Public Feedback on Sharing Learning from Adverse Events

September 2016
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Background and feedback mechanisms

On 10 and 20 June 2016, Healthcare Improvement Scotland facilitated two public focus group sessions in Glasgow and Edinburgh to discuss what the public would like to see in the public domain around learning from adverse events. For example, key lessons learned following the review of an adverse event, the improvements that were made, and what learning was subsequently shared across the service with other NHS boards and with the public. Seventeen members of the public, recruited through the Scottish Health Council, attended the sessions. The focus groups were chaired by Healthcare Improvement Scotland with input from members of the adverse events learning summaries short-life working group.

On 29 June 2016, NHS Tayside also held a focus group with five public partnership representatives. The focus group was facilitated by a clinical governance and risk management representative with support from a public partner.

During June and July 2016, an electronic survey was circulated to NHS board public involvement groups through the NHS board liaison co-ordinators to capture broader feedback from the public. Eighteen members of the public responded to the survey which closed on 15 July 2016.

In total, 40 members of the public provided feedback. The findings are summarised below and the detailed responses to each question and individual participant comments are provided on page 5.

Summary findings

The following points summarise the public feedback received through the focus groups and electronic survey.

- Public participants believed it is very or extremely important to feel assured or to know that NHS boards have processes in place to capture and share learning points from adverse event reviews.
- The majority of participants believed it would be very useful to see the actual learning points, lessons learned or recommendations from significant adverse events reviews for adverse events that involved them.
- Participants generally wanted to know what specific improvements were introduced or implemented following a significant adverse event review that involved them or their loved ones.
- All participants saw the benefit of sharing learning among staff within an NHS board and across other NHS boards.
- All participants thought a one-page summary of learning points would be useful if they were looking for information about significant adverse events.
- Of the 40 participants, 31 (78%) thought that learning summaries should be published on the NHS board website, while three (7%) participants thought they should “maybe” be shared. Six participants (15%) thought they should not be shared publically. Reasons for this included not wanting other people to know about an adverse event that involved them, or perceiving that information could potentially be upsetting for some members of the public. These participants also felt that many people are not really interested in hearing about adverse events unless it directly affects them or their family. They suggested that instead of publishing learning summaries, you could publish statistics. For example, the number of adverse events and the number resolved through completion of actions or improvements. However, some participants said they would not want to see statistics in the public domain.
Most participants thought that people should have access to information on learning points in other formats, such as large print or Braille, on request.

Participants favoured a variety of mechanisms to access general information about learning points or improvements such as an NHS board website, posters, information screens and public meetings. The NHS board annual report scored less favourably as a communication mechanism. Other formats were suggested, including radio, social media, local press, GP surgeries, community centres or through local participation or planning groups.

Reassuringly, many participants commented that it’s not about apportioning blame but to learn from mistakes and put systems in place to prevent adverse events happening again as far as possible.

**Detailed feedback**

The table below details the responses received to the questions asked of the public. The responses are categorised by the method of feedback including the electronic public survey, the two Healthcare Improvement Scotland focus groups and the NHS Tayside focus group.

<table>
<thead>
<tr>
<th>Question 1: How important is it for you to feel assured or to know that NHS boards have processes in place to capture and share learning points from adverse events?</th>
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<td><strong>Electronic survey</strong></td>
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| NHS Tayside focus group | All five representatives felt it was critical for the public to be assured that there are processes in place for staff to learn from adverse events. Processes were highlighted as key to providing assurance to the public that there are systems in place to learn from events and to reduce risk. The group also recognised that the language and terminology used within the NHS would need changed into lay terms. |
for the public’s understanding. The group also noted that as adverse events can be very personal, assurance would need to be given that personal details would not be shared and redaction of personal information is imperative. The group highlighted that the public are reluctant to complain when involved in frontline care. This may be because they are concerned that a complaint will impact on the nursing care that is being delivered at that time.

| Healthcare Improvement Scotland focus groups | “If an adverse event happened and I witnessed something which is not right, I would like to know there is a process for me to speak to someone about it and for it to be reported.”  
“I’d like to know that when an adverse event happens that staff are made aware of errors, are interested and have time to look at issues and to reflect, e.g. "oops we didn’t do that well – how can we improve things".”  
“I would like to feel assured that NHS boards are looking into the risks of computer system failures and how to pre-empt or manage it.” |

**Question 2: How useful would it be for you to see the actual learning points, lessons learned or recommendations from significant adverse event reviews?**

| Electronic survey | Of the 18 respondents, 15 (83%) believed it would be very or extremely useful to see the actual learning points, lessons learned or recommendations from significant adverse events reviews.  
“Authentic openness and honesty is vital.”  
“Important to have faith in the system.”  
“I don’t think the public are aware of most outcome reports after adverse events or for that matter what an adverse event is.”  
“Not sure how one could review if a member of the public.”  
“I like to know what is going on and as a member of our local PPF (Public Partnership Forum) - it is important that we know.”  
“If by "you" it is the patient to whom you are referring, it is imperative that learning points are shared. This confirms that others have been helped by their involvement and gives them back control of the situation.”  
“In my capacity as a public/patient representative, I want to be to be re-assured that the systems are robust. I want to know that any learning points are learned and what has been done or should be done to put matters right.” |

| NHS Tayside focus group | Three of the participants thought it would be useful to see the learning points, lessons learned or recommendations from significant adverse event reviews. The other two participants thought it would be “somewhat useful”. The focus group discussion reflected upon adverse events that could occur anywhere within the healthcare setting, although there is a public expectation that “the care given is as good as you can get”. Concern was noted about the way this information could be shared with the public: “Front page headlines in a newspaper are not helpful, although transparency is a must.” |

| Healthcare Improvement Scotland focus groups | “We need to share lessons.”  
“Health boards should look at best practice to help eradicate problems of the past. There don’t appear to be instances of sharing knowledge.”  
“Most people are not really interested in hearing about what happens with adverse events unless it affects them or their family.”  
“We see the benefit in NHS boards sharing learning with other health boards and that they are sharing learning with their staff.” |
**Question 3: How important would it be for you to know what specific improvements were introduced or implemented following a significant adverse event?**

<table>
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<tr>
<th>Electronic survey</th>
<th>All 18 respondents felt it would be important to know what specific improvements were introduced or implemented following a significant adverse event review.</th>
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<td>“It’s important that the public is informed about events so they can see how the NHS deals with these - it is not about looking for someone to blame but to know that such events are dealt with seriously and appropriately.”</td>
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<td>“Important to be able to see what is proposed then one can appeal if one feels this is not sufficient.”</td>
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<td>“I think it would be useful to have access to information if needed you couldn't follow every incident.”</td>
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<td></td>
<td>“This really is only important if it happened to someone you know I suppose others might view the improvement and wonder what happened as content details of events are not shared.”</td>
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<td>“Needed so that we can assure patients that the right decision has been made and no one is a scapegoat.”</td>
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<td>“I would also be keen to know how any new recommendations are to be implemented.”</td>
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| NHS Tayside focus group | If an adverse event occurred which involved them as patients, all five participants agreed it would be critical to know what improvements were made as a result to reduce the risk of the same event happening to another patient. For adverse events not involving them directly, four of the participants felt it was “very important” and one felt it was “important” to know what improvements had been made. |

| Healthcare Improvement Scotland focus groups | “It would be really helpful to know that good practice and improvements in one area are being translated into shared learning.” |
|                                               | “I would be interested to know something is being done when adverse events happen.” |
|                                               | “If something goes wrong we would want to know the outcomes of the adverse event and be given information.” |
|                                               | “If something happens and I got an apology but never heard the outcomes, I would just want to know this wouldn’t happen to someone else.” |
|                                               | “We would like to think that patients or family involved in adverse events are satisfied with what happens after the event.” |
|                                               | “I would like to be involved in the review process from the start.” |

**Question 4: If you would like access to general information about learning points or improvements following adverse event reviews, what format would suit you?**

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<thead>
<tr>
<th>Electronic survey</th>
<th>In general, respondents favoured a variety of mechanisms to access general information about learning points or improvements such as the NHS board website, posters or information screens and public meetings. The NHS board annual report scored less favourably. Other mechanisms suggested by participants:</th>
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<td>notice in the local paper with web details for where more detailed information can be found</td>
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<td>via the Health and Social Care Local Planning groups</td>
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• email similar to the Scottish Public Services Ombudsman
• regular email updates through local Public Partnership Forums
• personal feedback for individuals personally involved
• social media, and
• shared in GP surgeries, pharmacies, and community centres.

- “Reading about them in local press or hearing on local radio. Could there be a regular spot on a radio programme?”
- “I know this will be challenging to achieve however many people glean knowledge of what is happening in their community from this (local press or hearing on local radio) source.”
- “Too many leaflets and reports that public not interested in. Action speaks louder than words.”
- “I don’t think people read posters and many are out of date. I recognise that it an almost impossible task to identify where posters are put up and who is responsible for keeping them up-to-date. Information screens in waiting areas and cafes would be good but people need to be educated to look at them. I don’t know if it would be possible to put them in GP or dentist waiting areas and pharmacies but these, particularly pharmacies, would be good.”
- “There needs to be more options. For greater clarity and transparency these findings should be widely available to the public, so more user friendly settings such as social media, local press, shared in GP surgeries, community centres etc.”
- “If I reported an incident I would expect a written reply or at least be able to see something on a board’s website.”
- “Public feedback on posters, websites etc would be helpful but personal feedback is more important to patients or families concerned.”
- “I am not entirely clear about where this question is going. Is the idea that I would be personally informed (preferable) or am I as a public/patient representative to be left to find out "general information" - whatever that may be - for myself? What if I find the general information inadequate?”

**NHS Tayside focus group**
The group suggested the following mechanisms for accessing general information about learning points or improvements:

- the NHS board website
- posters including good practice, and
- one participant suggested the use of an information screen in hospitals with contact details if you have concerns.

One of the five participants said: “If an adverse event happened to me, I wouldn’t want other people to know about it.”

**Healthcare Improvement Scotland focus groups**
Three out of 14 participants (21%) thought information on learning points should not be publically shared (see comments against Question 6). For those who favoured sharing learning and improvements publically, they agreed there should be a variety of mechanisms such as NHS board or Healthcare Improvement Scotland websites, newspapers or through local participation or community groups.
### Question 5: When seeking information on significant adverse events, please rate how useful you would find a one-page summary

<table>
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<tr>
<th>Electronic survey</th>
<th>All 18 respondents believed a one-page summary of learning points would be useful if they were seeking information on significant adverse events. Thirteen respondents (73%) felt it would be very or extremely useful.</th>
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<tr>
<td></td>
<td>➢ “This seems sensible.”</td>
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<td>➢ “This can be used as a reference point to see if lessons have been learnt.”</td>
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<td>➢ “However there are often repetitions of learning points and the same ones keep arising.”</td>
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<td>➢ “Response is speculative as the adverse situation resolution may need more than a page.”</td>
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<td>➢ “Ensure it is easily read and understood and no jargon.”</td>
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<td>➢ “People don't read beyond the first page of detailed reports so feedback should be concise, appropriate and relevant.”</td>
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<td>➢ “A summary of learning points (in plain English - not &quot;health-service speak&quot;) would indeed be very useful. Can I take it this would be in addition to the real thing?”</td>
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<table>
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<tr>
<th>NHS Tayside focus group</th>
<th>Four out of the five participants agreed that a learning summary would be very useful, while one participant rated the learning summary as useful.</th>
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<tr>
<td>Healthcare Improvement Scotland focus groups</td>
<td>Participants liked the one-page learning summary format, although some thought that learning summaries shouldn’t be shared publically (see comments against Question 6).</td>
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| Healthcare Improvement Scotland focus groups | Of the 17 attendees, 11 (65%) thought we should share learning summaries within the public domain, while six (35%) thought we shouldn’t share them publically.  
- “I think it’s really useful for staff but not necessarily for the public.”  
- “I think you get something out of it and want to know what happened and what was learnt.”  
- “I think it makes sense to make the learning summary available if people want to see it.”  
- “I wouldn’t mind reading it in a newspaper.”  
- “I think learning summaries would be useful for some and especially for medical staff.”  
- “I don’t necessarily want to hear about adverse events, particularly through the media.”  
- “If an adverse event affected me or my family I wouldn’t want other people to know about it.”  
- “I would find the learning summaries interesting but it could be upsetting for some members of the public.”  
- “We could just get the statistics or could ask for the detail behind the adverse event.”  
- “You could perhaps inform the public of the number of adverse events and the number resolved or actions/improvement taken.”  
- “I don’t want to know about the number of adverse events especially through the media.” |

| Question 7: Would you like information on learning points in other formats such as available in large print, Braille, or alternative languages on request? | Of the 18 respondents, 11 (69%) favoured having access to information on learning points in other formats, if required, such as large print, Braille or alternative formats while three (19%) responded “maybe”).  
- “To know they can be made available.”  
- “I do not need this but others might.”  
- “Information in other formats should be available on request.”  
- “Again depends on who or how many people within a significant groups of people were adversely affected.”  
- “Everyone should have access to public documents.”  
- “Large print or Braille.”  
- “Also easy read for those with reading challenges.” |

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- “Everyone should have access to public documents.”  
- “Large print or Braille.”  
- “Also easy read for those with reading challenges.” |

| NHS Tayside focus group | All five participants agreed that the adverse event information in other formats, such as Braille, should be available on request. |

| Healthcare Improvement Scotland focus groups | All participants agreed that alternative formats should be available on request. |
**Q8) Have you ever requested information from an NHS board about an adverse event?**
If yes, what kind of information did you seek and were you happy with the response?

| Electronic survey | Of the 18 respondents, 4 (22%) had requested information from an NHS board about an adverse event. They provided the following feedback on whether they were happy with the response.  
|                  | — “Sending me home in nightie with bus pass and a NHS blanket on a Sunday morning. I wrote a letter and got an apology over the phone.”  
|                  | — “A pneumothorax whilst having a biopsy, the likelihood of this happening was printed in the patient information before the CT scan.”  
|                  | — “Only answers to specific questions through our local PPF and not often do you get an answer.”  

| NHS Tayside focus group | One participant had requested information from an NHS board about an adverse event in the form of a complaint. This information sought was about consent and a language barrier with the clinician and involved the services of a solicitor on behalf of the family.  

| Healthcare Improvement Scotland focus groups | One participant experienced an adverse event while in hospital when someone inadvertently switched off their insulin pump. While a clinician apologised at the time, the event was not written up in the participant’s notes and the participant felt it was unlikely to have been reported as an adverse event.  
|                                              | Another participant had experienced a misdiagnosis regarding a cardiac issue but received a letter of apology from their GP which they were happy with.  

**Q9) Are there any other comments you would like to make about information on learning from adverse events and what is available to you as a member of the public?**

| Electronic survey | “Folk just want today be treated with respect not a statistic!”  
|                  | “It is essential that the public have trust in the NHS - but if it is not open and transparent this is of no use - we need to know what is happening, how it has been dealt with and how such a situation will be avoided in the future - in simple and plain language that anyone can understand and no ‘JARGON’- far too often it is simply put aside and forgotten.”  
|                  | “Where appropriate, patient and family should be involved at every step. This should include a review of how they thought the review was handled as well as reviewing the actual adverse event.”  
|                  | “I should like health boards to be much more open and transparent and allow their staff to speak up without fear.”  

| NHS Tayside focus group | “Put practice in place from learning and the improvements identified to reduce the risk of a similar event happening to someone else.”  
|                          | “Explain what an adverse event is within the learning summary template.”  

| Healthcare Improvement Scotland focus groups | “We don’t know how much the public is aware of what adverse events are or the numbers involved.”  
|                                              | “You could share trends or statistics such as comparisons about adverse event numbers across NHSScotland and how quickly they were resolved (without creating a data collecting and reporting industry)”  
|                                              | “In our experience professionals don’t always write up proper notes or report adverse events.”  
|                                              | “A lot of the public are frightened to complain in case it compromises their care.”  

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It’s may be best to give them a form when leaving hospital to give feedback when they are back home – at which point they are far more likely to give an honest assessment.”

- “It would help if more patients complained.”
- “The level of work overload is impacting negatively on the time spent with patients.”
- “I’m worried about the number of managers and the lack of matrons who used to deal with things there and then.”
- “Senior management need to have the view and vision beyond just coping.”
- “There seems to be a different culture between health boards but also between different hospitals. This needs to be improved.”
- “NHS boards need to be better at listening to patients/relatives/carers. Staff (nurses in particular) have too much paperwork and don’t spend enough time speaking with or listening to patients, family or carers.”
- “We hear of issues about hospitals being short staffed and there’s not enough staff to look after patients. Nurses always get criticisms and complaints but they need support and praise.”
- “In-service training should be more than just governance or health and safety and be about caring for patients needs.”
- “We need to get away from a blame culture which is still there.”
- “A lot of patients (particularly older people) are frightened to complain due to concern it might adversely affect their treatment.”
- “You need to allocate time to analyse planned changes and potential impact before introducing different ways of working. It’s important to involve the public in this (without involving so many people as to make the change process unmanageable). It’s also essential that staff who know about the complexities of the system are given the job of shaping the changes.”