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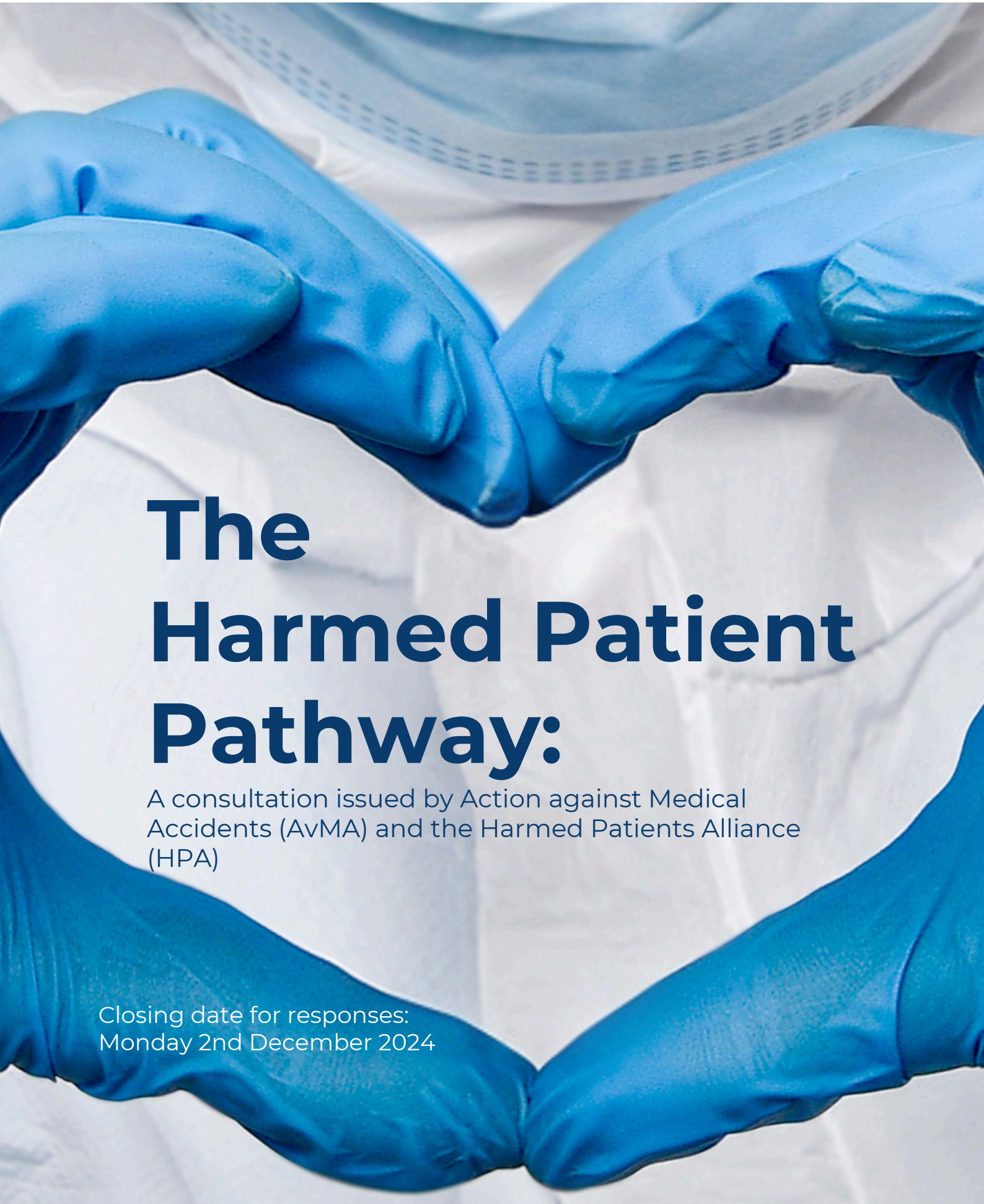
HPA
HARMED PATIENTS ALLIANCE



The Harmed Patient Pathway:

A consultation issued by Action against Medical Accidents (AvMA) and the Harmed Patients Alliance (HPA)

Closing date for responses:
Monday 2nd December 2024

Introducing the Harmed Patient Pathway

1. Introduction

Who we are

This Harmed Patient Pathway is a collaboration between people with a wealth of experience of the impact on patients caused by an avoidable medical accident. The project was launched, and is being led, by the patient-safety charity Action against Medical Accidents (AvMA) and the Harmed Patient Alliance (HPA). The core group that developed the draft pathway includes colleagues from the Maternity and Newborn Safety Investigations programme and the charity, Making Families Count. And, at various points, there has been input from patient-safety specialists at NHS trusts who kindly offered views and suggestions.

Why we have developed the Harmed Patient Pathway and why a new way of responding to patient harm is needed.

When things go wrong in healthcare, there is, rightly, focus on learning and change to protect future patients, not least through the development of NHS England's Patient Safety Incident Response Framework (PSIRF). However, if there is not equal focus on how to mitigate the impact on the harmed patient and their family and a genuine striving for just relations with them in the aftermath, then they will almost certainly experience compounded harm and healing will be compromised. Breakdowns in relations, poor communication and deepened mistrust between the patient and healthcare professionals causes additional suffering for everyone affected.

While in recent years there has been a positive focus and investment on quantifying and reducing other types of avoidable healthcare harm, nowhere near enough energy, focus and investment has been put into developing systems and processes to meet the needs of harmed patients and families to spare them further avoidable distress. This pathway complements the progress that has been made with the compassionate engagement elements of PSIRF while also addressing experiences outside the safety-investigation process so that all the currently known sources of compounded harm from the actions of NHS trusts and staff can be addressed.

What we hope to achieve

Healthcare providers are used to pathways that guide them in how to care for patients with a particular diagnosis. This pathway is intended to encourage providers to recognise harmed patients as suffering a particular form of trauma for which there should be a pathway that seeks to optimise recovery. It is also intended as an obligation for providers to do what is possible to ease suffering and avoid causing further distress.

We have a wealth of patient evidence that demonstrates that compounded harm could be eliminated – or at least minimised – if the commitments in this pathway towards harmed-patient wellbeing are sincerely adopted.

2. Current Challenges

The limitations of and harm caused by current practice

Suboptimal healing and recovery and/or avoidable compounded harm have become an almost inevitable consequence of the way the current system operates. Harmed patients and families routinely do not have their needs understood and met when truthful answers and explanations emerge only after prolonged adversarial processes involving constantly reliving what happened. The landscape to be navigated is complex and can be experienced as cold, defensive, neglectful, legalistic and isolating rather than caring, attentive, supportive and healing.

The knock-on effects on staff are harmful too

The adversarialism we describe above takes its toll on staff, who we recognise are already under immense pressure due to the well-documented wider strains on the NHS. Staff who feel genuinely supported to act according to the commitments in this pathway will be better able to communicate compassionately and openly with harmed people, which should relieve some unnecessary stress for them.

The tendency for a tick-box approach to improvement

This pathway is not a tick list that healthcare providers without a deliberately restorative and just ethos can be seen to have adequately adopted. The pathway is a series of commitments for trusts to take seriously, and one measure of success will be real harmed-patient testimony. We believe that this work requires firm commitment and engagement for it to be truly effective at minimising avoidable distress for harmed patients/families. Any initiative that is designed to bring positive change will require effort to implement; that effort will pay dividends for patients and staff.

3. A new way of working

An explanation of the Harmed Patient Pathway and how it is structured

The Harmed Patient Pathway is built around **six key commitments** based on what real harmed patients and their families explain is needed. The six commitments are:

- effective and compassionate communication in line with patient/family needs and experience
- providing support and independent specialist advice to patients/families
- meaningful patient/family involvement in patient-safety investigations
- meaningfully involving patients/families in safety-improvement work
- accepting and respecting the needs of patients/families using parallel processes to achieve satisfactory answers and/or accountability that they perceive as unattainable without using those processes
- promotion of a just and restorative culture that is as attentive to the needs of harmed patients and families as it is to organisational and staff needs.

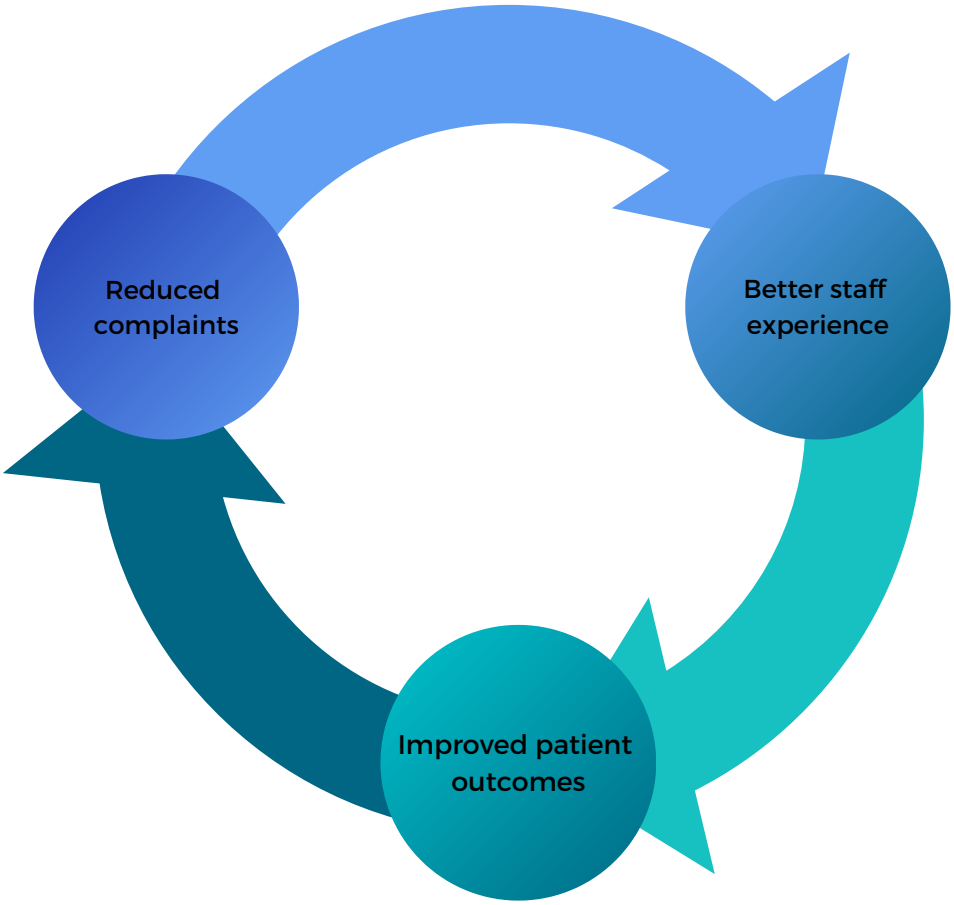
The Harmed Patient Pathway's main features and components, including its intended alignment with restorative principles

In developing this draft, we have given considerable thought to aligning the work with the principles of restorative practice*, i.e., to the mindset and behaviours required to support just and trusting relationships, resolve conflicts and repair harm. We also promote the exploration of the use of restorative principles and practices in any alternative dispute-resolution process to try to achieve a non-adversarial, safe and dignifying experience for all affected thereby avoiding the compounded harm and significant financial costs associated with traditional legal processes.

*Restorative practice is a field concerned with improving and repairing relationships. It brings those harmed together with those responsible into communication, enabling everyone affected by the incident to a play a part in repairing the harm and finding a positive way forward

The benefits it will bring, with a focus on better outcomes for patients and the potential benefits for staff

This pathway is intended to achieve better health and wellbeing outcomes for harmed patients and families, which is its number one aim. Properly and sincerely adopted, we believe the commitments will also result in better experiences for staff involved in incidents and will have a positive impact on reducing complaints and litigation.



4. Implementation

Some guidance on how an organisation would introduce and start to embed the Harmed Patient Pathway to change practice

Given the considerable local autonomy with which the NHS operates, it would not, in our view, be appropriate for us to prescribe how to embed these commitments; we recognise that what might work in one place may not in another. However, we believe, two key elements are leadership support and buy-in, and a recognition that it will require effort and transparency to work through the six commitments and honestly self-assess how near or far you are from achieving each of the 34 underlying essential elements.

Suggestions as to the resources and support that might be needed

We have decided to consult on the Harmed Patient Pathway at this draft stage before we go further with developing guidance or resources. A more detailed how-to guide is in development, which we will consult on in due course to get feedback on what stakeholders feel would be most useful to support the embedding of the pathway in healthcare settings.

5. A Call to action

The people and organisations behind developing this guidance have many years' experience working with patients who have been avoidably harmed because of a medical incident and some have lived their own experience. Each harmful incident is unique. If healthcare providers focus on genuinely honouring the commitments in this pathway, then a context-specific, human-centred route to healing and learning can be achieved despite this uniqueness. If this is the case, then much of the compounded harm that results from 'process over people' could be eliminated once and for all. We hope you agree and will make the commitments necessary for your organisation.

6. How the Harmed Patient Pathway sits alongside other patient-safety guidance

Early work on this pathway was referenced in the compassionate engagement guidance issued by NHS England in support of the development of the Patient Safety Incident Response Framework (PSIRF). Adopting the pathway is a necessary accompaniment to the PSIRF to ensure both healing and learning are optimised after harm. As importantly, outside of England, elsewhere in the UK, where there are other patient-safety incident protocols, we believe that this pathway can be applied as it is not limited to a PSIRF-only environment.

7. How to respond to this consultation

Set out below are the six key commitments and a number of questions. Please note that in the questions we use the term ‘those affected’ to mean harmed patients and any family member or friend/helper who lends them support in anything other than a professional capacity.

The purpose of the questions is to help us refine the commitments and any associated guidance that we may develop. Regarding the answers to question 17, we are keen to understand what barriers you may face. The answers will shape both the future development of the pathway and our campaigning work and other priorities as we will want to overcome obstacles especially those relating to resource prioritisation.

The closing date for responses is 2 December 2024. If you would like to discuss further involvement in this work with us, please e-mail us at hpp@avma.org.uk.

Our commitments for responding to patient harm

1. We ensure compassionate and honest communication with harmed patients and their families that supports dignity, trust and just relations.
2. We do our best to ensure that harmed patients/families get the support they need, including access to specialist independent advice and support.
3. We support meaningful involvement of harmed patients/families in investigations or other review processes related to their treatment.
4. We provide harmed patients/families with opportunities to contribute to patient-safety and patient-experience improvements in a meaningful way.
5. We respect that harmed patients/families may choose to use external or parallel processes to seek answers and accountability as well as to improve safety for others. We will not allow this to change or needlessly delay our engagement with them.
6. We promote a just and restorative culture in our organisation that is fair to harmed patients/families and to staff, and we have policies, systems and support for staff to enable this.

Our commitments in more detail and why they are essential

Commitment 1

We ensure compassionate and honest communication with harmed patients and their families that supports dignity, trust and just relations.

Why?

We recognise that being honest, giving clear explanations and making meaningful apologies are essential for restoring dignity and wellbeing. These are also key factors in re-establishing trust that has been damaged. For apologies to be meaningful, they need to be made with compassion: those apologising must show they are conscious of the person's distress and need to make sense of what happened to them, and they must want to alleviate that distress. Meaningful apologies include acknowledgement of responsibility for harms caused, genuine regret and the facilitation of dialogue aimed at agreeing and committing to actions that support healing and learning.

	ESSENTIAL ELEMENTS OF THIS COMMITMENT
1a	Communications with harmed patients/families are compassionate and dignifying.
1b	Communications with harmed patients/families are open, honest and transparent.
1c	Explanations for the cause of the harm are as full and clear as possible and in accordance with the patient/families' needs.
1d	Acknowledgement of the harm caused is made in an honest and open manner.
1e	Apologies are sincere and meaningful and in accordance with the patient/families' needs.

Q1. Do you believe that commitment 1, including its essential elements, is what those affected by avoidable medical harm are entitled to expect and receive in terms of honest communications? YES/NO

Q2. Do you have any suggestions for improvements? YES/NO
If yes, please provide details.

Commitment 2

We do our best to ensure that harmed patients/families get the support they need, including access to specialist independent advice and support.

Why?

People affected by harm in healthcare are often traumatised and have little or no knowledge of the processes that organisations must follow or what they themselves should do next. Their trust in the organisation may be damaged. They may have emotional or psychological needs as well as a need for practical advice or advocacy; they may experience compounded (or a second) harm if these needs are not met. Some of these needs can be fulfilled by the organisation itself or the NHS, but others are best met by organisations entirely independent of the organisation where the harm occurred, provided by people with the relevant specialist knowledge and experience. This can help patients/families take part in processes, such as investigations or reviews, in a meaningful way and get the outcomes they seek. It can also benefit the organisation by improving the quality of investigations/reviews and avoiding unnecessary litigation costs or protracted complaints.

	ESSENTIAL ELEMENTS OF THIS COMMITMENT
2a	We communicate with those who have been harmed to understand the impact the harm has had on them and what needs have emerged for them as a result. We work with them to explore achievable ways to meet those needs.
2b	We try to ensure that harmed patients/families can access the specialist independent advice and advocacy they require based on their individual needs.
2c	Where the harmed patient/family is impacted psychologically or emotionally, we do our best to ensure that they receive the appropriate support to cope/aid recovery.
2d	We listen to, and explore, how we can respond to other impacts and needs of the harmed patient/family.
2e	We support harmed patients/families to meet with the organisation's staff, in accordance with their needs, in safe and supportive ways.

Q3. Do you believe that commitment 2, including its essential elements, is what those affected by avoidable medical harm are entitled to expect and receive in terms of support and access to independent specialist advice? YES/NO

Q4. Do you have any suggestions for improvements? YES/NO
If yes, please provide details.

Commitment 3

We support meaningful involvement of harmed patients/families in investigations or other review processes related to their treatment.

Why?

Sense-making is an essential phase of recovery from a traumatic event. Giving people who have been harmed a comprehensive and coherent explanation of what has happened is crucial for them to be able to process the experience. The way in which that explanation is given should contribute positively to the harmed patient/family's wellbeing, not add to their distress. Similarly, an investigation process that prioritises dignity, wellbeing, trust and just relations is one that works with those most directly involved in/affected by the event, including staff, not one that works separately from them. This approach can reduce the risk of compounded harm and increase the potential for evidence-based findings and meaningful learning.

Commitment 3

	ESSENTIAL ELEMENTS OF THIS COMMITMENT
3a	We provide appropriate support to help patients and families understand the process and make informed decisions about their involvement in accordance with their preferences wherever possible.
3b	We signpost patients/families to independent sources of information, specialist advice or advocacy in relation to any investigation or learning-review process and, if necessary, consider paying for specialist independent advocacy for them.
3c	We consult patients/families on the terms of reference of any investigation or review related to their treatment.
3d	We respect the information provided by the patient/family about what happened, and we support them in giving opinions on other sources of information.
3e	We take a compassionate and dignifying approach to sharing findings with the patient/family.
3f	We include harmed patients/families in identifying what we should learn and do differently for future prevention.
3g	Depending on the patient/family's wishes, we make the report of any review or investigation as personal and sensitive as we can, for example, by using photographs or real names or including an introduction written by them.
3h	We support patients/families to comment on the draft investigation/review report (with the help of specialist independent advice/advocacy if appropriate) and respect and act on their feedback if we can.
3i	We obtain, and act on, qualitative feedback of the experience of any learning process from harmed patients/families.

Q5. Do you believe that commitment 3, including its essential elements, is what those affected by avoidable medical harm are entitled to expect and receive in terms of meaningful involvement in any investigation? YES/NO

Q6. Do you have any suggestions for improvements? YES/NO
If yes, please provide details.

Commitment 4

We provide harmed patients/families with opportunities to contribute to patient-safety and patient-experience improvements in a meaningful way.

Why?

For many patients and families, meaning making is a helpful part of their healing journey. Having opportunities to do something positive with the insights gained from the experience can bring comfort and purpose and make a huge difference to their ability to move forwards. Organisations that value the contributions made by harmed patients/families, and are inclusive and supportive of their participation, make an important contribution towards the patient/family's healing and are better able to make meaningful, lasting improvements.

	ESSENTIAL ELEMENTS OF THIS COMMITMENT
4a	We offer all patients/families to whom we cause harm meaningful opportunities to use their experience, knowledge and skills to help inform improvements within our organisation.
4b	We offer patients/families affected by patient-harm events opportunities to share the facts of their case in meaningful ways.
4c	We offer harmed patients/families more general involvement in our patient-safety/patient-experience work so that they can use their experience for positive change.

Q7. Do you believe that commitment 4, including its essential elements, is what those affected by avoidable medical harm are entitled to expect and receive in terms of meaningful involvement in patient-safety improvements? YES/NO

Q8. Do you have any suggestions for improvements? YES/NO
If yes, please provide details.

Commitment 5

We respect that harmed patients/families may choose to use external or parallel processes to seek answers and accountability as well as to improve safety for others. We will not allow this to change or needlessly delay our engagement with them.

Why?

Harmed patients/families who do not feel their needs have, or can, be met via the organisation's own processes are likely to explore other processes and, indeed, have a right to do so. Organisations must be understanding and respond by helping them access reliable information about external processes. This is essential to avoid additional harm and to help guard against further damage to trust and confidence.

	ESSENTIAL ELEMENTS OF THIS COMMITMENT
5a	When it appears that harm may have been caused by our errors or omissions, we will always act in the best interests of the patient by supporting NHS Resolution's (NHSR) assessment without delay and ensuring prompt settlement of deserving claims. If litigation is still required, we will arrange or pay for additional support to minimise the distress a litigation process can sometimes cause.
5b	We do not treat a patient or their family any differently should they need to use an external or parallel process such as an inquest, complaint, legal action, fitness to practise or other regulatory process.
5c	We support harmed patients/families to understand the range and aims of the processes available to them and signpost them to sources of specialist independent advice or advocacy (see commitment 2).
5d	We do not allow protection of our own organisation's liability, interests or reputation, or those of our staff, to influence how we deal with reviews, investigations or reports about harmed patients' treatment.

Q9. Do you believe that commitment 5, including its essential elements, is what those affected by avoidable medical harm are entitled to expect and receive in terms of their rights to use parallel processes to seek answers and accountability when harm has occurred? YES/NO

Q10. Do you have any suggestions for improvements? YES/NO
If yes, please provide details.

Commitment 6

We promote a just and restorative culture in our organisation that is fair to harmed patients/families and to staff, and we have policies, systems and support for staff to enable this.

Why?

When avoidable harm occurs, staff, patients and families need organisations to balance their efforts to learn and improve against the needs of the patient and their family if dignity is to be restored and compounded harm avoided. It is the culture of the organisation, not simply compliance with guidance, standards and toolkits, that has the greatest potential to deliver a just and restorative response.

	ESSENTIAL ELEMENTS OF THIS COMMITMENT
6a	Our leadership and staff accept and understand that we owe a moral duty of care to the patients and families for whose harm we, as an organisation, are responsible.
6b	We prioritise fair accountability and responsibility taking in response to an avoidable, unwanted event and do not take a self-protection approach.
6c	Our leaders understand and uphold just and restorative principles and they support others to do the same.
6d	We care about our staff's wellbeing and strive for their psychological safety so that they feel comfortable about being open and accountable in relation to patient-harm events.
6e	Across the organisation, we invest in the right people, knowledge and skills to enable responses to harm events based on restorative principles.
6f	We care for the wellbeing of staff working in after-harm processes.
6g	We ensure our systems, policies and procedures are aligned with our values and restorative principles.
6h	Harmed patient/family insight and knowledge is valued in our organisation and we seek out opportunities to embrace it.

Commitment 6

Q11. Do you believe that commitment 6, including its essential elements, is what those affected by avoidable medical harm are entitled to expect and receive in terms of a restorative culture that treats them fairly and with dignity and respect? YES/NO

Q12. Do you have any suggestions for improvements? YES/NO
If yes, please provide details.

Q13. Overall, do you support the development of the six key commitments that make up a pathway for harmed patients? YES/NO

Q14. Do you have any real patient case examples you can share where you consider some of the commitments in this document have had a positive experience for the harmed patient and/or their family? YES/NO
If yes, please provide details.

Q15. Would you be interested in supporting the development of the guidance that will underpin these six key commitments? YES/NO

If yes, please provide your name and e-mail address, and your role and organisation if applicable, to hpp@avma.org.uk

For healthcare providers Only

Q16. Would you be interested in piloting the Pathway and adoption of the Commitments within your provider? YES/NO

Q17. Do you foresee any barriers to implementation of the Harmed patient Pathway? If yes, please provide details.

For harmed patients only

Q18. Having considered your own experience of the aftermath of patient harm, do you believe that these 6 core Commitments, if delivered effectively by healthcare providers, would have made for as positive experience as possible in the circumstances for you? YES/NO

Q19. If No, please explain why and what you believe is still missing.