

Health and Community Care: Patient Experience

Better Together: Scotland's Patient Experience Programme

Building on the Experiences of NHS Boards

Report No. 1/2008



**BETTER TOGETHER: SCOTLAND'S PATIENT
EXPERIENCE PROGRAMME**

BUILDING ON THE EXPERIENCES OF NHS BOARDS

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GLOSSARY OF TERMS

Patient Experience: The quality of care from the perspective of patients.

NHS Board: National Health Service (NHS) care in Scotland is currently provided by 22 Health Boards. Fourteen are geographically-based local NHS Boards, eleven of which cover the mainland: Ayrshire & Arran, Borders, Dumfries & Galloway, Fife, Forth Valley, Grampian, Greater Glasgow & Clyde, Highland, Lothian, Lanarkshire and Tayside and three of which cover the island groups Orkney, Shetland and Western Isles . There are also eight National Special Health Boards: NHS 24, NHS Education for Scotland, NHS Health Scotland, NHS Quality Improvement Scotland, Scottish Ambulance Service, State Hospitals Board for Scotland and The National Waiting Times Centre Board (Golden Jubilee National Hospital).

Patient Choice Agenda (England): From December 2005, it has been Government policy that National Health Service (NHS) patients in England who may require elective surgery are offered a choice of four to five hospitals at the referral stage.

Scottish Health Council: The Scottish Health Council is an organisation established in 2003 to improve the quality of healthcare in Scotland. The Scottish Health Council has its own identity and responsibilities but is linked to NHS Quality Improvement Scotland. The Council has a national office in Glasgow and has established local offices in each NHS Board area, where the majority of its staff are based. Members of the community are appointed to serve as voluntary members on a Local Advisory Council for each NHS Board area.

HEAT target: HEAT targets are a core set of Ministerial objectives, targets and measures for the NHS Scotland. HEAT targets are set for a three year period and progress towards them is measured through Local Delivery Plan's which is the process where by NHS Boards explain how targets will be achieved.

EXECUTIVE SUMMARY

Introduction

1. This research was commissioned by the Scottish Government as part of Better Together Scotland's Patient Experience Programme. Better Together is NHS Scotland's programme to improve patient experience. It will build upon the improvements already happening across the health service by working with patients, carers and staff to further enhance the quality of care. The programme will support NHS Scotland to make year-on-year improvements for patients. This research explores Scottish Health Boards' current uses of and attitudes towards patient experience information

2. The objectives of this work were to document Scottish Health Boards' current patient experience activities and Boards representatives' experiences of and attitudes towards patient experience. The research also examined expectations of the Scottish Patient Experience Programme and beliefs about patients' priorities.

Methods

3. Thirty-five telephone interviews were carried out with NHS (National Health Service) Board staff between September 2007 and February 2008. All of them were checked by the interviewee and approved by them. The interviewees were from the 18 Health Boards which provide services directly to patients, and included 16 Chief Executives and 19 members of staff who were identified as having primary responsibility for implementing and co-ordinating patient involvement and patient feedback.

Main findings

Patient experience activities

4. Almost all Boards that participated were currently engaged in a variety of patient experience activities. There was wide variation among Boards in the extent of their patient experience activities. Smaller rural boards tended to be less active in this area, but this was also true of some of the larger Boards.

5. Patient experience activities included self-completion questionnaire surveys, suggestions boxes, complaints and compliments, patients' panels and forums, patients as members of governing bodies, focus groups, collecting patient stories and patient diaries. The most common patient feedback activity was self-completion questionnaire surveys. For some surveys, questionnaires were handed out on-site, while others carried out postal surveys, many of them are undertaken with the help external survey contractors.

6. Most of the reported patient experience activity was in secondary care.

Preferences for types of patient experience information

7. Most interviewees said it was important to use both qualitative and quantitative information to obtain a full understanding of patients' experiences. Of those that expressed a preference for one type of information, more preferred qualitative information than quantitative information. However, most interviewees thought that a full understanding of patients' experiences could only be achieved by looking at a variety of different sources of information.

8. It was considered important that patient feedback tools focus on issues that are known to be important to patients. The criterion perceived to be most important for useful patient feedback tools was that they should provide actionable feedback: that is, they should provide information about what needs to be done to improve services.

9. Many interviewees were concerned that patient feedback tools should conform to rigorous methodological standards. For example, they should use representative sampling techniques. The importance of patient feedback tools in assessing the "softer" issues of patient experiences, as opposed to clinical outcomes was mentioned by many respondents.

10. While there seemed to be a general overall preference for qualitative information, surveys were the single most trusted source of information about patients' experiences, followed by patients' representatives' feedback through panels and forums, feedback through suggestions boxes, letter and compliments, and formal complaints. Other trusted information sources included focus groups and patient stories. Interviewees recognised the limitations of "patient satisfaction" surveys, and they tended to prefer to use a "patient experience" question style, focussing on "what happened" to patients, rather than asking them to rate their satisfaction with services.

Learning and development of patient experience activities

11. When asked what they had learned as a result of implementing patient experience activities, many said that their main learning had been simply to discover the importance and benefits of doing it.

12. Some had changed the way they asked questions, involving patients in the development of measurement tools and focusing on experience and actionable feedback, rather than patient satisfaction. Other interviewees said they had learned the importance of following up on results by implementing quality improvements, and feeding results back to front-line staff.

Benchmarking

13. Almost all interviewees said they would be interested in some form of benchmarking of their Board on patient experiences, but their main concern was that it might be difficult to make fair comparisons among different types of organisation. Another concern was that benchmarks could lead to complacency if an “above average” score was thought to be acceptable, particularly if standards were generally low among comparator organisations.

14. Many Board representatives thought that the best comparator group for their Board would be the rest of the Scottish Boards, but an approximately equal number thought that the best comparators would be Boards like themselves (in terms of urban/rural and size). Interviewees from Special Boards tended to think it would be difficult to find a suitable comparator and some suggested comparator organisations outside Scotland.

15. Most would be interested in three types of comparison: comparisons among Scottish Boards, tracking changes in their own Board over time and comparing different units within their Boards. Where interviewees expressed a preference for one type of comparison, within-Board comparisons over time were the most popular, with almost half of the interviewees saying that information would be the most valuable to them. Many also thought that comparisons of different units or departments within their Board would be particularly useful for quality improvements.

Motivations and barriers to implementing patient experience activities

16. Almost all interviewees saw patient experience activities as central to their roles, and to the overall aims of their Boards.

17. The most important barriers to implementing changes as a result of patient feedback were thought to be defensiveness from clinical staff and a lack of a patient-centred culture within the Board. Many also said that capacity was an important barrier: they did not have enough time, or the right skills, or there were too many other competing priorities. Not knowing what to do with patient experience findings was also an important barrier to implementing changes.

Examples of measured quality improvements

18. Many interviewees volunteered interesting and inspiring examples of changes they had implemented as a result of patient feedback.

19. About half of the changes implemented were supported by evidence of improvement in patients' experiences, but many responses indicated that it was not central to the Board's culture routinely to measure the effects of quality improvement interventions.

Expectations of forthcoming Scottish Patient Experience Programme

20. There was wide variation in interviewees' knowledge of the Programme, but most had positive expectations of it. They hoped it would provide rigorous, reliable tools with which to measure patients' experiences, and that the tools would be standardised across Boards so that they could make reliable comparisons and it would provide benchmarks. They wanted support for making quality improvements and sharing best practice. Several people thought the Government programme would help them to promote the importance of patient experience.

21. The main concern about the programme was that there would be too strong a focus on targets at the expense of improving patients' experiences. However, some cautiously welcomed the setting of standards for patient experience. There were also worries that the programme would impose too high a bureaucratic burden on Boards, there would be a loss of autonomy, the cost of the programme would be too high, that the methods would not be sufficiently rigorous, and that there would be unfair adverse media coverage of results.

Views on patients' priorities

22. There was considerable consensus among interviewees in their views on the issues that matter most to patients. Top patient priorities were perceived to be: high quality safe care; being treated with respect and dignity; prompt access; clear communications about their condition and treatment; being involved in treatment decisions; being treated as individuals and avoiding hospital-acquired infections.

Conclusions

23. Patient experience activities were viewed positively by Scottish NHS Board representatives and, on the whole, Boards welcome the forthcoming Patient Experience Programme. The main concerns about the Programme were that there would be too strong a focus on targets and it would impose too great a bureaucratic burden.

24. There was a demand for both quantitative and qualitative information about patients' experiences. Qualitative information was thought to be particularly useful for inspiring and driving quality improvements, while quantitative information was valued for its use in benchmarking and highlighting areas of concern or excellence. Patient surveys were the single most common patient experience activity currently taking place in Scottish NHS Boards.

25. Most Board representatives would be interested in benchmarks, either with the rest of Scotland, or with Boards similar to their own. Most would also be interested in using the results of standardised quantitative patient experience tools to compare their own organisations performance over time, and to compare different units within their Board.

Recommendations

- Standard patient experience tools for use across NHS Scotland should provide reliable robust measures of patient experience. Self-completion postal questionnaire surveys would fulfil this function.
- The standard patient experience tools should focus on the issues that are known to be important to patients, and should be designed such that the results offer actionable feedback.
- To ensure reliable comparisons, sampling techniques should be explicit and standardised across Boards, and should ensure that sampled patients are representative of the populations of patients treated.
- For the fourteen geographical Boards, benchmarks should allow them to compare themselves with all other Scottish boards as a group, and with subsets of other similar Boards and/or with particular single Boards.
- Boards should be offered support for collecting qualitative information about patients' experiences and analysing it.

- Boards should be offered support in understanding the implications of their patient feedback and implementing changes.
- Boards should be offered support in sharing best practices among Scottish Boards, and from wider sources.
- It may be possible and desirable to benchmark some Special Boards' services against those of geographical Boards, but for some types of care (e.g. ambulance care) this will not be appropriate.
- Special Boards providing services directly to patients are likely to need targeted support for patient experience activities, particularly where their services are very different from those of the other Boards.

CHAPTER ONE: INTRODUCTION

1.1 As part of a Better Together Scotland's Patient Experience Programme, the Scottish Government commissioned an independent research organisation, Patient Perspective, to research the views of Chief Executives and patient involvement leads across NHS Scotland. This research covers Scottish Health Boards' current uses of and attitudes towards patient experience information. Interviewees were also asked about their beliefs about patients' priorities.

1.2 The purpose of this work was to find out about Boards' current patient experience activities; interviewees' experiences of assessing patient experience, and of acting on the findings, their opinions about different types of patient experience tools; their attitudes towards measuring patients' experiences and their expectations of the Scottish Patient Experience Programme.

1.3. The following is a summary of 35 telephone interviews with NHS Board representatives, carried out as part of the Scottish Government's *Building on Experience* programme. The interviews took place between September 2007 and February 2008. All of the interviews included in this report have been checked and approved as accurate by the interviewees.

CHAPTER TWO: METHOD

Sampling

2.1 All Chief Executives from NHS Boards in Scotland with direct patient contact were invited to take part in the research. In addition, at least one other person in each Board was interviewed. This was usually the person with the greatest responsibility for patient experience within the Board, and, where more than two people were interviewed in one Board, the additional person was someone with direct or particular experience of implementing patient experience work.

Procedure

2.2 At the beginning of the project, Chief Executives were sent a letter from the Chief Nursing Officer, outlining the purpose of the project and informing them that a researcher would call to arrange an interview. Chief Executives were also asked to name one primary contact person for the researchers. In most cases, but not quite all, the named contact person was also the second interviewee. In a few cases, the named contact person recommended that someone else would be a more appropriate interviewee.

2.3 Potential interviewees were contacted by telephone to arrange a suitable time for a telephone interview. They were called back at the agreed time and a semi-structured interview was carried out, while the researcher made notes. Shortly after the interview was completed, the researcher sent the interviewee a copy of the interview notes, asking that they check them for accuracy. In all cases, interviewees made only minor amendments before returning the agreed interview notes.

Interviewees

2.4 This report covers 35 interviews. Sixteen were with Chief Executives, covering all but one of the territorial Boards and three of the Special Boards: Scottish Ambulance Service, NHS24 and the Golden Jubilee Hospital. An interview was carried out with the Chief Executive from the remaining territorial Boards, but it was not possible to obtain an approved version of that interview due to the time constraints.

2.5 The remaining interviewees were other representatives of each of the geographical boards and all four of the Special Boards that have direct contact with patients, the additional special board being State Hospitals. These included:

- ◆ eight Nurse Directors

- ◆ an Associate Director of Nursing
- ◆ an Assistant Director of Nursing
- ◆ a Director of Communications
- ◆ a Director of Corporate Planning and Policy
- ◆ a Quality Manager
- ◆ a Clinical Governance Co-ordinator
- ◆ a Community Health Partnership (CHP) Manager, a Service Improvement Manager
- ◆ an Involving People Facilitator
- ◆ a Patient Focus Manager and
- ◆ a Head of Patient Affairs.

Interview topics

2.6 The interviews covered the following topics:

- ◆ patient experience activities;
- ◆ preferences for qualitative and quantitative patient experience information;
- ◆ criteria for a good patient experience tool or measure;
- ◆ learning for patient experience information;
- ◆ benchmarking;
- ◆ motivations for using patient experience information for quality improvements;
- ◆ barriers to using patient experience information and implementing change,
- ◆ examples of measured changes
- ◆ expectations of the forthcoming Better Together programme; and
- ◆ views on patient priorities

Analysis

2.7 The verified interview notes were manually coded and initial themes were identified by the interviewer. After discussion between the interviewer and one other researcher, the themes were modified and reduced by merging them where responses were sufficiently similar. Where appropriate, the number of interviewees that had responded in a similar way were counted, so that statements such as, “about half of/most respondents said...” could be made.

CHAPTER THREE: RESULTS

Patient experience activities

3.1 Interviewees were asked to give an outline of the patient experience activities currently carried out within their Board. The interviewer explained that it was not necessary to give an exhaustive list of activities, since this was not an audit, but the interviewee should mention their most important or most significant activities. Interviewees were also asked if there was one source of patient feedback information they trusted more than others, or that they would look at first if they wanted to answer the question, “What do my patients *really* think?”

Surveys

3.2 The single most-mentioned patient experience activity was patient surveys, with most interviewees saying that their Board had carried out a self-completion paper questionnaire survey. Many found the surveys to be valuable tools.

On-site questionnaire surveys

3.3 Some had handed out questionnaires to patients on the premises to be completed while patients waited to leave. Some Boards described the involvement of members of the Patients’ Panel or the Patients’ Council in the administration of questionnaire surveys.

Members of the Patients’ Council hand out survey forms to patients, offering to help them to complete the form if they need it.

3.4 At the State Hospital, the on-site approach was the only option, and their method had yielded very good response rates. The interviewee noted that patients had been very concerned about confidentiality and needed a lot of reassurance that their responses would be anonymous.

The last time we did the [annual] survey, 79% of our patients [who are all inpatients] took part.

Surveys designed in-house

3.5 Some had designed their own surveys in-house, many of which were “satisfaction” surveys. A few respondents noted the typically high satisfaction scores obtained by such surveys.

As with almost all surveys, if you take the “Very satisfied” and “Satisfied” together you get slightly under 90%. That’s always been true, even when things were not so good here in 2004/05.

3.6 Two of the Special Boards used different types of surveys: the Golden Jubilee National Hospital had carried out a telephone survey and NHS24 were planning face-to-face interviews in people’s homes, run by an independent survey organisation.

Postal questionnaire surveys

3.7 Eight Boards, including all but one of the larger central belt Boards, had carried out postal questionnaire surveys, using rigorous methods: probability sampling, a patient experience (rather than satisfaction) questionnaire and reminders to non-responders. Most had used specialist independent survey contractors to carry out these surveys.

Perceived value of surveys

3.8 When asked which sources of patient experience information they trusted most, eight interviewees gave particularly high value to surveys.

I have confidence in the surveys because we have looked at them in a lot of detail.

3.9 However, some thought that there was room for improvement in the surveys they currently used. For example, they wanted more rigorous methods, better-designed questionnaires and sampling throughout the year.

Some of the surveys [we currently do] don’t tell us things we don’t know already. The surveys are home-made, not based on evidence. But I would value surveys more if we had a systematic survey.

Comments cards, suggestions boxes, compliments and patients' letters

3.10 The next most common source of patient feedback was informal patient feedback such as comments cards, suggestions boxes or letters from patients. Almost half of the interviewees said these were an important part of their patient experience work, one advantage being their tendency to pick up positive feedback, which could boost staff morale. Seven interviewees said that these were the most valuable type of information.

The most interesting thing is the letters we receive, comments and complaints. We learn a lot more from those, particularly about the softer issues of the service.

3.11 Two interviewees also described schemes for collecting comments and suggestions in a verbal, rather than written, form using "Speak Easy" to record comments and a "talking mat" for use by patients with communication difficulties.

Focus groups and interviews

3.12 Around a third of the interviewees said they had used focus groups or face-to-face interviews. For some, the impetus for running the groups was the need to get patients' (or the public's) views on service redesign projects.

We used a lot of focus groups. We were moving three hospitals on to a single site. The professionals learned quite a lot about what the public were thinking.

3.13 Six interviewees gave particularly high value to the information obtained from user focus groups or interviews.

With focus groups we can get an insight into people's perceptions.

Complaints

3.14 Around half of the interviews mentioned complaints as a method of getting patient experience feedback some recognised that complaints did not necessarily fit the definition of patient experience activity. A particular strength of complaints was that the procedures for dealing with them often included measures designed to ensure they were properly followed up.

Every complaint that comes in goes into a feedback loop: the clinicians involved completed a “Lessons Learned” sheet, that is also fed back to the complainants.

3.15 Two interviewees commented that face-to-face contact with complainants was an important aspect of their resolution, and helped staff to learn more from them.

We put a lot of emphasis on face-to-face contact with patients, rather than a cold exchange of letters. Nothing has more impact on a doctor or nurse than hearing directly what it was like for a patient.

3.16 Complaints were mentioned by several interviewees as one of the most valuable sources of patient experience information. One of their strengths was that complainants were thought to represent broader patient concerns, raising issues that others might have felt but would have been reluctant to raise formally.

Apart from one or two people who “like complaining”, my experience of complainants is that they have thought long and hard about whether they should complain.

3.17 Two interviewees noted that their interest in complaints was partly because most of their patient experience activities to date had focused on this area. However, several mentioned limitations of complaints. The small number of complainants relative to the number of patients treated was one of the main concerns.

[Complaints] are the tip of the iceberg of dissatisfaction with the service. They don’t give the full story.

3.18 Others were concerned that the negative focus of complaints did not necessarily give them accurate representations of patients’ views.

The danger is that you get a skewed picture: the focus [of complaints] is all on bad things. If you focus just on the disaffected, it’s dispiriting [for staff].

Patients' stories and diaries

3.19 Some interviewees said they had used patient stories and diaries, and many of them had found the process and outcome particularly useful for engaging the interest of staff and for training. Three interviewees had used, or were planning to use, patient diaries.

[Diaries] are very useful ways of examining the care patients and carers receive.

3.20 Three Boards had collated patient stories on film or audio-tape, or were planning to do so. Four interviewees mentioned patient stories as an important information source but, of those, three wanted a better system for collecting the stories.

I would really like a system for collecting patient stories, supporting patients to tell their stories, and dealing with the findings.

Direct observation and staff feedback

3.21 A few interviewees thought that the most valuable source of patient experience information was their own observations and conversations. Staff observation also included senior nursing staff working some shifts. Some interviewees mentioned the usefulness of staff feedback as a way of channelling patient feedback.

It's difficult to explain but I just instinctively know. I can walk into a ward and I can tell what kind of care is going on through small and subliminal signals.

3.22 Two Chief Executives mentioned the usefulness of feedback from staff who had been patients. One described a new programme that makes use of Board staff's own experiences of being patients, or those of their relatives.

We have started a patient safety programme. The first step was to talk to staff who have recently been patients (or whose relatives have). The richness of information is incredibly illuminating.

Patients' forums, councils, panels and representatives

3.23 Interviewees had been asked to focus their responses on patient experience work, rather than public involvement. However, some thought there was considerable overlap among these activities. Around a third of the interviewees mentioned patients groups, such as forums or councils, which had been specifically set up as opportunities for patients to give their views.

We have a Patient and Public Panel - a group of about 30 people. For example, they do spot checks on hospital cleanliness, hand washing, etc.

3.24 One Board had asked patients' representatives to carry out a cleanliness audit, going round the wards inspecting them and feeding back their findings. Twelve interviewees thought that patient representatives on committees and in their governance procedures provided the best information about patient experience.

I would probably place most value on patients bringing their own experiences as representatives in the work we do.

3.25 Two Boards had started initiatives to try to widen the opportunity to take part in involvement activities to sections of the population that might not usually get involved. This meant offering support and training for patient participation.

There are lots of people that want to get involved, but it's a tall order to expect everyone to have the skills to contribute effectively.

Patient consultations

3.26 Service re-design and patient information were areas in which patient and public involvement seemed to be closely associated. One representative described a wide-ranging consultation the Board had undertaken throughout their region. However, one Chief Executive expressed concerns about the usefulness of consultation exercises.

We would never have a redesign project without having patients involved.

We have diverse populations with different needs. In public meetings, [we are] finding out how health services should be provided.

Big public meetings are mainly a way for people to let off steam. What they add to quality of the debate and the decisions made is very limited.

Informal feedback

3.27 For a few interviewees, the most valued source of feedback was unsolicited, voluntary information offered informally. One interviewee noted that patient involvement was part of clinicians' interactions with patients in their day-to-day care.

Different sources of patient experience information

3.28 Around half of the respondents said that it was important to look at a wide range of information, or that it was important to "triangulate" information from different sources.

I would trust an amalgam of results, including patient experience measures, documentation and patient, relative and staff interviews/ focus groups.

3.29 Clinical indicators and clinical incident reports although not strictly patient feedback, were highly valued by some interviewees.

It's very helpful to look at patient feedback alongside incidents, complaints, and claims.

Primary care

3.30 The interviews were not designed to distinguish primary and secondary care activities, but, after the first twelve interviews, it was noted that most responses focused on secondary care. Therefore, later interviewees were prompted to say whether any patient experience activities were taking place specifically in relation to primary care. Most Boards did not have specific primary care example, but two had programmes with that specific focus.

We have suggestions slips in GP surgeries, completed by GPs or patients, telling us about issues that arise after the patient leaves secondary care.

3.31 Some mentioned the Quality and Outcomes Framework (QOF) surveys carried out in general practice as part of the new General Medical Services (nGMS) contract, and their views of these surveys was not very positive.

In general practice we use GPAQ, but it's not the tool of choice. We would like to have different questions.

It's a bit of a tick-box as to whether the QOF surveys are done. There is no audit on whether things are followed up or make a difference.

The need to do more

3.32 Two interviewees (from the same small island Board) admitted that their patient experience activities to date had not been extensive. These views were echoed by the Chief Executive of another rural board. A Chief Executive of a large central belt board suggested that they could do more surveys. Another Chief Executive noted that the special circumstances of emergency ambulance care presented particular challenges to obtaining useful patient feedback.

We understand that our patient focus is not as good as it should be.

Preferences for qualitative or quantitative patient experience information

3.33 We were interested to find out whether interviewees had a preference for qualitative or quantitative information. Almost all interviewees said they were interested in both quantitative and qualitative information, and thought that it was important to look at both types together to get the full picture.

We are interested in the richness of personal stories but having numbers really helps to engage some Board members and the public.

I like both. The scientific part of me likes hard numbers but the nurse in me likes the qualitative stuff.

Qualitative versus quantitative information

3.34 Of the interviewees that favoured one type of information over the other, more favoured qualitative information than quantitative. Many of them thought that the persuasive power of qualitative information was a particular strength.

Very often it is the words people use to describe their experiences that are the most powerful.

3.35 Some, mostly those who had already conducted more rigorous patient experience surveys using external contractors, said they were more interested in statistics and numbers, rather than words and stories.

After the first survey, we concentrated on improving a few things. When you saw [by looking at the quantitative data] that the things we'd been working on had improved, that was very powerful.

[The quantitative survey] was by far the most successful thing we did on patient experience. That's why I'm so keen on this programme. We can make real differences to patient care using this kind of information.

3.36 Three interviewees said that the nature of the questions being asked, the type of patient experience, or the audience for the results were important considerations in deciding which type of information would be more useful.

Criteria for a good patient experience tool or measure

3.37 Interviewees were asked to think about the general principles that were important in making a patient experience tool valid and useful. A few found this question rather too abstract, and most found it more difficult to answer than other questions, but a number were able to make useful suggestions.

3.38 **Actionable Feedback:** One of the most common responses was that the results should help managers and clinicians understand what needs to be done to improve services for patients.

A measure must tell us what we need to do to change things.

3.39 **Focused on patient priorities:** It was important for many interviewees that feedback instruments focus on the issues that are known to be important to patients. Several of them said that related research to establish patients' priorities must involve patients themselves, and must be carefully designed.

[It should be] something you've already checked out as mattering to patients.

3.40 **The right methodology:** A sound, reliable method for obtaining feedback was important for many interviewees. The wording of the questions and the manner in which they were asked were important issues for some. For many interviewees, random probability sampling was an important aspect of a rigorous method. On the other hand, two interviewees were not concerned about the rigour of the sampling method.

You need to have random sampling. It should not be skewed by people with strong opinions - either positive or negative.

It has to be a statistically valid sample size that gives an acceptable level of "confidence" otherwise the results can be open to question.

3.41 **Satisfaction Surveys:** Two interviewees noted the pitfalls of satisfaction surveys while one interviewee found a single satisfaction question very useful.

One of the criticisms [of patient satisfaction surveys] is that you get what you expect: for example, "The staff were lovely".

The very last question in our survey: "How satisfied are you overall? is really useful.

3.42 **Providing specific information by departments:** Three people thought it was important that the feedback could be traced to the specific areas to which it referred.

It needs to be owned by the people who have to make the changes. Staff will say, "That doesn't happen in my ward."

3.43 **Independent data collection:** One person said that it was important that patient experience information was collected by people who are not directly involved in the patient's care.

An independent collector of data would be more likely to be trusted with the truth when people are feeling vulnerable.

3.44 **Timing:** One person thought it was useful to allow patients time to reflect on their experiences before asking them for feedback.

3.45 Feedback directly from the patient: For some, it was important that the feedback came as directly as possible from the patient, rather than being filtered through different channels before being heard by staff.

The fewer people the information goes through, the more reliable it is.

3.46 Capturing “softer” issues: A few interviewees mentioned the importance of capturing information about subjective or emotional aspects of patients’ experiences.

It would have to have some sort of emotion about it.

3.47 Focus on older people: It is interesting that two people mentioned the importance of including or focusing on, elderly people, either because they tended to be under-represented in patient feedback activities or because they were significant users of health services.

Learning from patient experience information

3.48 Interviewees were asked how their practices might have changed through their experiences: both in the ways they gathered patient experience information and in how they made use of the findings.

3.48 Importance of patient experience: For the majority, the main learning had been the discovery of the importance of patient experiences, and a change in the culture of the organisation towards valuing it.

*Over the years we’ve learned to respect more and fear less the patient’s view.
Patients don’t ask for the moon.*

3.49 Easier for chronic illnesses: Several interviewees said they had found patient involvement easier to do in areas that deal with chronic illnesses than in acute services because patient turnover tended to be lower in those areas.

The long stay ward has a patient and carer group: they helped to decide on the décor, for example.

3.50 Changing what is measured/ how it is measured: some perhaps those who have more directly involved with patient experience had changed the way they measures it. Some had had changed the way they asked questions focusing on what happened to patients, rather than on satisfaction. Some had changed the topics they asked patients about, and a few had conducted their own research to find out what mattered most to patients. Some had learned that patient experience needs to be understood using a variety of different methods.

At first, we assumed we knew what the issues were. If you design a questionnaire that way, you get the answers you want.

It has to be a number of things with different opportunities to engage with patients.

3.51 Gaining buy-in: Three interviewees felt that it was important to gain the agreement and confidence of front-line staff at the start of the process.

You need to secure buy-in of managers and staff before you start.

3.52 Follow up on results: Five people had become more systematic about following up on results.

If we find something is poor, people often put their energy into explaining why it was like that but they should put more energy into fixing the problem.

There's no point in finding out what patients think if you aren't going to try to make improvements.

3.53 Feeding back to patients and staff: For some, an important part of following up on results was feeding them back to staff and patients, and they had learned that it was important to do that sensitively, particularly when involving patients in that process.

If you involve patients [in feeding back results], they have to be well trained and well supported.

3.54 Not trying to do too much at once: Three people emphasised the importance of tackling improvement at a realistic pace: not trying to do too much at once and taking a longer-term view.

People are looking for quick fixes but realistically we should be looking over 2-3 years before we see sustained change and improvement.

3.55 **Difficulty of obtaining reliable feedback:** The main learning experience for some had been that it was difficult to gather reliable information on patient experience. Conversely, others had found that it was not as difficult as had been supposed.

Generally it's very difficult to get good quality information. Often the person representing the patient or customer is motivated to tell you certain things that are not necessarily the most important for patients.

3.56 **Perverse incentives:** one Chief Executive said it was important to ensure that the benefits of a Patient Experience Programme were appropriately incentivised.

If you are going to turn the findings into an indicator, you have to be careful it doesn't generate perverse behaviours.

Benchmarking

3.57 On benchmarking, participants were asked, first of all, to give their general views on benchmarking and who they thought would be the best comparators for their Board. Almost all interviewees said they would be interested in benchmarking their Board against others, and some were very enthusiastic about it.

You are wasting your time if you don't benchmark.

But patient experience is about what they go through. They're all going to have similar issues.

3.58 Other interviewees were concerned that benchmarks could lead to complacency. For example, Boards might be satisfied with "above average" scores, without taking into account that overall performance among their comparator organisations might fall below acceptable standards. Others had worries that comparisons would not be fair because of differences between their own Board and the rest of Scotland.

I don't know what value it adds to tell us we are better or worse than others.

What if the service is poor everywhere? We need to know what is the best practice benchmark.

3.59 Those who said they would be interested in benchmarking were asked which organisations they thought would be the best comparators for them. Most said that the overall Scottish average would be the best benchmark against which to compare their own Board's performance.

Patient experience in one part of Scotland has got to be comparable with anywhere else in Scotland. I don't think the people of [this Island Board] would expect to receive a service different from anywhere else in Scotland.

3.60 Others wanted to compare with *similar* Scottish Boards, either in addition to comparing with the rest of Scotland or as an alternative. The criteria for similarity varied, but the most important one seemed to be that rural and island Boards would form one subset, while larger urban Boards would form another. Two interviewees thought that there was particular value in comparing themselves with local Boards, in one case because they commissioned services from other local Boards.

It would be useful against other smaller boards.

Yes, I would be interested in benchmarks, mainly with other complex teaching hospitals or services.

Other tertiary centres with university affiliations.

3.61 Some interviewees thought that comparisons outside Scotland – with other UK countries, particularly England, European countries and the USA - would be useful, in addition to within-Scotland comparisons.

I would like to see us in a national four countries context, and internationally.

We should include England, Wales, Northern Ireland and the private sector.

3.62 Some, particularly interviewees from Special Boards, thought it would be difficult to find a suitable comparator within Scotland. However, an interviewee from a Special Board Hospitals, while acknowledging their unusual status for comparison purposes, noted that some within-Scotland comparisons would also be useful.

[Special Board interviewee] *There wouldn't necessarily be a good comparator in Scotland.*

[Special Board interviewee] *We can only really compare with [organisation], which we already do, where they are willing to share information.*

[Special Board interviewee] *We are fairly unique, but there are lots of things that are not specific to us. For example, patients have physical health needs and there's no reason why we shouldn't benchmark with others on those things. We often have to point out that we are not that different from other Boards.*

[Special Board interviewee] *We often have to point out that we are not that different from other Boards.*

3.63 Interviewees were asked which of three comparisons would interest them most: comparisons with other Boards, comparisons of their own Board over time and comparisons of different units within their Board. Responses to this question were very mixed, although most were interested in all three types of comparison, or a least in two of the three. Overall Board comparisons of their own performance over time were the most popular, with almost half of the interviewees saying that would be the information that interested them most. However, one interviewee was concerned that comparisons over time would not be fair.

We would probably be most interested in benchmarking our own performance over time with regular surveys.

3.64 The second most popular type of comparison was within-board comparisons of different units or departments, which were valued because they helped to identify areas of poor and good practice, and because results would be more useful if looked at in the local context. However, some were not enthusiastic about internal comparisons because they believed it was not useful or fair to compare results from different services.

It's very useful to pinpoint where there are problems or areas of best practice.

Internal comparisons of different units are probably better because we can understand them better. Everybody knows the situation within their own area.

3.65 Three interviewees said they were most interested in external comparisons. Two interviewees said that it would be important for the usefulness or credibility of the results to compare similar types of services.

In England you could pick the comparator group. Organisations need to compare themselves with the units they think appropriate (i.e. by hospital, site or board).

People are less likely to dismiss the results if they compare patients on similar pathways.

Motivations for using patient experience information for quality improvements

3.66 Interviewees were asked to say what motivated them to collect and use patient experience information. Most interviewees found this question difficult to answer because their motivations for providing high quality care and understanding patients' experiences were integral to their general motivations for doing their jobs well. However, there was a general sense that patient' experiences were important and valued and that the culture was changing in that direction.

That's at the heart of what we do. If we don't understand patients' experiences we are ignoring the customer of our businesses.

I value [patient experience] hugely because patients, whether you want to treat them as customers or not, they are.

3.67 Many interviewees saw patient experience activities as integral to improving standards of care. One interviewee noted that understanding patients' experiences could lead to greater efficiency. Another important use was that results could be used to demonstrate the success of policies.

We are motivated to get better services for patients. If you listen to people telling you what it's like to go through different services, you end up with better services.

One of my teaching techniques is to point out to people how much it costs when you have to deal with a complaint - not just in money, but in time and other resources.

The survey is about the best strategic indicator we have of how well we're doing.

Barriers to using patient experience information and implementing changes

3.68 Interviewees were asked about any scepticism they had encountered about the value of patient experience information and difficulties they had experienced in implementing changes in patient care based on the findings of the feedback. They were asked to think about the question both as individuals, and in terms of their Board. Most interviewees said that they had experienced barriers.

3.69 **Defensiveness:** The most common barrier to making full use of patient feedback was thought to be clinical staff's defensiveness, particularly if they felt criticised. In some cases, clinical staff were concerned that patient involvement was a threat to their professional standing. Related to this defensiveness, several interviewees thought that there was cultural resistance within their Board to accepting patients' views as valid.

People are naturally defensive, especially if they have worked in the area for a long time. There can be "them and us" attitude. "We work here; we own it."

The culture of real stakeholder involvement is not where it should be yet. Not all people really believe that patients should have a significant say yet.

3.70 **Lack of Government incentives:** Other interviewees mentioned Government policies (or the lack of them) in driving an interest in patient experiences. One interviewee said that the Patient Choice Agenda in England was an important policy driver that was lacking in Scotland.

An overall challenge is one of leadership. If each Chief Executive gives this leadership and priority to this, it will happen. If it infiltrates the HEAT target methodology, it will be a priority.

3.71 **Limited capacity:** Many respondents said that competing priorities limited their time for patient experience activities, particularly when there were a number of other initiatives that required their attention. Three people said that a culture of focusing on targets distracted them from patient experience activities. Related to concerns about lack of time, two people said that limited financial resources were a barrier.

It's another chore on top of people's day jobs. Capacity is a problem.

You get action plan-itis. People feel overloaded.

The pressure of priorities. Everything's a priority so nothing is. Targets.

3.72 **Lack of knowledge or skills:** Some interviewees said that, once they had received the feedback, it was difficult to know what needed to be done to improve standards, or how to implement changes. Others felt that their methods of gathering patient experience information were not yet sufficiently reliable.

Staff are often very keen to [implement changes] but they don't feel they have the skills and knowledge to do it.

I would like to have the in-house skills to run patient focus groups.

3.73 Impracticality of making changes: One interviewee was concerned that patients might not understand the reasons why some of their suggested changes could not be implemented.

In some cases, there's nothing we can do about the experiences people relate to us. We have to be careful that we do not raise expectations inappropriately.

3.74 Methodological challenges: Others had met with various methodological challenges, either in measuring patient experience, or in demonstrating that their findings were valid. One interviewee was concerned that brief lengths of stay gave little time for asking patients about their experiences.

We do not currently have a comprehensive and structured way of gathering information on patient experience.

3.75 Concerns about patients: Four interviewees mentioned concerns about patients: one thought that responder fatigue was a potential problem and another was concerned that patients might react negatively to being contacted. Two others thought some patients' limited communication skills could exclude them from responding.

Not all patients feel adequately skilled and competent to engage with the process of involvement.

Examples of measured changes

3.76 Interviewees were also asked to think of examples of changes they had made, and of the ways they had measured the change. Most found it difficult to come up with clear examples of paired pre- and post-intervention measurements of patient experiences. A few said that they expected to have such evidence in the near future.

We probably have. I can't think of an example off the top of my head.

It's too early on in our journey. One of the things we have been traditionally bad at is closing the feedback loop. I don't have any data that I can say shows what's changed but I hope in 12 months I will.

3.77 Many of the examples given referred to changes made as a result of patient feedback. Most assumed that the change they had implemented had improved patients' experiences but they had not explicitly measured experience after the change had been made. However, some were in the process of measuring the effects of their interventions and, encouragingly, there were some clear examples of measured changes, which were demonstrated by changes in patient experience measures. Some examples of potentially transferable quality improvement interventions are given in Appendix A.

We are just about to do that in the elderly care ward. We had a complaint: things like how the day room was used, and that there was little stimulation for patients. The ward staff introduced measures to change things. We will soon be asking patients, carers and relatives about their experience.

[We worked on] each member of the team telling patients a consistent message, and patients being given an appropriate amount of information and we have seen improvements on our scores on those things.

The cleanliness surveys (undertaken on-site by Patients Council representatives). The compliance rating has improved since we have been working on improving cleanliness.

[The repeat survey] demonstrated that we'd improved on the things people said they weren't happy with: cleaning, food and noise at night.

We are seeing reductions in complaints about communications and attitudes – there is a definite downward trend. It's difficult to identify the cause of that but we think the Excellence in Care programme has been very important. The reduction started after the programme had been running for 6-8 months.

[We improved disabled] patient access, then we went back to see if they were content with changes.

Expectations of the forthcoming Better Together Programme

3.78 Interviewees were asked what they expected of the forthcoming programme, what they wanted from it, and what, if anything, they feared or hoped would not happen. Respondents varied in how much they knew about the forthcoming programme. Some said they had heard about it. Several interviewees said that their Board's patient experience activities had been put on hold while they waited to find out what would be covered by the central programme from the Scottish Government. About half of the interviewees said they had very little information about the programme.

We decided to wait to see what happens with the national programme so we are in a bit of limbo at the moment.

I persuaded senior colleagues that it would be premature to do our own thing this year because there would be a national programme, so I hope there is.

3.79 Many interviewees were hoping for, and expecting, a high quality programme that would help them to understand patient experiences with reliable data. One of the most important aspects of the programme would be that its design would be methodologically rigorous. Several people expected the programme to include, and focus on, self-completion patient surveys, standardised across NHS Scotland. Avoiding “patient satisfaction” measures was thought by some to be an important aspect of reliable methodology. Others were hoping that the programme would produce a selection of rigorously tested tools that they could use locally, including qualitative and quantitative methods. Some were worried that the programme would not be applied with sufficient knowledge of front line service activity and issues.

I have a high expectation that it will make a big impact.

It needs to be sophisticated; not just devising a questionnaire and asking a few people to fill it in. In the past, we have just left suggestions boxes around but we need to do more than that.

I expect there will be a standardised patient experience questionnaire, which will be carried out annually.

I already know we're not looking at patient satisfaction but their real experiences [so that's good].

I hope the programme will put us in touch with a range of different methods we can use, including qualitative stuff. And that it will help us to reach some groups that need quite specialised approaches, not just acute inpatients; they represent 10% of our care and maybe 2% of the patients' journey.

I would like to think that the people involved in the programme will spend a lot of time at the clinical level, actually seeing what goes on, rather than trying to conduct it as an intellectual exercise from an office in Edinburgh.

3.80 For some, benchmarks were an important aspect of the programme because they would provide Boards with reliable comparisons with other Boards, and would help them to identify Boards with best practice, so others could learn from them. One of the most common hopes was that the programme would provide support for making quality improvements and “closing the loop”. Many hoped that the programme would facilitate the sharing of best practice to support quality improvements.

[I hope we will have] a structured survey that works across Scotland, rather than all Boards doing something different.

I expect it to give us a clear direction and structure on how we need to close the loop.

I hope there will be sharing of best practice; that it will pull out key learning themes.

I am looking forward to being able to learn from one another, to share ideas.

3.81 Some interviewees thought that the forthcoming Government programme would help them to promote the importance of patient experience in their own Boards.

The programme will give me a real platform to promote the importance of enhancing the patient experience.

3.82 The main concern was that the programme would become too politically-focused or concerned with targets - at the expense of improvements in patient experience. Some were concerned that such targets would not necessarily be a true reflection of the quality of patient care. Others thought that national targets on patient experience results might not take sufficient account of the particular issues faced by their Board. Similarly, some were worried that targets or league tables would be used to penalise them. There was a feeling that patient experience results should not be used to “name and shame” poorly-performing Boards at the expense of concentrating efforts on making quality improvements. On the other hand, some interviewees, while sharing concerns about targets being too rigid or distracting, would welcome clear standards on patient experience set by the Government, and thought it was important for the success of the programme that it was performance-managed.

[The danger is that] people will find ways of getting good scores without actually improving patients’ experiences.

I’d like it to be less politically focused than the English survey programme - more focused on things that matter to patients.

[Targets] don’t take account of local circumstances.

I fear it will become a game of numbers: a league table with no cognisance of the journey people travelled on.

The danger is that it will be another stick to beat us with.

They should ask us difficult questions about how we have tackled patient experience, rather than prescribing what we should do.

3.83 Many interviewees did not want the programme to be over-bureaucratic, or to create unwelcome administrative burdens. Several others were worried that the Government would take too long to implement the programme.

I don't want heavy-handed performance management, a bureaucratic imposition from the centre and league tables, or a heavy administrative burden to fill in returns.

I worry that it will be a paper exercise but little or nothing will come of it. They want to tick boxes.

[I fear that] it will all get bogged down at the Executive and that it takes 2 years to actually do something.

It might be over-ambitious so there could be too long a delay between doing things and getting feedback.

3.84 Alongside fears of bureaucracy, some said they were concerned that their control of their patient experience processes would be eroded. Some thought that, if their feedback came through a third party, they would feel less engaged with the process.

I hope they don't interfere too much with how we run it.

I don't want to feel disempowered – that it takes away my responsibility to engage with my patients.

3.85 Some people were concerned that the new programme would not take sufficient account of the development work already done for patient experience programmes outside Scotland.

I hope they don't have a home-made Scottish version that's not reliable or valid and doesn't give us quantitative information.

3.86 Two interviewees were concerned that the programme would require them to replicate work they were already doing, for example for the Scottish Health Council assessments.

I hope someone doesn't come along with a new survey that just replicates everything we are doing locally.

I don't want it to ask us things that others are asking of us.

3.87 Some people were concerned that the programme would cost them too much financially, especially if they were already spending money on patient experience programmes.

The danger for us is that we won't get anything in addition to what we already have but it will cost us more money.

3.88 One respondent was concerned that patient feedback would not be treated with sufficient sensitivity to patients' confidentiality. Others were concerned that too many surveys or other feedback processes would over-burden patients and could lead to survey fatigue.

If patients highlighted a negative comment I would hope they wouldn't be harassed. I don't want them to be exposed. They are doing us a favour.

3.89 Interviewees were concerned that the media would mis-represent patient experience findings.

Publishing league tables would be deeply unhelpful. It's a worry because if somebody wanted to know in terms of freedom of information they'd have to have it. But the public's confidence in health care could be further eroded.

View's on patient priorities

3.90 Interviewees were asked to say what issues they thought were most important to patients. The purpose of this was to check that a parallel research project – to establish patient priorities in Scotland – included as test items the issues Board representatives believed to be important.

3.91 **Being treated with respect and dignity:** Respect, dignity and courtesy were the most commonly-mentioned priorities. Twenty-one interviewees mentioned these issues.

3.92 **Prompt access and treatment:** Fourteen people said that access to prompt treatment was a high patient priority.

Prompt treatment: short waiting times and they are seen on time when they arrive.

3.93 **High quality, safe clinical care:** Thirteen interviewees noted that high quality clinical care was a top priority for patients, while some said that it was often not mentioned as a patient priority because it was widely understood to be very important.

Clinical outcomes are the most important, although people tend to take that for granted.

3.94 **Treated as individuals:** Thirteen interviewees said that it was important for patients to be treated as individuals.

Having people come and talk to them, make eye contact, relate to them as individuals.

The system should be sufficiently flexible to meet people's individual needs. We should not simply apply the system to them.

3.95 **Information and communication:** Nine interviewees said "information" was a high priority for patients and five mentioned "Communication".

Clarity of information on their condition, prognosis treatment, etc.

3.96 **Involvement in decisions:** Eight interviewees said that patients' involvement in decisions about their care was important, which for some included being listened to. One noted that carers' involvement was also important.

Patients want involvement in their care and good communications about it.

3.97 **Being safe:** Six interviewees said that safety was one of the most important things for patients. On a related topic, seven people said that avoiding hospital-acquired infections was an important priority for patients. Five people mentioned cleanliness.

They've got to feel safe.

Infection control is one of the first things our patients mention.

They don't want to catch MRSA.

3.98: **Bering treated with empathy:** Six people thought that it was important to patients that staff show they care.

[Patients want] to have their needs met and they don't want to have to ask for things, like an extra blanket. They are sometimes shy to ask.

It matters that we show how we care about people.

3.99: **Co-ordinated care:** Consistent, co-ordinated care was considered an important aspect of care by three interviewees.

They want all the important parts of their care to work together.

3.100 **Local Services when possible:** Three mentioned the importance of local services being available as well. However, an interviewee from an island Board noted that many of their patients recognised the limitations of their local Board and did not always want to travel to the mainland for specialised care.

There is a clear acknowledgement that that they have to travel for specialist things and not everything can be provided locally.

3.101 **Other issues:** Two people said that fairness of access was important to patients. Two interviewees from rural boards raised the importance of transport. Other issues mentioned by relatively smaller numbers of interviewees included pain control and high quality food. A few interviewees commented on the influence of the media in shaping patients' perceptions of their priorities.

Transport: free and convenient. If they are coming in from a remote island it is difficult for them to get buses and ferries to coincide with their appointment times. We do what we can to book their appointments at convenient times.

They are concerned about things that are in the media: infection control, access and waiting.

People are afraid of coming into hospital now because of stories in the press about superbugs, old people being left on trolleys, etc.

CHAPTER FOUR: CONCLUSIONS

4.1 Overall, attitudes towards patient experience activities were positive and interviewees welcomed Better Together Scotland's Patient Experience Programme. Their main concerns about the programme were that there would be too strong a focus on targets and it could impose too great a bureaucratic burden.

4.2 Most interviewees were interested in both quantitative and qualitative information about patients' experiences, but where they expressed a preference for one type of information, qualitative information was viewed more positively and it was thought to be particularly useful for inspiring and driving quality improvements. However, those who had carried out postal questionnaire patient experience surveys tended to give greater value to this type of quantitative information.

4.3 Self-completion questionnaire surveys were the most common patient experience activity taking place in Scottish NHS Boards. Surveys were the most trusted source of accurate information about patients' experiences.

4.4 Quantitative information was valued for its use in benchmarking and highlighting areas of concern or excellence and most interviewees said they would be interested in benchmarks, either with the rest of Scotland, or with Boards similar to their own. Their main concerns about benchmarks were that they might not be fair comparisons and that they might lead to complacency.

4.5 Perceived barriers to implementing changes as a result of patient feedback included defensiveness from clinical staff, a lack of a patient-centred culture within the Board, lack of time, lack of the right skills, competing priorities, not knowing what to do with patient experience findings, and difficulties ensuring that methods of measuring experiences were sufficiently rigorous.

4.6 Many Board representatives volunteered interesting and inspiring examples of changes they had implemented as a result of patient feedback. About half of the changes implemented were supported by evidence of improvement in patients' experiences.

APPENDIX A: EXAMPLES OF IMPLEMENTATION OF PATIENT EXPERIENCE IMPROVEMENTS

Making appointment times more patient-centred

[Shetland] *In day surgery we followed patients through their entire day. Before, we had quite a traditional approach, so everyone coming in for day surgery had to come in at 8am so, for many of them, there was a lot of waiting around. There is currently no pre-assessment service either so all of that happened on the morning they were admitted. In the future, based on patients' feedback, we are remodelling the service. We will change the system so that not all patients have to come in at 8am.*

[Tayside] *Patients were telling us it was difficult for them to come in for a 9am appointment if they had a long way to travel. Now we are looking at post codes so we can adjust the appointment times for those who have further to travel.*

Giving senior nurses more patient contact

[Grampian] *One of our most important projects is called Back to the Floor (based on a project from one of the large London acute NHS trusts). It involves everyone in nurse management. They all do a nursing shift once or twice a month. So now, when they are trying to make changes, they can illustrate effectively with the things they see with own eyes. They all now routinely wear uniform so it's clear to everyone they are all part of the same team. It has reinforced the crucial role that nursing staff have to play in coaching and mentoring staff at ward level, and modelling behaviours. (There was a time when they were seen more as administrators.) It has generated huge enthusiasm among them and it's starting to make a big impact. The feedback has been phenomenal from patients and staff. We don't call it an initiative. The word initiative was been banned: it's the day job.*

Language support

[Western Isles] *The work we are doing for patients who don't have either English or Gaelic as their first language. We had quite a lot of incidents of poor communication. We are a seafaring community here, the fishermen's co-operative told us that a lot of foreign people, for example Spanish sailors on trawlers, were finding our services difficult to use. So we implemented a different system, put in Language Line.*

Re-organising outpatients appointments

[Western Isles] *We have done systems changes in outpatients. We realised that we were expecting people to be in different places at once: going for bloods and other tests, etc. So we worked with people in outpatients, deployed staff differently so they helped patients get from A to B and back again.*

Flexible dining times

[State Hospitals] *We have more flexible dining times. Patients said they wanted somewhere to sit outside when the weather is nice so now we have seats. Patients are now much more actively involved in their treatment planning than they were 5 years ago.*

Car parking

[Tayside] *Car parking – an emotive subject. We involved service users as part of a group to come up with solutions. We looked at patients coming in for treatments who were unwell, making sure they could park as close as possible and not be penalised financially.*

[Golden Jubilee] *A patient who had come for an X-ray had great difficulty getting to the department and he said, “Your parking is a bit far away. It was too far for me to walk.” Also, he said he expected somebody to meet him with a wheelchair, but no-one did. When I fed this back to the management team, they agreed to have wheelchairs at the entrance but at first they said, “It’s only one patient who said it. We don’t see anything wrong with the disabled parking.” The patient’s comment that changed their minds was “You have spaces at the front allocated for the Chief Executive and the surgeon. If that surgeon is fit enough to stand on his feet for 8 hours to perform the operation on me, isn’t he more able to walk than me?” Then the disabled parking places were changed.*

Improving patient privacy

[Golden Jubilee] *A patient who had been to the cath lab complained that the consultant came in after her angio and spoke about what he found. There was no confidentiality because there were only curtains between her and the next patient. Now we have a new unit with separate rooms so patients don’t overhear the other patients. In each cubicle there is also an en-suite toilet so patients don’t need to walk down the corridor with their gowns flapping open at the back. We also have a policy that patients are offered two gowns so they can put one on over the other.*

Supporting people with learning difficulties

[Ayresshire and Arran] *We have been working on how learning disabled people use hospital day surgery services. This was partly prompted by a complaint, but also by other factors. The changes were mainly about communication, the way the list was organised to give more time to those patients, consent issues, listening to the carer and involving the carer as a partner.*

Improved speed of response to emergency calls

[NHS24] *Our feedback told us that when patients would call with cardiac chest pain, saying they think they're having a heart attack, the call handlers would take their details, then pass them on to a nurse, the nurse would then ask many of the same questions, and keep the patients on the line while they contacted an ambulance to take them to hospital. Then, the average contact time was over 12 minutes, which is a long time if people are having a heart attack. So we trained our call handlers to ask people who presented with chest pain just two or three extra questions, then contact the ambulance directly. Then, the average contact time was reduced to seven minutes. Then, we did an audit with the ambulance service on how appropriate the referrals were: it was over 90%.*

[NHS24] *Aspects of the service that have been addressed and improved as a result of survey findings coupled with input from other stakeholders would include an improvement in access times and a reduction in the number of patients that have to be called back.*

Improved hand-cleaning

[Dumfries and Galloway] *In the patient safety agenda, we realised hand hygiene was not always what it should be so we introduced mandatory hand hygiene training for all staff. Now the hand washing audits have shown an increase in healthcare staff hand washing from 40% to 90-100%.*

APPENDIX B: STRUCTURED INTERVIEW SCHEDULE

NHS Board
Job title
Interview date
<p>What, if any, patient experience activities have been carried out within your NHS Board? e.g. Patient surveys; Complaints and compliments; Feedback to patient liaison staff; Patient representatives in decision-making groups; Patient forums; Suggestion boxes; Focus groups?</p> <p>Anything in primary care?</p>
<p>What kind of information about patient experience interests you most?</p> <ul style="list-style-type: none"> • Qualitative or quantitative? • Statistics or words?
<p>Which sources of information do you/would you trust most?</p> <ul style="list-style-type: none"> • Complaints • Compliments? • Surveys? • Patients' panels? • Focus groups? • Something else?
<p>What makes a good patient experience measure?</p> <ul style="list-style-type: none"> • Powerful patient stories? • A representative sample? • Independent data collection? • Targeted feedback?
<p>Benchmarking</p> <ul style="list-style-type: none"> • Would you be interested in benchmarking your Board against others? • Who are the best comparators for your Board? • Are you more interested in between-Board comparisons or within-Board comparisons among departments or over time?
<p>What are your (and your Board's) motivations for using patient experience information to make quality improvements?</p>

<p>What are the barriers (to you and your Board) to using patient experience information? Have you overcome some barriers? If so, how? What do you need to help overcome barriers? Is there other patient experience work that you would <i>like</i> to be doing, but currently you aren't?</p>
<p>Where are you currently or recently focusing quality improvement efforts? To what extent are quality improvement initiatives driven by patient experience reports?</p>
<p>Do you have any examples of measured changes? If so, how did you measure change?</p>
<p>What have you learned about using patient experience information? What do you do differently now?</p>
<p>What do you expect from the forthcoming Patient Experience Programme in NHS Scotland?</p> <ul style="list-style-type: none"> • Benchmarking with other Boards? • Prompt publication of results? • The ability to make comparisons among different divisions within their own Board? • Information and support on how to make quality improvements? • What would be on your wish list?
<p>What do you fear? What DON'T you want? (from the forthcoming Patient Experience Programme in NHS Scotland?)</p>
<p>PATIENT PRIORITIES What issues do you think are most important to patients?</p>
<p>Is there anyone else in your Board should I talk to?</p>

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