The voice of people who use services, families and members of the public in fitness to practise proceedings

Public and stakeholder engagement report

June 2019
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Executive summary

Traverse, an independent research and engagement organisation, was commissioned by the Nursing and Midwifery Council (NMC) to engage their stakeholders in a dialogue about their proposals to update their approach to fitness to practise.

Capturing the voice of people who use services, families and members of the public in fitness to practise

The NMC’s Fitness to Practise strategy launched in September 2018 committed to putting individual service users, families and members of the public at the centre of how they work. Alongside improving the way they communicate with people and the support they provide, it also involves understanding when what a person has to tell them could have an impact in the context of the regulatory decisions we make in fitness to practise.

This represents a different approach. In principle, it will involve a change in mindset, with a move towards appreciating the value of emotional narratives in fitness to practise proceedings. This would be achieved by inviting service users, family and members of the public to tell the NMC how an incident has affected them in a personal experience statement. The personal experience statement could have the following purposes:

- It could help the NMC to assess harm, including the impact of an incident on a person’s mental health, wellbeing or their family.
- If shared with the nurse or midwife, the statement gives them an opportunity to reflect on and improve their practice.
- It could allow service users, family and members of the public to share their experience and get an acknowledgement or apology from the nurse, midwife or nursing associate in question.
- It may contain information that could be used by the case examiners and independent panel members to help establish what happened.

The fieldwork took place between May and July 2019 and was a combination of group discussions and one-to-one interviews. Traverse heard from 125 people from across the UK, from the following groups:

- Members of the public, including those with caring responsibilities
- Service users with kidney disease and their carers
- People with mental health conditions
- People with learning disabilities
- Patient representatives
- Recent mums
- Registered nurses and midwives, including those with fitness to practise experience
- NMC staff
Legal and union representatives

Key findings

General views on the new approach

Whilst there were differences of opinion within participant groups, overall the response to the NMC’s proposals was largely positive amongst patient representatives, the public, NMC staff and registrants, but more negative amongst union and legal representatives who were concerned about its implications for nurses and midwives.

Research participants were largely positive about the idea of introducing elements that are more ‘human’ into what has always been a formal, legalistic process which has made little room for people’s emotions and which can thus leave many feeling dissatisfied. It was seen as an opportunity to ‘put people back into the process’, allowing those involved to talk about how an incident has made them feel, on both sides. This was tempered by anxieties – some significant – about where to draw the line, how to protect registrants from further emotional strain, and how service users, families and members of the public can be given a stronger voice without also unfairly biasing a process of judgement on registrants.

Through the discussions with participants we can see a preference for inviting and sharing referrers’ statements early in the process; seeing the proposals as a way to diffuse and moderate anger from referrers and reducing anxiety and upset from registrants. It is also seen as a way to provide more nuanced responses to an angry or disappointed referrer when the fitness to practise process may not deliver this result.

Associated strengths

- A new prominence for service user/family/public experience, which does not feel valued in the current process.
- The ability to diffuse anger and frustration and reduce emotional strain: People are most positive when they believe this proposal will reduce emotional strain for staff and service users/families/public and help to diffuse the anger and frustration that they can feel as the fitness to practise process goes on around them.
- The opportunity to shed new light on incidents through collecting a different source of evidence.

Associated weaknesses

Union and legal representatives were most likely to identify risks and challenges in the new approach, as were some registrants. These included:

- Accentuating and prolonging the strain and distress of those involved, especially registrants: people are less positive when they believe this proposal could make the process more emotionally demanding – especially for staff, more personal and more adversarial.
• Stacking the odds against registrants: participants expressed concern about fairness, as it was thought that elevating the value of personal reaction and emotion on the part of service users/families/public would give their views – and perceptions of events – undue weight in the fitness to practise process.

Barriers and opportunities to implementation

• Capturing service user/family/public voice could help the NMC to close cases at the earliest opportunity and could encourage remediation – as it’s something the registrant can reflect on.
• Inviting the personal experience statement at Screening stage is the most favoured option but it also places the biggest administrative burden on the NMC – especially, if as many had suggested, complainants should be offered support to make their statements.
• NMC staff training to be able to analyse the statement content and offer support.
• Offering referers lots of support and a tailored process will be costly and time-consuming.

Tolerance and boundaries for the new approach

There is high tolerance for the proposals overall, with legal/union representatives and senior stakeholders the main exception. They were concerned about how the proposals would undermine the legal process, and so wanted any new process to be kept entirely separate or suggested that tweaks be made to the existing fitness to practise process – such as adapting the witness statement instead of introducing the personal experience statement. The main ‘grey areas’ around acceptability relate to:

• How and whether registrants should be expected to respond to the personal experience statements. It was often said that this would depend on the situation.
• How and whether the personal experience statement should be admissible as evidence for the fitness to practise process (this could be in the registrant’s favour if it shows a complaint to be unfair).
• How and whether service users/families/members of the public should be able to access support for drafting their statement – most felt it was right that support be provided and different formats of response accepted, but there were mixed views about whether they should be able to access professional help to write the statement as this was arguably ‘not in the spirit’ of the proposals.

Reflections on the engagement process

Participants engaged well with the content and questions around the fitness to practise proposals and there were high satisfaction levels in terms of the design of the workshops and quality of facilitation (see Appendix 3). They also valued the fact that they had been asked for their views early in the
process and were keen to be updated and involved in what happens next.

**Recommendations**

1. Work on resolving some of the questions most often raised by participants which affect the acceptability of the proposals, e.g. whether or not a registrant’s response to a personal experience statement can be used for or against them in the fitness to practise process, or how – if this is felt to be preferable – it would be possible to keep this entirely separate.

2. Start to develop some options for how the personal experience statement could be completed – online, over the phone etc – and how service users/families/members of the public and registrants could be supported to complete the personal experience statement and respond to it. Examples of these elements of the proposals would help people to give a clearer opinion them.

3. View the proposals as a vehicle for reviewing how the NMC presents itself and engages with registrants and the public. Some participants talked about the proposals as embodying – or demanding – a wider sea change in how the NMC is perceived. For members of the public, this was about the NMC being more visible. For registrants, it was about the NMC being a more accessible, approachable organisation that emphasised its learning and support role – as well as its ‘policeman’ role.

4. Building on the success of this stakeholder engagement, the NMC should continue to look for opportunities to carry out ‘upstream’ dialogue and co-production with people who use services, families and members of the public and should ensure they have ongoing opportunities to stay informed and give their views.
1. Introduction

Traverse, an independent research and engagement organisation, was commissioned by the Nursing and Midwifery Council (NMC) to engage their stakeholders in a dialogue about their proposals to update their approach to fitness to practise.

What is fitness to practise?

Being fit to practise requires a nurse, midwife or nursing associate to have the skills, knowledge, health and character to do their job safely and effectively.

The Code sets out the professional standards that nurses, midwives and nursing associates must uphold in order to be registered to practise in the UK.

The NMC will investigate whether someone on the register is fit to practise if an allegation is made that they don’t meet their standards for skills, education and practise.

If necessary, they will act by asking them to complete some training or by removing them from the register for a set period of time, or in some cases, permanently.

Background

The NMC launched their new Fitness to Practise Strategy in September 2018. Alongside a focus on keeping people safe, their new approach aims to put service users, families and members of the public at the heart of what they do. Alongside improving the way they communicate with people and the support they provide, it involves understanding when what a person has to tell them could have an impact in the context of the regulatory decisions they make in fitness to practise.

This represents a different approach. In principle, it will involve a change in mindset, with a move towards appreciating the value of emotional narratives in fitness to practise proceedings.

Traditionally, emotions have been seen as having no place in legal proceedings as they challenge the presumed rational and dispassionate consideration of evidence and the law, especially in a system underpinned by adversarial confrontation. The NMC’s new strategy takes them away from this, with fitness to practise becoming an inquisitorial process that seeks to resolve issues in a learning environment.
Capturing the voice of service users, families and members of the public

The NMC has proposed that the voice of service users, families and members of the public would be captured by inviting them to tell the NMC how an incident has affected them in what is being provisionally called a **personal experience statement**.

### What’s a personal experience statement for?

Whilst the format and process of capturing a personal experience statement has not yet been agreed, it could have the following uses within fitness to practise:

- It could help the NMC to assess harm, including the impact of an incident on a person’s mental health, wellbeing or their family.
- If shared with the nurse or midwife, the statement gives them an opportunity to reflect on and improve their practise.
- It could allow service users, families and members of the public to share their experience and get an acknowledgement or apology from the nurse, midwife or nursing associate in question.
- It may contain information that could be used by the case examiners and independent panel members to help establish what happened.

### Questions to be explored in the dialogue

Given that this approach represents a significant shift in how the NMC currently capture the voice of people who use services, families and members of the public, they wanted to engage their stakeholders in a dialogue about how best to achieve their aims. The key questions explored in the engagement were:

- General views on the proposals
- Associated strengths and weaknesses of the new approach
- Barriers and opportunities to implementation
- Tolerance and boundaries for the new approach
- Associated risks and mitigations
2. Methodology

2.1. Overall approach

Traverse worked with the NMC to co-design an engagement plan and materials. The fieldwork took place from May to July 2019.

Fieldwork involved workshops where participants took part in small group discussions, one-to-one interviews conducted face-to-face or by telephone, and small group discussions.

2.2. Sampling and recruitment

Traverse heard from 125 people from across the UK. The table below summarises the stakeholder groups who took part and the format, location and recruitment approach used. Further details about the profile of participants who took part in the public and registrant workshops can be found in Appendix 1.

Table 1. Stakeholder engagement summary

<table>
<thead>
<tr>
<th>Stakeholder group, no. of attendees</th>
<th>Format, location</th>
<th>Recruitment approach</th>
</tr>
</thead>
<tbody>
<tr>
<td>Public (22)</td>
<td>Workshop, Edinburgh</td>
<td>Recruitment by fieldwork agency</td>
</tr>
<tr>
<td>Registrants (22)</td>
<td>Workshop, Birmingham</td>
<td>Email sent to registrants on NMC mailing list</td>
</tr>
<tr>
<td>Registrants w/experience of fitness to practise (6)</td>
<td>1-1 interviews, various</td>
<td>Email sent to registrants on NMC list</td>
</tr>
<tr>
<td>NMC staff (16)</td>
<td>Workshop, London</td>
<td>NMC managed invitations</td>
</tr>
<tr>
<td>NMC decision makers (14)</td>
<td>Workshop, London</td>
<td>NMC managed invitations</td>
</tr>
<tr>
<td>Union and legal representatives (9)</td>
<td>Workshop, London</td>
<td>NMC managed invitations</td>
</tr>
<tr>
<td>Stakeholder group, no. of attendees</td>
<td>Format, location</td>
<td>Recruitment approach</td>
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<td>-------------------------------------</td>
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<tr>
<td>Patient representatives (7)</td>
<td>Workshop, London</td>
<td>Traverse managed invitations to identified list of NMC stakeholders</td>
</tr>
<tr>
<td>People with learning disabilities (12)</td>
<td>Workshop, Leeds</td>
<td>Recruitment led by CHANGE, a disabled people’s user led organisation</td>
</tr>
<tr>
<td>Mental health service users (3)</td>
<td>1-1 interviews, various</td>
<td>Traverse led recruitment, working with charity/community group contacts</td>
</tr>
<tr>
<td>Recent mums (6)</td>
<td>1-1 interviews, South End</td>
<td>Traverse led recruitment, working with charity/community group contacts</td>
</tr>
<tr>
<td>Service users with kidney disease and their carers (8)</td>
<td>Workshop, High Wycombe</td>
<td>Traverse led recruitment, working with charity/community group contacts</td>
</tr>
</tbody>
</table>

### 2.3. Design and format

The dialogue materials and engagement plan was co-produced with the NMC. The format and level of information provided in the interviews and group discussions was tailored to the needs of each group. However, the fieldwork typically included:

- An introduction from Traverse about the aims of the engagement and the ground rules for the discussion.
- Warm-up and icebreaker activities to help make participants to feel comfortable and get to know one another.
• Presentation/information giving from Traverse about the background and proposals, e.g. who are the NMC, what is fitness to practise?

• Facilitated discussions structured around a series of questions, using three fitness to practise scenarios (see Appendix 2).

• Collection of participant feedback at the end of each discussion.

• Issuing thank you incentives for public, registrants, and patients.

Each discussion group had a dedicated Traverse facilitator who guided participants through the questions, recorded notes in a data capture template and digitally recorded the discussion. The session held with people with learning disabilities was co-facilitated by a member of the Traverse team and a staff member from CHANGE who has learning disabilities.

2.4. Analysis and reporting

Each interviewer/facilitator wrote up a detailed note of the discussion they led, drawing on the handwritten notes they had taken during the sessions. This data was transferred into an excel analysis framework. A framework analysis approach was taken. Digital recordings were revisited where necessary to add further detail and to source quotes.

2.5. How to read this report

This report provides a summary of the findings that came out of the discussions and interviews. In each section we provide a summary followed by the detailed findings. Throughout the report we compare the views of different stakeholder groups, drawing out areas of consensus and divergent views.

The main body of the report has six main sections:

• Section 3.1 explores participants’ overall views on the proposals.

• Section 3.2 explores views on the format of the personal experience statement and how it would be made accessible.

• Section 3.3 explores when the personal experience statement should be included within the fitness to practise process.

• Section 3.4 explores whether the personal experience statement should be shared with registrants and, if so, when?

• Section 3.5 explores whether registrants should be invited to respond to the personal experience statement, when and how this should be considered within fitness to practise?

• Section 3.6 explores the NMC’s proposals to identify and act where context factors are found to be the cause of a fitness to practise case.
3. Findings

3.1. Overall views on the proposals

This section summarises participants’ overall views on the proposals. At the start of each interview/workshop participants were asked the following questions: What are your initial thoughts on the NMC’s proposal to capture service user/family/public voice? What might be the benefits and downsides of this approach? Towards the end of the discussions and interviews these questions were revisited to see if participants’ views had shifted.

3.1.1. Summary

Overall, unconditional support and outright opposition were extremely rare. More often than not, participants agreed with the guiding principles of the proposals, acknowledging the validity of understanding the emotional impact of cases on individuals, but had at least some concerns about how they would be implemented and suggested a number of improvements or risks that would need to be considered. These most often focused on protecting the mental wellbeing of registrants and clearly communicating how the personal experience statement works to all parties to avoid misunderstandings and unrealistic expectations, especially where a service user/family/member of the public makes the referral. Some NMC staff members, union and legal representatives felt that these proposals risked undermining the legal integrity and fairness of the fitness to practise process for registrants because of the way in which a personal experience statement could unduly influence the decision-making process.

3.1.2. Detailed findings

In terms of benefits, participants, particularly the public and patients, believed that the proposals would allow referrers to be heard and may in some cases provide emotional closure or help with the grieving process. They perceived the current process as “bureaucratic” and “legalistic” and valued the prospect of a more ‘human’ approach which encouraged sharing, reflection and an acknowledgement of how care could be improved.

“I think [the proposals] could allow patients to feel listened to. When FtP starts rolling the person concerned often gets lost in it and their voices aren’t heard, when the process ramps up everything gets very legalized.” (Registrant with FtP experience)

Registrants tended to agree that as care by its nature is given and experienced with emotion, it is important to recognise service user/family/member of the public emotions as valid.

Participants across stakeholder types also saw the personal experience statement as a valuable tool for supporting registrants’ learning and development, including about how to support people with different needs and backgrounds, such as those with learning disabilities. Rather than
focusing on the binary opposition of ‘good care’ versus ‘bad care’, they recognised the statement’s potential to highlight the subtler nuances of interpersonal and emotional exchanges that may not be picked up by the current fitness to practise process which is focused on gathering facts.

“I think the NMC are trying to encourage a learning culture.”

(Registrant)

“It can help the nurse to learn more about people with learning disabilities, it could help them to change their attitudes. Nurses don’t always have much interaction with people learning disabilities, so they may have made assumptions or formed bad habits. (Focus group with people with learning disabilities)

The importance of managing expectations was by far the most common point expressed by participants across all stakeholder groups. This reflects a concern that by giving referrers the chance to describe their experience and the impact of an fitness to practise incident, they will assume that their statements will automatically have a material impact on the outcome of the fitness to practise case. With this risk in mind, participants stressed that the NMC must clearly communicate from the beginning of the process – and throughout – what the purpose of the personal experience statement is and why cases may not progress. NMC staff in particular thought it would be important to make it clear that the regulator’s purpose is to determine registrants’ fitness to practise, not to punish individuals for wrongdoing or to seek ‘justice’.

“We need to be clear we can’t be all things to all people.” (NMC case examiner)

Participants across the groups often expressed concern around the risk the proposals pose to the mental wellbeing of registrants. They argued that registrants, who may already feel guilty or upset about something that went wrong, could be made to feel worse once the statement is shared with them and a response is requested. Registrants themselves feared that this process could be used by a minority of referrers to launch personal and vexatious attacks upon them.

“My concerns would be that some patients could be quite vindictive. And they could make everything sound worse than it was as they want the nurse to feel really bad due to impact, when it may not have been that bad.” (Registrant with FtP experience)

Some members of the public and patients had a related concern about the risk that senior staff or employers could use the personal experience statement and fitness to practise as a route to blaming registrants for wider failings and shortfalls in services.

A significant risk associated with the proposals was that referrers subjective emotional testimony had the potential to bias the fitness to practise process, working against the interests of the registrant. This was especially in situations
where a referrer could exaggerate the negative impact of an incident with the motive of punishing the registrant or where the complaint and recollection of what happened was based on a misunderstanding about what had happened. This was of particular concern to NMC panellists, lawyers and case examiners. They argued that fitness to practise should only consider evidence that is ‘fair and relevant’.

It was felt that the referrer’s account of what happened was currently fulfilled by the formal witness statement, and that the addition of the personal experience statement could allow _spurious testimonies and legally irrelevant narratives_ to unfairly influence the legal process. Union and legal representatives similarly expressed concern that an emphasis on service user/family/public voice had the potential to prejudice registrant’s cases, increase the adversarial nature of these proceedings, and could ‘tip the balance’ in favour of a more punitive fitness to practise outcome being reached.

With these concerns in mind, participants emphasised that it would be vital to clearly set out what the personal experience statement was for, how the information would be used, and how case examiners and independent panel members could go about detecting vexatious or unreasonable statements.

Some union and legal representatives, along with NMC case examiners, went further and challenged the overall purpose of the personal experience statement. They argued that the NMC should remain focused on facts and regulation, rather than people’s subjective emotions and feelings. For similar reasons, some registrants suggested that the personal experience statement and response should be _kept separate from fitness to practise_, allowing valuable learning and remediation to take place but without undermining the integrity of the evidence-gathering process.

Some of the patient representatives challenged the proposals from a different angle. They argued that if the NMC does not communicate these proposals effectively they could be seen as a _resource-saving measure_ to reduce the number of cases the NMC have to process.

Some members of the public and some patients were worried that if the new approach was not effectively resourced and implemented, it could end up being a ‘public relations exercise’ that attempts to portray the NMC as welcoming and open without having to make any substantive improvements to the way they work with referrers during the fitness to practise process.

**3.2. Format and accessibility**

Participants were asked to consider the benefits and downsides of different ways of collecting personal experience statements. During discussions and interviews participants were asked the following: _Would your preference be for a structured form or an open format? What might be the benefits and disadvantages of these two options?_
3.2.1. **Summary**

Overall, across different stakeholders, most felt that a highly structured and prescriptive form would not be in line with the principles of the proposals, as this would likely steer participants towards saying certain things and limit their scope to be authentic and honest. Equally, giving participants a blank page with minimal guidance could be intimidating and difficult for many referrers. For this reason, most participants felt that there should be a form with a small number of open questions and some basic guidance.

Many participants believed that interviews either face-to-face or by telephone would be the optimal way for people to share their experiences, especially for those who were less confident communicators, while others expressed concern around resourcing an interview based approach and the potential to disadvantage those who could not take part in an interview.

3.2.2. **Detailed findings**

Participants highlighted the risk of an unstructured or ‘blank page’ format privileging those with the time, resources, education and confidence to be articulate about their experience. Patients felt that an open format could be too overwhelming, “I wouldn’t know where to start… I may just end up waffling”, a recent mum shared. At the same time, participants recognised that a highly structured questionnaire could oversimplify the diverse range of feelings and situations experienced by referrers or lead them towards saying certain things.

Some registrants, public, patients and NMC panellists suggested a variation on the semi-structured questionnaire; rather than a mix of open and closed questions, they suggested a single open text box but with clear guidance, advice and prompt questions to create a certain level of consistency. A registrant suggested that the NMC use “wording that guides people to record what is needed,” for example, “What do you feel went wrong?” This suggestion was echoed in patient interviews:

“I think it would be more like an agenda, ‘these are the point we want to cover’ but allowing the conversation to flow.” (Recent mum).

In addition to combining open and closed questions, many participants also believed that interviews especially in a face-to-face format could benefit those referrers who are less confident when it comes to written English. Participants, including the group with learning disabilities argued that emotional recollections could come more easily when spoken as it feels more like a conversation and less like a formal exercise.

“Face-to-face is good because people might be able to communicate more – they might be more open and they might be able to reflect more.” (Participant with learning disability)

A number of NMC staff expressed support for a more open form for
capturing service user/family/public voice. As per their overall views on the personal experience statement, case examiners believed that an open form would better suit its potential remediation purpose and could help to manage expectations about its impact upon each case’s outcome.

Similarly, union and legal representatives saw the proposal as closer to an open-ended counselling session rather than the current formal witness statement. These representatives, along with some registrants, felt that an open format would avoid restricting referrers. Some registrants made the point that an interview-based approach would be more likely to yield balanced and reflective statements compared with written statements where there could be a temptation to complain and condemn.

NMC staff, across all stages of the fitness to practise process, often raised the tension between inclusivity and feasibility in terms of resourcing the process. They recognised the importance of giving referrers the opportunity for catharsis, but expressed concerns around having to read, process and respond to very lengthy statements. Across the groups, participants suggested that some kind of word or character limit (if using a written approach) would seem sensible. Participants also suggested that an interview-based approach would support efficiency, since the interviewer could produce a concise and proportionate summary, which would then be signed-off by the referrer.

Some public and patients believed that they should be given the choice between submitting a form or taking part in an interview. This, they believed, is important when considering different levels of free time, referrers emotional states and other accessibility and communication issues.

In relation to accessibility, participants were asked: **How should the NMC consider people’s varying ability to make an experience statement? What forms of guidance and or support should the NMC be offering?**

Registrants, the public, patients and patient representatives all highlighted the importance of making the process as accessible as possible and suggested a variety of possible adjustments, which are set out below.

- ✓ Logistical help for disadvantaged referrers
- ✓ Local/regional interviews/meetings to reduce time and expense
- ✓ Safe and neutral venues for face-to-face interviews
- ✓ Allowing support worker or a relative to support process
- ✓ ‘Soft’/emotional/mental health support for referrers where needed
- ✓ Choice of the channels/formats for submission
- ✓ Recording and transcription of discussions for transparency
- ✓ Referrers able to check statements interpreted correctly by staff;
- ✓ Translation and interpreter services and access to an advocate
- ✓ Easy read versions and tools and techniques for people with communication challenges and learning disabilities to be heard
Across the groups, participants felt that the NMC staff leading the new approach would need to be suitably trained to support an accessible and consistent process which can sensitively and accurately interpret and make use of the information collected through the new process. This includes what people say, but also other things such as people’s body language.

In addition to these specific suggestions, participants stressed the importance of having some flexibility in the process rather than a ‘one-size-fits-all’ approach. Patient representatives specifically linked this to groups who face discrimination and/or are in vulnerable situations; they argued that accessibility adjustments, whilst welcome, must treat referrers as people rather than judging them on a single demographic trait. For example, people with learning disabilities emphasised the importance of designing a process and materials that would suit varying needs and preferences, making use of resources such as easy read, Makaton and visual materials. They also felt that for people with learning disabilities it would be crucial to keep the language and process simple and jargon free, and to not rush them if asking them to share their experiences.

As with the method of data collection, both frontline and decision-making staff from the NMC highlighted the tension between accessibility and available levels of resourcing. They all expressed the desire to be as inclusive as possible but from their own experience recognise that resource constraints limit what is possible. As a result, they suggested that the support offered should be proportionate to needs. NMC Lawyers and some investigation staff believed that the resource applied should be based on the severity of the case. Other NMC staff disagreed, arguing that it is the subtle experiences of seemingly ‘mild’ cases which need to be picked up by the personal experience statement. As one NMC staff member explained, “If we are offering this as an option, then we have to be offering support alongside it.”

To save resource, panellists suggested that employers or the CQC could collect the statements locally rather than the NMC doing this. In contrast, case examiners believed that the same level of support should be provided for personal experience statements as for witness statements, including recording what was said, to avoid the bias of a written summary.

Union and legal representatives raised a concern that in offering extensive support during the personal experience statement process, the NMC could risk give a false impression of how much weight the personal experience statement will carry within the fitness to practise process. Again, the point around the importance of managing referrer’s expectations about the process was emphasised.

### 3.3. Timing within the fitness to practise process

To gauge the preferred timeline for incorporating the voice of service users, families and members of the public into the fitness to practise process,
participants were asked to identify benefits and challenges of inviting and considering a personal experience statement at various fitness to practise stages. Participants were informed that the NMC want to have a personal experience statement as early as possible. After learning about the NMC’s preference, they responded specifically to the following question: **Could you foresee any challenges or downsides associated with inviting and considering an experience statement at the screening stage?**

### 3.3.1. Summary

Across most of the groups, participants felt that on balance asking for statements early in the process was the most appropriate option. They believed this would capture the emotional response to the situation while the memories are at their freshest. With that said there were risks and challenges that would have to be managed, included not upsetting referrers at an early stage where feelings were likely to be ‘raw’. In a few of the groups, participants suggested a compromise, taking a short initial statement from referrers, followed by a longer statement if the case progresses to the investigations stage.

### 3.3.2. Detailed findings

In answering this question, several stakeholder groups, including NMC panelists, lawyers, case examiners, and registrants, identified a central challenge relating to **managing patient expectations**. These groups raised concerns about giving the patients ‘false hope’ by asking them for a personal experience statement, especially since, as the NMC lawyers pointed out that around 40% of cases are closed after screening. Registrants emphasised that the NMC would need to manage expectations, and identified the **high expense** associated with capturing a personal experience statement during screening given the high volume of cases coming through each year. For this reason, they suggested that inviting a shorter statement at screening and a more robust personal experience statement if it gets to investigation might be sensible.

“To avoid disappointed patients, the NMC just needs to make very clear ‘this is the process, and it may not go further than the statement’.” (Registrant)

Despite potential challenges, most groups identified clear benefits to inviting and considering the personal experience statement during the screening stage and preferred this earlier option. A better ability to **accurately recall what happened and the impact** was often the key argument given. NMC staff, registrants including those with fitness to practise experience, the public, and patients all thought an early personal experience statement would be more detailed and accurate and therefore more useful.

Patients and the public identified a perceived tension between memory and emotional vulnerability. They argued that while an early personal experience statement avoids poor recollection and captures a fresh experience, this
may also be wrapped up in **anger and grief**. One new mum interviewed described this challenge:

“If there’s grief involved, there’s a lot going on in terms of the logistics and emotion[s]. You’ve got to think about what’s feasible to ask of someone at that time. On the other hand, if you think about a new mum, they need to get [the statement] written down soon, before they forget.” (Recent mum)

Patients and the public suggested that for patients experiencing grief, who may be unwilling to share experiences early in the process, the ‘door be left open’ for a later submission. This view was also supported by patient representatives who felt that it is unfair to limit those who are grieving to a single opportunity to provide a statement.

“People need to be able to update their statement, not face a ‘dead end’.” (Patient representative)

Having a chance to **update one’s statement** is consistent with the view that service user/family/public voice in fitness to practise cannot be a one size fits all approach, as discussed in response to other questions. However, some NMC staff groups, including the case preparation and investigation teams, were worried that an ‘open door’ policy that allows updating and resubmitting the personal experience statement could add bias and complexity to the process.

Although ‘intense emotion’ in the early stages of fitness to practise was seen to make writing a personal experience statement difficult, participants also identified emotional benefits to asking for this at the screening stage. NMC lawyers thought this could help prevent increased anger later, which aligns with fitness to practise’s potential for remediation. The NMC investigation team pointed out that the screening phase tends to be less adversarial than the meeting and hearing stage. Sharing an emotional charged statement in the less adversarial phase was seen to allow for increased openness and resolution.

Participants were also asked: **Is there a case for inviting and considering an experience statement at the investigation or meeting or hearing stage?** The group with the strongest preference for inviting the personal experience statement in a later stage were the union and legal representatives. They argued that incorporating service user/family/public voice at the screening stage risks interfering with the ‘fact finding mission’. There was a view that having the personal experience statement following the screening process was seen as important if the NMC is to remain a regulatory rather than a ‘complaints handling’ organisation.

“Our role as a regulator is to listen to the facts.” (NMC Case Examiner)

At the other end of the spectrum, the NMC screening team and members of the Employer Link Service were keen to keep the personal experience
statement in the screening stage to reduce the risk of influencing the decision-making with subjective accounts. In both cases – preference for an early and late personal experience statement – participants wanted to keep it confined to a single stage to prevent it from confusing the goals of establishing objective facts. Some participants from across stakeholder groups suggested that information relevant to the case could be drawn from the statement. Union and Legal representatives, who felt strongly about inviting the personal experience statement at a later stage, suggested that it should be a part of the witness statement, rather than separate from it. It is unclear whether this meant that they were suggesting the witness statement occurs at a later stage, as this is currently done at screening.

3.4. Sharing the experience statement with registrants

Participants were asked for their views about the proposals to share the personal experience statement with the registrant/s concerned. The following questions were posed to participants: Could you see any challenges or downsides associated with sharing the experience statement with registrants at the screening stage? Is there a case for sharing the experience statement with them at the investigation or meeting or hearing stage?

3.4.1. Summary

While many participants across the groups thought that the personal experience statement should be shared with registrants, there was a broad range of views on exactly how and when this should be done. While some thought it was important, for transparency, to carry this out in a consistent way, others believed it should be done with discretion when registrants’ mental wellbeing could be at risk. Similarly, while some thought the personal experience statement should be shared as soon as possible to avoid uncertainty for the registrants and to give them an opportunity to learn and reflect, others believed that only those that proceed to investigation or hearing should have to be seen by registrants.

3.4.2. Detailed findings

As participants discussed the trade-offs between transparency, registrants’ learning and the adversarial nature of the process, most came to the view that a discretionary approach to sharing the personal experience statement would be most appropriate. Participants suggested that the NMC should ‘filter out’ the most malicious and harmful responses in order to protect registrants’ wellbeing. They argued that, while it is important to acknowledge referrers’ feelings, they remain subjective and may not always be constructive or useful. One alternative suggestion to filtering was that the statements are redacted or summarised to separate useful learning from more harmful statements.

In relation to the suggestion that the NMC ‘filters out’ the malicious and/or harmful statements, some members of the public and patients believed that
these statements should be shared with registrants, but only at the **investigation stage** to protect their mental wellbeing. NMC panellists suggested a phased approach to sharing details with registrants, starting with a short statement at screening and only proceeding to sharing the full statement if the case progresses to investigation.

Some members of the public, patients, union and legal representatives highlighted the perceived risk of stress and uncertainty that could be caused by not sharing personal experience statements with registrants. They believed it was ‘right’ and ‘fair’ to be transparent and allow learning at the earliest possible stage. Union and legal representatives specifically argued that withholding these documents could lead to registrants becoming more anxious and unhappy and wanting to quit the profession. Some used this as justification for sharing the statement as soon as possible during the **screening stage** of fitness to practise. Case preparation staff from the NMC also believed that this was important for transparency.

Within public and patient groups there was not a clear consensus on this. While some believed it should only be shared later in the process (by which point it has been proven as ‘serious enough’ to merit consideration), others argued that all cases must be ‘serious enough’ if they have not been dismissed at the screening stage.

Although there was no consensus among registrants on the precise point in the process, ‘the sooner the better’ was seen as a useful guiding principle.

> “I’d welcome seeing it as early as possible – I’d want to know what the issues are and see the whole picture that [the patient/relative] is seeing.” (Registrant)

Some registrants suggested a more specific point at which the statement should be shared within the fitness to practise process: during screening but after the decision has been made rather than at the point of referral. This, they believed, would avoid uncertainty around the outcome.

However, registrants were split on how the statement should best be shared to reduce the emotional impact; some would prefer a letter while others would prefer a face-to-face or telephone briefing from the NMC. Patient representatives argued for complete transparency, primarily to ensure maximum registrant learning and development.

In contrast, NMC staff from the Screening, Employer Link Service and lawyers believed that sharing the personal experience statement with registrants could do more harm than good, negatively affecting registrants’ mental health, rendering the fitness to practise process more adversarial and ‘muddying the waters’ of the ongoing case. Similarly, some members of the public believed that sharing the statement could allow registrants to change or control the case’s ‘narrative’. As above at section 3.3 in relation to where the personal experience statement should fit within the fitness to practise process, some NMC investigation staff expressed a concern that sharing the
statement at the early stage could bias decision-making; as a result, they suggest only sharing the statement at the investigation or hearing stage.

3.5. Registrant’s response to the experience statement

Participants were asked three questions with regard to whether registrants should reply to the personal experience statement and, if so, how this response should be considered within the fitness to practise process:

- What response if any should be provided by the nurse or midwife to the service user/family/member of the public?
- How should the NMC consider the nurse or midwife’s ability to produce a response?
- Do you think that the quality of the response the nurse or midwife gives should have a bearing on the outcome of the fitness to practise case?

As participants often discussed the answers to these questions in tandem, we report on these together.

3.5.1. Summary

While there was support for a response from participants across different stakeholders, opinions about how this response should be considered within the fitness to practise process varied. While some believed that emotions should be recognised as valid and material to each case, others expressed concern that this could bias the legal process and unfairly disadvantage registrants.

3.5.2. Detailed findings

By far the greatest concern around this proposal was that providing a response could make the process more adversarial. Participants expressed a concern that an unedited and unmediated ‘raw’ or unapologetic response received from the registrant could worsen the emotional state of referrers or, on the other hand, a lack of response when expecting one could create or exacerbate feelings of anger or disappointment. A member of the public described this as a “tricky situation” that could cause further upset.

“What if it starts to become a blame game?” (Member of the public)

As a result, participants across stakeholder groups suggested that responses should be provided by registrants on a discretionary basis. For example, some believed that if a registrant is found to be at fault, they should respond, but if there is no case to answer then there should be no such expectation.

Others argued that discretion should be based on the mental health of the registrant and their ability to respond without undue harm on their wellbeing. In light of this, registrants, members of the public and patients suggested that support should be given to registrants to help them write responses.

NMC case preparation staff, union and legal representatives believed that the registrant’s response should be optional rather than expected. In
addition to the negative mental health impacts of compulsory responses as mentioned previously, these participants believed that in an effort to be sympathetic and conciliatory, registrant’s responses could be wrongly perceived as an admission of guilt. Furthermore, it was felt that the lack of a response from a registrant could raise suspicion or unfairly count against registrants. Additionally, some members of the public and patients suggested that it should be optional for referrers whether they wish to receive a response. They argued that people grieve or process difficult situations in different ways and that this should be respected.

Some members of the public and patients wholly supported registrant responses to personal experience statements; to them this would help those affected to better understand and process what has happened.

“If the patient’s perception of what happened isn’t accurate, the nurse could use the response to explain what happened.”

(Recent mum)

Members of the public and patients believed that the response provides a valuable opportunity for registrants to see themselves as human beings and learn how to provide better care. Registrants also recognised the need for openness, reflective practice and the duty of candour. Some registrants however felt that senior colleagues or employers should support responses, and that a face-to-face meeting rather than a written response should be a possible option. They also suggested mediation services through a third party to ensure the response is not misconstrued as an admission of guilt, a fear shared by the public, patients and union and legal representation. As one nurse articulated, “If we’ve said sorry, it cannot be used against us.”

Some members of the public and patients believed that emotions and feelings, though subjective, are a key part of care and as such should be considered in fitness to practise cases. They also believed that, as a certain level of literacy is required of registrants, it was fair for the NMC to judge the quality of responses. Some case preparation staff from the NMC, along with union and legal representatives, believed that the consideration of responses should also be discretionary; in some cases, displays of remorse and learning could be material, while in other cases it may not be relevant.

Other NMC staff across different roles and departments, believed that a registrant’s ability to respond is less important since registrants already have the chance to do so within the current fitness to practise process. In addition, a few registrants felt that this that this would be going beyond the NMC’s remit, which should be confined to protecting the safety of the public rather than extending to remediation and conciliation. In the view of case examiners, responses from registrants should only be considered within fitness to practise in exceptional circumstances, since they are so subjective.

“The nurse’s response won’t make a difference – maybe in a very extreme case where a nurse has a bad attitude.” (NMC Case Examiner)
NMC panellists believed considering such responses would be unfair to registrants who may not be able to articulate themselves effectively enough to defend their position. A few members of the public and patients agreed that this would be placing a lot of pressure on registrants and suggested that 

**service user/family/public voice is separated out entirely from the fitness to practise process.** This, they believed, could elicit deeper reflection and more genuine apologies.

Participants made some suggestions as to how a separate process could work. Registrants suggested that responses are collected anonymously, to capture feedback but without the emotional and legal ramifications of fitness to practise. Patient representatives suggested that registrants are named, but that this response is shared only after the conclusion of the fitness to practise, focusing on restorative justice rather than complicating an ongoing case.

> “Giving registrants a chance to respond should be at the end of the process; as a form of ‘restorative justice’. This could help the referrer deal to with trauma and grief and help them recover.”
> (Patient representative)

Legal representatives made the point that it is likely not possible to create a parallel process, where the personal experience statement and the registrant’s response to it could not be fed into litigation.

### 3.6. Considering context

Alongside the service user voice proposals, participants were asked to consider the NMC’s plans to better understand context in the fitness to practise process. As well as giving their general reactions to this, they were asked the following questions: **How would you feel if a family member was the subject of a case where there was ‘no case to answer’ when context was taken into account (as in Scenario 2)?** What would you expect from the NMC in terms of how they handle cases like this one?

#### 3.6.1. Summary

Across different stakeholder types, participants welcomed the NMC’s focus on detecting where contextual factors are the underlying causes of fitness to practise cases. Participants often expressed a desire for improved communication around this, presenting ‘no case to answer’ as less of a ‘dead-end’ and working with other regulators who could pick up the case. Many also wanted to be kept up to date where systems and service level improvements were being pursued. A few participants expressed a concern that a greater focus on context could allow the NMC to ‘push’ cases onto other regulators where this was not appropriate.

#### 3.6.2. Detailed findings

Participants often highlighted the importance of closure to those involved

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1 See Appendix 1
with the fitness to practise process. To members of the public and patients, a ‘no case to answer’ outcome must not be communicated as the final step. They suggested that if a registrant is not found personally responsible, the employer must make it clear how they will nevertheless take steps to make improvements.

“[If its context] be honest about this, don’t be afraid to tell the truth about what and why it happened, tell everyone who was involved, say what you will do differently as a result.” (Person with a learning disability)

“[The complainant] should get a response from the employer: ‘this is what we are doing to ensure the same thing doesn’t happen again.” (NMC Panellist)

Furthermore, the NMC must inform those concerned if the case is being referred to another regulator. Patient representatives suggested that ‘no case to answer’ is changed to a phrase that expresses that while the registrant was considered fit to practise, something else may have gone wrong.

Union and legal representatives believed that considering and acting more on context factors could help to restore patients’ and families’ faith in the health and care system following serious incidents. A range of stakeholders felt that if context factors were what had caused a fitness to practise incident, this should be sensitively explained to referrers (e.g. through a conversation and letter). They would also want to be kept up to date about what action was taken to improve the situation, and if this has made a difference.

Case preparation staff from the NMC and some members of the public, expressed support for considering context but with the caveat that this is clearly communicated at the start of the process. They believed that if referrers know from the beginning that an individual registrant may not be to blame, but it is linked to context factors, the NMC will be better able to manage referrers’ expectations.

Registrants had the view that a focus on context could help both to reduce an endemic ‘blame culture’ within the NHS and help the NMC to position itself as a more open and approachable organisation focused on learning and improvement. Currently, according to union and legal representatives, there was a view that registrants do not feel supported and confident about referring to context factors during fitness to practise cases. For this reason, it was suggested that registrants are given training on how to discuss context in relation to their own practise.

Some NMC investigation staff expressed concern that the NMC may use context as means of ‘pushing’ cases onto other regulators such as the CQC. Similarly, NMC lawyers were worried that considering context may portray the regulator as a remediating and ‘justice-seeking’ organisation, as
opposed to an organisation that protects public safety.

As with giving registrants an opportunity to respond, NMC panellists and case examiners believed that this proposal potentially duplicates existing processes; according to them, any context of evidential value in the personal experience statement should already be in the witness statement.
4. Conclusions and recommendations

Conclusions

Whilst there were differences of opinion within participant groups, overall the response to the NMC’s proposals was largely positive amongst patient representatives, the public, NMC staff and registrants, but more negative amongst union and legal representatives who were concerned about its implications for nurses and midwives.

General views on the new approach

Research participants were largely positive about the idea of introducing elements that are more ‘human’ into what has always been a formal, legalistic process which has made little room for people’s emotions and which can thus leave many feeling dissatisfied. It was seen as an opportunity to ‘put people back into the process’, allowing those involved to talk about how an incident has made them feel, on both sides. This was tempered by anxieties – some significant – about where to draw the line, how to protect registrants from further emotional strain, and how service users, families and members of the public can be given a stronger voice without also unfairly biasing a process of judgement on registrants.

Through the discussions with participants we can see a preference for inviting and sharing referrers’ statements early in the process; seeing the proposals as a way to diffuse and moderate anger from referrers and reducing anxiety and upset from registrants. It is also seen as a way to provide more nuanced responses to an angry or disappointed referrer when the fitness to practise process may not deliver this result.

Associated strengths

• A new prominence for service user/family/public experience, which does not feel valued in the current process.
• The ability to diffuse anger and frustration and reduce emotional strain: People are most positive when they believe this proposal will reduce emotional strain for staff and service users/family/public and help to diffuse the anger and frustration that they can feel as the fitness to practise process goes on around them.
• The opportunity to shed new light on incidents through collecting a different source of evidence.

Associated weaknesses

Union and legal representatives were most likely to identify risks and challenges in the new approach, as were some registrants. These included:

• Accentuating and prolonging the strain and distress of those involved, especially registrants: people are less positive when they believe this proposal could make the process more emotionally demanding – especially for staff, more personal and more adversarial.
• Stacking the odds against registrants: participants expressed concern about fairness, as it was thought that elevating the value of personal reaction and emotion on the part of service users/families/public would give their views – and perceptions of events – undue weight in the fitness to practise process.

Barriers and opportunities to implementation

• Capturing service user/family/public voice could help the NMC to close cases at the earliest opportunity and could encourage remediation – as it’s something the registrant can reflect on.
• Inviting the personal experience statement at Screening stage is the most favoured option but it also places the biggest administrative burden on the NMC – especially, if as many had suggested, complainants should be offered support to make their statements.
• NMC staff training to be able to analyse the statement content and offer support.
• Offering referrers lots of support and a tailored process will be costly and time-consuming.

Tolerance and boundaries for the new approach

There is high tolerance for the proposals overall, with legal/ union representatives and senior stakeholders the main exception. They were concerned about how the proposals would undermine the legal process, and so wanted any new process to be kept entirely separate or suggested that tweaks be made to the existing fitness to practise process – such as adapting the witness statement instead of introducing the personal experience statement. The main ‘grey areas’ around acceptability relate to:

• How and whether registrants should be expected to respond to the personal experience statements. It was often said that this would depend on the situation.
• How and whether the personal experience statement should be admissible as evidence for the fitness to practise process (this could be in the registrant’s favour if it shows a complaint to be unfair).
• How and whether service user/family/public should be able to access support for drafting their statement – most felt it was right that support be provided and different formats of response accepted, but there were mixed views about whether they should be able to access professional help to write the statement as this was arguably ‘not in the spirit’ of the proposals.
Reflections on the engagement process

Participants engaged well with the content and questions around the fitness to practise proposals and there were high satisfaction levels in terms of the design of the workshops and quality of facilitation (see Appendix 3). They also valued the fact that they had been asked for their views early in the process and were keen to be updated and involved in what happens next.

Recommendations

1. Work on resolving some of the questions most often raised by participants which affect the acceptability of the proposals, e.g. whether or not a registrant’s response to a personal experience statement can be used for or against them in the fitness to practise process, or how – if this is felt to be preferable – it would be possible to keep this entirely separate.

2. Start to develop some options for how the personal experience statement could be completed – online, over the phone etc – and how service users/families/members of the public and registrants could be supported to complete the personal experience statement and respond to it. Examples of these elements of the proposals would help people to give a clearer opinion them.

3. View the proposals as a vehicle for reviewing how the NMC presents itself and engages with registrants and the public. Some participants talked about the proposals as embodying – or demanding – a wider sea change in how the NMC is perceived. For members of the public, this was about the NMC being more visible. For registrants, it was about the NMC being a more accessible, approachable organisation that emphasised its learning and support role – as well as its ‘policeman’ role.

4. Building on the success of this stakeholder engagement, the NMC should continue to look for opportunities to carry out ‘upstream’ dialogue and co-production with people who use services, families and members of the public and should ensure they have ongoing opportunities to stay informed and give their views.
# Appendix 1 - Profile of public workshop

## Public workshop in Edinburgh

Traverse worked with a fieldwork agency to recruit members of the public in Edinburgh. As shown below, this allowed us to achieve a range in terms of age, gender, ethnicity, urban/suburban/rural, social grade, working status and caring status.

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Registrant workshop in Birmingham

We recruited registrants by working with the NMC to send out an invitation to registrants in the area Birmingham area. The workshop achieved a mix in terms of gender, provider setting and there was good representation from BME registrants. The majority of participants were nurses, and all participants were aged 40+.

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## Appendix 2 - Scenarios and questions

Scenarios to help participants make sense of the proposals

### Scenario 1: Ben

Ben had a poor care experience when in hospital for a minor operation. He raises a concern with the NMC. The case is considered, and the case does not pass the screening stage.

However, Ben’s experience raises some potential learning points for the nurse about what good patient care looks like. While the NMC does not proceed to the investigation stage, the patient remains upset by the experience and their confidence in using health services is damaged.

### Scenario 2: The Edwards Family

The Edwards family lose an elderly parent after a nurse makes a medications error. The NMC decides to investigate the case. The patient’s daughter Mrs Edwards is asked to produce a witness statement AND she is invited to provide a personal experience statement. The family feels that someone should take responsibility for the mistake and they seek professional advice about what to include in the personal experience statement to make sure that it is hard hitting.

The Case Examiners and independent panel members review the evidence and find that ultimately there is no case to answer, even though the consequences of the error have contributed to a tragic outcome. This is in part because of the wider context of a short-staffed unit where staff missed opportunities to pick up on and address the error.

### Scenario 3: Sara

Sara is a young mother who recently gave birth is very unhappy with the care she received from a midwife in a postnatal ward and makes a complaint to the NMC after seeking advice from her GP. Sara has not been in the UK for long and has limited English. She lacks confidence when it comes to verbal and written communication.

The NMC decides to investigate the case and it progresses to a hearing. Sara’s personal experience statement and a response from the midwife contains details which could be used by the panel to help them understand the impact that the event had on Sara and to establish what happened.
Questions explored in the workshops and interviews

Q1: The NMC is considering the most appropriate formats for capturing service user/family/public experience. Would your preference be for a structured form or an open format? What might be the benefits and disadvantages of these two options?

Q2: People have different levels of confidence in reading, writing and communication. How should the NMC consider people’s varying ability to make an experience statement? What forms of guidance and or support should the NMC be offering?

Q3: The NMC want to have a personal experience statement as early in the fitness to practise process as possible, so that they can make the right decision at the earliest opportunity.

Could you foresee any challenges or downsides associated with inviting and considering an experience statement at the screening stage?

Is there a case for inviting and considering an experience statement at the investigation or meeting or hearing stage?

Q4: The NMC would like to share the personal experience statement as early as possible in the fitness to practise process, to give the nurse, midwife or nursing associate time to reflect and consider. Could you see any challenges or downsides associated with sharing the experience statement with them at the screening stage?

Is there a case for sharing experience statement with them at the investigation or meeting or hearing stage?

Q5: What response if any should be provided by the nurse or midwife to the service user/family/member of the public?

Q6: Do you think that the quality of the response the nurse or midwife gives should have a bearing on the outcome of the fitness to practise case?

Q7: How should the NMC consider the nurse or midwife’s ability to produce a response?

Q8: The NMC’s fitness to practise strategy underlines the importance of considering the context of a fitness to practise case. Most times when things go wrong, the person didn’t intend for it to happen. If they don’t think the person intended to cause harm, they think they should focus on the reasons why something happened. In some cases, this may mean they don’t take any action against the person who made a mistake or a bad decision, even if service users/families/members of the public have suffered harm. Instead, they will share information with others if they think they can make changes to prevent a similar thing happening again.

How would you feel if a family member was the subject of a case where there was no case to answer when context was taken into account? What would you expect from the NMC in terms of how they handle cases like this?
Appendix 3 - participant feedback on workshops

Towards the end of each workshop, participants were invited to complete a feedback form on the experience of taking part. This feedback has been collated in the tables below. Not all participants who attended completed a feedback form.

The feedback shows high levels of satisfaction with the design, organisation and facilitation. A few participants across the groups, sought more information about how the information that was collected would be used.

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### Service users with kidney disease and their carers

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