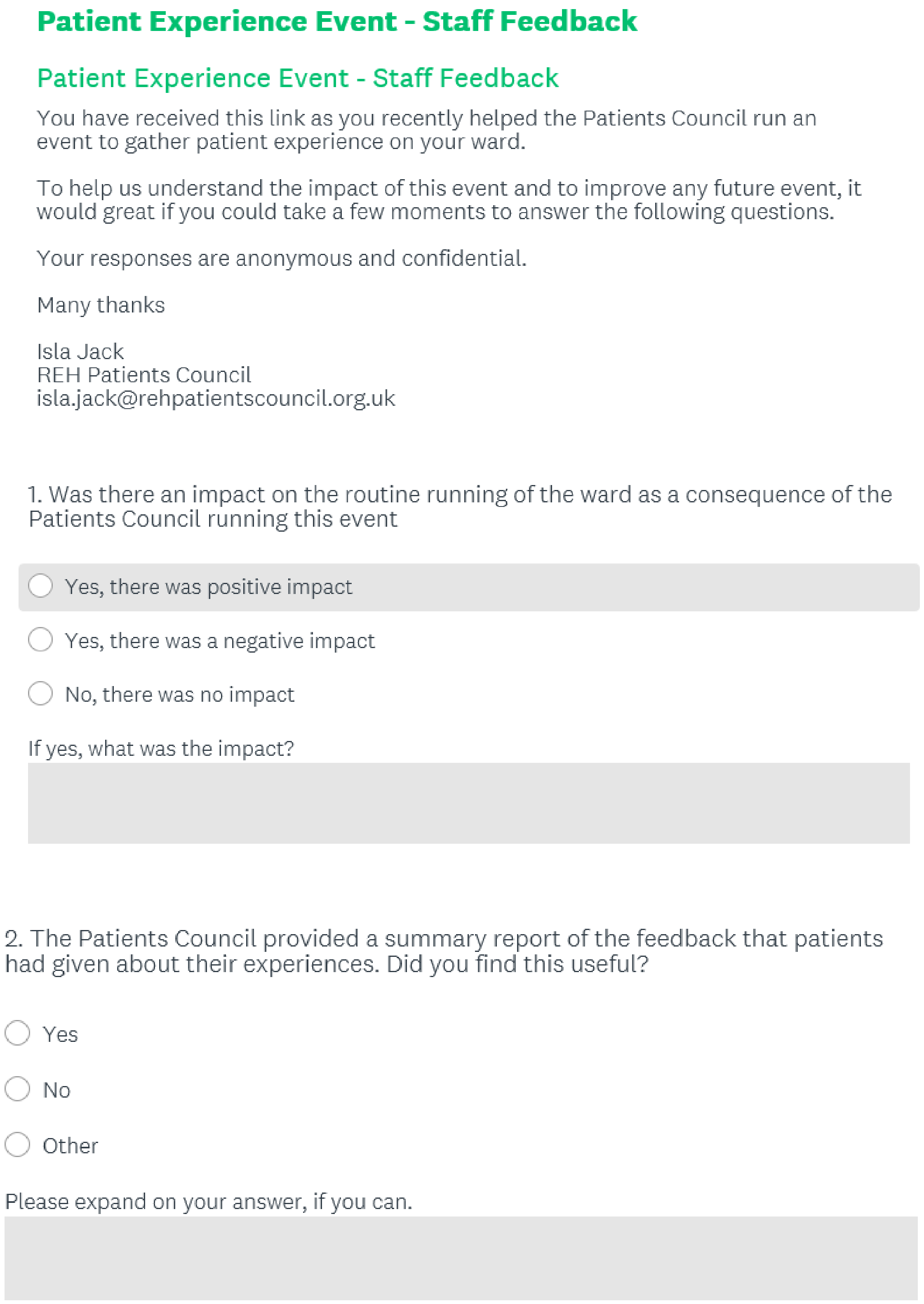
That is the end of the survey. We will feed back the results to you next month.

Thank you for taking part.

☺

You can use this space if there is anything else you want to tell us about your experience or if you need more space to the answers the questions.

Annex B: SurveyMonkey® survey for staff supporting events



Patient Experience Event - Staff Feedback

Patient Experience Event - Staff Feedback

You have received this link as you recently helped the Patients Council run an event to gather patient experience on your ward.

To help us understand the impact of this event and to improve any future event, it would great if you could take a few moments to answer the following questions.

Your responses are anonymous and confidential.

Many thanks

Isla Jack
REH Patients Council
isla.jack@rehpatientscouncil.org.uk

1. Was there an impact on the routine running of the ward as a consequence of the Patients Council running this event

○ Yes, there was positive impact

○ Yes, there was a negative impact

○ No, there was no impact

If yes, what was the impact?

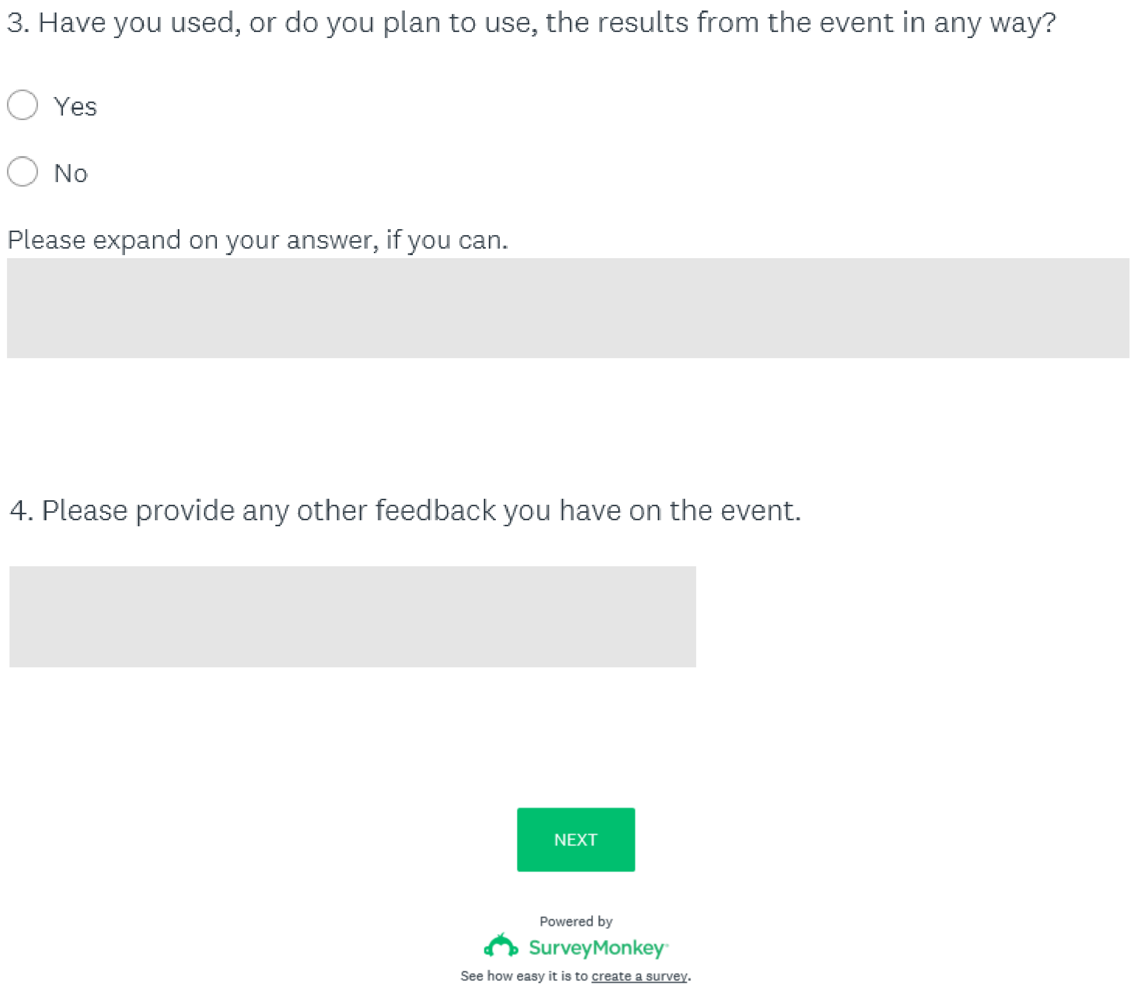
2. The Patients Council provided a summary report of the feedback that patients had given about their experiences. Did you find this useful?

○ Yes

○ No

○ Other

Please expand on your answer, if you can.



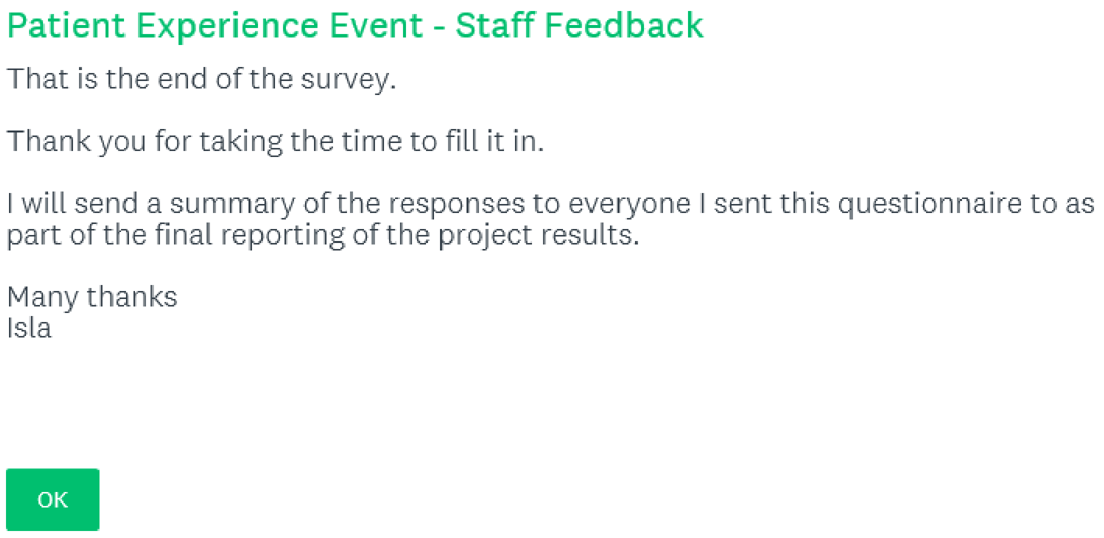
3. Have you used, or do you plan to use, the results from the event in any way?

○ Yes

○ No

Please expand on your answer, if you can.

4. Please provide any other feedback you have on the event.



Patient Experience Event - Staff Feedback

That is the end of the survey.

Thank you for taking the time to fill it in.

I will send a summary of the responses to everyone I sent this questionnaire to as part of the final reporting of the project results.

Many thanks
Isla