

## **Full Open Letter to all Directors of HSSIB, both Non-Executive and Executive (October 2023)**

### **Challenging feedback from the exit door of HSIB and a health warning for patients and families**

**What HSSIB needs to address urgently and openly to be on course to be an exemplary investigatory safety learning service and, more vitally, not to contribute compounded harm to patients and families**

**Richard von Abendorff**

**October 2023**

Dear Ted and Rosie and all incoming Directors to HSSIB,

#### **Introduction and context for my concern and my urgent demand for change**

As HSSIB emerges from HSIB, I have major concerns which I strongly believe need to be brought to all your attentions. Many of these have been discussed in some form in the Advisory Panel over the years, with some extended comments in the minutes of September 2023. In my outgoing role on the Advisory Panel, I believe that I have a responsibility to make a fuller exposition from a patient perspective that deserves a wider public discussion and explicit response from HSSIB in the coming months.

I speak frankly as a harmed patient family advocate who has tried to get robust patient-centred learning for over 13 years in numerous systems in England, including HSIB in various roles. I have been committed to this role with HSIB for nearly 7 years, believing it to be the only viable place to lead the necessary transformational developments in patient safety learning that are so sorely needed. Note 1 at the end of this letter spells out more on my experience and my focus on complex national investigations.

**I raise my concerns in this public way as I believe if these issues are not transparently and explicitly addressed as a matter of urgency, I cannot assure other patients and families who may wish to become involved with HSSIB. I write this for fear they will experience compounded harm and that they also may have significant concerns about the quality and output of HSIB investigations in achieving their maximum potential impact by utilising the patient and family perspectives. *This is a key reason for writing this letter.***

HSSIB must prioritise its development if it is to become exemplary and better than what has gone before, based on real evidence I start to explore below, and also to demonstrate that it is valuable and not harmful for patients and families. The healthcare system needs a place where trust and faith are restored, providing evidence showing it listens, learns and acts by putting patients and their advocates at the centre.

The current inadequacies, some of which I summarise below, cannot be allowed to continue given HSSIB's primary role of developing a novel model of learning, drawing on both a variety of scientific expertise and also the voices of patients and families. It has been set up to provide powerful independent recommendations freed from the shackles and interests of the NHS hierarchy, which operate from local to national to professional levels, and has been shown to mitigate against frank, open, discussion of reasons for harms to patients and how to properly address them.

The issues I go on to highlight below can be examined from three perspectives, which are so relevant at this juncture given that:

- HSSIB will get new powers and independence, and it's an opportune time to review what it has done before as HSIB.
- New governance arrangements are coming into place, but without patient voice at its heart.
- Issues that have been raised over the last 6 years cannot be ignored, and a recognition already expressed by Ted and Rosie that the patient involvement aspects require more work.

#### **Evidence - the need for HSSIB to self-reflect and develop based on independent insights**

You may argue where I got my evidence from.

Firstly, yes there is a lack of evidence in any direction. Indeed, I strongly believe that the lack of independent transparent quality evaluation and lack of adequate response to various forms of private and public feedback is one of the most shocking things I have observed of HSIB. I write this given my own scientific and research background. I also note HSIB's acknowledgement and public promotion - that it is an internationally ground breaking and novel service in healthcare. I believe it is unethical and dangerous for new services with public expenditure to not be thoroughly assessed for their impact, both positive and negative. This must involve independent experts, some with a clear patient-centred framework and no interest in protecting the current system should there be any evidence that it contributes to avoidable harm.

Secondly, as Note 1 at the end of the letter shows, my 'evidence' and concerns come from my own close reading of many HSIB reports, my own years of observations and discussions with some senior managers, my own reading of publicly available concerns about HSIB and, finally, my own experience as a family participant in a national investigation. In the latter case I provided extensive feedback and observed HSIB's response to this feedback.

HSSIB requires some quality research, as what has occurred to date has been minimal, poorly designed, non-transparent evaluation with little if any patient family contribution and no evidence of co-production in all its processes. Here I make no reference to some very public concerns raised in mainstream and social media about HSIB over the last few years. However, I believe many of these echo concerns expressed in this letter.

I am not saying HSIB hasn't done some useful work and I know the serious pressures it has operated under. And when it comes to my specific comments on investigations, I am focusing my comments on national not maternity investigations (though many issues will be similar) and on the more complex type of HSIB investigations where insights and experience of patients and their advocates with complex needs in complex service systems are being examined, as opposed to the more highly technical and limited scope nature of some HSIB investigations.

I have been raising many of these issues along with others since at least 2017

<https://phsothetruestory.com/2017/02/17/will-hsib-be-patient-centred/> and was invited on the Advisory Panel with these explicit concerns accepted by the first Chief Investigator at HSIB as worthy of consideration. I do not believe these specific concerns have been a focus of HSIB at all. Some of

my greatest fears about HSIB have been sadly realised. HSSIB cannot continue in this vein, yet I am not assured that the concerns raised are being actively considered in its new direction. In the spirit of hope rather than expectation I present this to the incoming Board

The Advisory Panel had no explicit or expected role in even commenting on these types of issues, but some members did at times. In contrast to HSIB, governance systems at HSSIB are now being established in a more recognised, explicit and conventional way, and I believe the Non-Executive Directors and Executive Directors have a vital role to immediately address the thread of concerns drawing on independent expertise.

### **What a patient-centred model has to address - some issues that have explicitly emerged since 2017**

HSIB prides itself on its Engagement model <https://www.hsib.org.uk/investigations-and-reports/giving-families-a-voice/>. This model has not been evaluated in any kind of rigorous way, so there is little, if any, hard evidence.

From my experience and observation, this model does not do what it *says on the tin* when it says it will address patient questions and make patients' vital system perspective and evidence the centre of investigations, looking at all factors contributing to harm and, finally, with patients involved in investigations to the extent they want.

Furthermore, the reality spelt out in the details of the HSIB model, in my opinion, are little different from the relevant linked areas of work around 'Patient engagement' developed in the PSIRF framework (<https://www.england.nhs.uk/patient-safety/incident-response-framework/>) and the Learn Together models (<https://learn-together.org.uk/investigation-resources/our-people/>), which are a family of closely related projects. Essentially, patients in all three models just provide a story and then comment on the accuracy of a draft report. And while Investigators may get broader guidance and training the **reality for patients and families are their insights are excluded from all other aspects of an investigatory process conducted 'independently'**. **This resembles in many ways how patients are involved in healthcare, a common concern of patient leadership advocates** (<https://qualitysafety.bmj.com/content/25/8/626>). This tokenism will not do.

### **HSSIB, independence and patient centredness**

When HSIB and now HSSIB prides itself on its independence (unresearched) this surely refers to independence from NHS interests. This is the context in which HSSIB has been set up to examine harm events that the NHS system has been unable to be adequately address for decades. It does not mean independent from patients' insights. The fact that adequate governance processes finally created for HSSIB, with an appointed Non-Executive Board, have no person with explicit patient experience is a great concern.

The explicit use of the terms independence and balance by investigators used to exclude the role of patient voice in my own national investigation by HSIB is gravely worrying and some of the further consequences for the quality of investigations are raised below.

### **Authentic, accurate, accounts of events in investigations**

Timelines of events that are the subject of investigations need to ensure they have full support of both providers and patients and closely argued evidence for any significant differences. Patients' views, concerns and insights being ignored, omitted and forgotten in processes are a common factor leading to health harm events in the first place. From my experience, despite repeated feedback, this occurred in the final product of an investigation process. This not only means compounding of harm and stress but is also unacceptable practice when the simple singular goal is to provide the evidence base for learning about systems failings by listening fully to all perspectives. This directly leads to the following issues that concern me.

**The need to avoid NHS and service bias - which means traditional, often medical models and frameworks, dominate the whole process**

HSSIB has to do much more to ensure accounts of harm events truly, accurately and fully reflect the experience of family members and patients and do not have a bias and distortion reflecting service-based information (e.g. medical notes, conversations with providers). This was my family's experience, both methodologically (the processes by which we were 'consulted') and substantively (the report conclusion process) and led to various errors right up until publication of the report. It added to the stress.

Factors contributing to this include the role of generic HSIB investigators drawing on NHS subject matter experts. The latter then base their case consideration and investigation on patient timelines solely drawn up by investigators, and also the scoping without the full involvement of patients, families and campaigners. It means investigations can remain within narrow service-centred boundaries and exclude wider issues posed by families that should not be ignored.

One big question remaining is why these limitations still exist after more than 6 years of HSIB. One issue has to be moving away from a solely or predominantly technocratic and medically centred and medically organised framework. This also requires further consideration.

**Scoping of investigations and representative cases - system not service-centred investigations**

There has been discussion presented to the Advisory Panel about the need for 'representative' cases when investigations are used and moving away from simply reference case referrals. First, it should be noted this never happened from my observation that HSIB as an Intelligence Unit existed to ensure cases met national criteria. This is absolutely correct in a general sense as HSIB and HSSIB's valuable investigatory resource must be used to address wider system issues, not merely unique or very specific issues relating to particular cases. However, most harms are due to wider system failings and few are unique issues. Indeed, who would exclude, or indeed challenge based on 'representativeness', the well-expressed insights of family advocates like James Titcombe, Merope Mills and the families of Lucy Letby's victims, as well as the doctors involved in the latter case.

The outgoing Advisory Panel of HSIB has been led to believe (minutes September 2023) that HSSIB will continue to focus on expert case investigations, not just thematic reviews, and consult wider patient campaign groups and family and patient views to optimally scope of investigations. Significant relevant issues to any harm event raised by families need to be expertly and independently considered and cannot be simply scoped out and disregarded.

To restate one of the reasons for HSSIB existence: *The family experience of how a whole service system impacts and causes harm in a systemic way to family and patients and then these impact on wider services input and then services ability to address challenging care situations*, has to be considered as a key basis of any thorough investigation. Patients provide more than stories and that is why their input can be as vital as services, by definition, are service-centred. An example of what can be missed is reported here <https://www.pslhub.org/learn/patient-engagement/patient-stories/patients-who-experience-harm-provide-stories-but-who-will-really-engage-with-their-insights-and-opinions-r9817/>

### **Patient involvement models - much more than mere engagement**

HSSIB needs to explicitly address how to utilise different levels of patient involvement and indeed patient centredness of a patient family perspective in their investigation. There are many scientifically valid methodologies available that HSIB has not yet engaged with, with the initial focus being on safety science, human factors, and the clinical and technical challenges of healthcare.

Articulating, developing and testing a variety of models of family involvement, not mere engagement (which has the vital but simple accessibility only focus), is important to allow fuller participation of patients. It is interesting to note that 'patient leadership' in certain investigations has not even been considered by HSSIB. From my experience, even some harmed patients fear this is a step too far. However, I cannot see the problem when properly supported and monitored with accompanying evaluation, which I once again urge is vital.

This also relates to the whole role of patients and families in the service from governance to scoping and investigation strategies, and how findings are reported and the service evaluated. It must involve patient voices, groups, individuals and leaders at all levels. **Much can be learned from innovators in this field like David Gilbert with his framework**

<https://www.inhealthassociates.co.uk/wp-content/uploads/2020/05/Patient-Leadership-Triangle-Ebook.pdf> . This issue must be considered urgently, especially given the lack of any expertise like this at a governance level in HSSIB. The Non-Executive Director board does not, in my opinion, represent the diversity needed given the tasks and challenges HSSIB faces. This kind of expertise must develop and be incorporated so it pervades all HSSIB'S work.

### **Patient and family advocacy and support - HSSIB must address this**

HSSIB needs to offer support and advocacy to family members to allow better, fuller and less stressful engagement with the investigation process. Patient support, parallel with the investigation process must be offered by HSIB. It does not exist in the wider system and this gap is recognised and of concern <https://harmedpatientsalliance.org.uk/hpa-publish-report-signpost-to-nowhere/>. If HSSIB does not consider offering it and evaluating how to do this better, who else can? HSSIB's primary goal must be expert, safe, quality, non-traumatic investigations. There are no short cuts.

### **Restorative justice versus patient-centredness and patient leadership**

Restorative roles in investigative processes are being widely encouraged. This must be considered if HSSIB is to be novel and exemplar. But restorative approaches are not just an add-on, however valuable. I believe they must also be seen in the full investigative context, as spelt out in some aspects above. Avoidable harm caused by health services' acts of omission and commission has

traumatic implications for patients and families. Poor quality investigations, excluding families, not authentically or accurately or adequately reflecting their insights contributes to their trauma and compound this trauma.

Even worse, the poor investigation outcomes that result can add to the trauma as lessons to prevent trauma to others and the motivation for patient involvement, continue, unchallenged. Leading to a second level of avoidable trauma and breaking of relationships of trust, hope and mutual respect, which are the bedrock of positive healthcare relationships.

Patient leadership in all aspects of the HSSIB process is the mechanism by which a restorative approach among others can be considered, developed and evaluated. The resistance of systems to report the trauma they cause has been well-researched in other contexts (Trauma and Recovery: The Aftermath of Violence - From Domestic Abuse to Political Terror 2022 edition by Judith Lewis Herman). The unique variations and aspects of this trauma when applied to health service harm requires fuller exposition and cannot be ignored as it affects both staff, patients and the whole service system. Challenging a service model developed over years is itself challenging for all.

A restorative framework means investigatory approaches must avoid causing further distress and that they do not repeat what has caused harm in the first place, like powerlessness, exclusion, lack of trust and harmed relationships. HSSIB must start to articulate better and evidence how good investigations can contribute to addressing trauma and consider what this all means for an exemplar, novel, educational service. System defenses and exclusion of patient authentic voices cannot continue, given the betrayal at the heart of healthcare harm and how trauma needs addressing. The HSIB engagement model, based on a policing model of engaging with victims of crime, is not sufficient at all.

### **Whistleblowers**

I believe the treatment of whistleblowers by HSSIB also needs urgent consideration, once again based on evidence and learning from experiences of HSIB. This should include:

- Collecting feedback from HSIB staff who have raised concerns, about their experience of raising concerns, using a format that has been agreed with your group. This is very important assurance evidence.
- Conducting and sharing regular thematic reviews of the themes raised by HSIB whistleblowers with your advisory group.
- Collating evidence to demonstrate whether whistleblowers' concerns have been investigated and resolved.

From what I have read, NHS England has not yet answered questions about whether concerns raised by the HSIB whistleblower whose case was investigated by Susan Newton have ever been investigated: <https://minhalexander.com/2023/04/26/finally-revealed-the-suppressed-susan-newton-report-on-whistleblowing-governance-at-hsib-nhs-england/>

### **Final comments and urgent demands**

I write this as my final input as a 'critical friend' of HSIB since its origin, desperately wanting it to successfully work, staying involved as long as I could as I believed it was the only service that could

deliver what was needed. I have also been acutely mindful at the same time that many wise, experienced and traumatised patient and family campaigners and whistleblowers have been understandably skeptical and cynical about HSIB and now HSSIB.

In summary, I believe HSSIB needs to improve in many areas around patient family involvement and working. Until it does, I cannot unambiguously recommend any family member go through the **process due to the stress and falsely raised expectations. I am issuing a health warning!**

In this letter I have tried to highlight the challenges that need to be addressed and possible directions for solutions, but given the stage HSSIB is at, building on HSIB, and given the observations I have from my experience of HSIB they are also **urgent demands I make to HSSIB. They are demands I make for me to be able to assure others to contribute to HSSIB. Patient leadership, patient-centredness and a variety of models and the subject of co-production need implementing and researching immediately.**

Yours sincerely

**Richard von Abendorff, October 2023.**

#### **NOTE 1:**

##### **More on my background and the origin of my perspective**

I write this in a personal capacity as:

- An outgoing member of the Advisory Panel of HSIB since its inception
- A member of the recently disbanded Citizens Partnership of HSIB
- A member of the Citizens partnership design group
- A campaigner for more than 13 years for something like HSIB to be set up based on my experience as a family advocate for four elderly frail relatives and close friends who all died receiving healthcare that included some significant avoidable harm
- As a family member or advocate who has explored nearly all avenues, most on numerous occasions that can be taken in the patient harm learning system in England since 2011 via Complaints, meeting senior clinical managers, PHSO(7 year journey), an Inquest, CQC, CCG, Healthwatch, AVMA, Patients Association, Parliamentary committee submissions(PACAC), other Inquiries(e.g. Liverpool care pathway.
- As part of a family, a reference case, of a national HSIB investigation.

Finally my contribution has to be seen in the context of my previous 15 year education and career in provision of specialist assessment and support, organising of care and University-based research on health and social care predominately with frail older adults.

**So that it is clear to those reading this, as an Advisory Panel member and Citizens Partnership member, I did not have much special access knowledge of processes and procedures. Our role was limited and at times highly ambiguous as minutes of meetings of the Advisory Panel reveal.**

I have read very many HSIB national Investigation Reports closely. I respect the intentions and aspirations of all staff I met at HSIB.

However, many of my worst fears and concerns about its patient centredness (a fact that has concerned me for many years about all investigation processes) were confirmed when I became a subject (as a family member) of a HSIB investigation.

I have not made these thoughts explicitly in public before but nearly all these thoughts have been expressed over the last few years to senior managers and some investigators at HSIB through various panels and meetings I have been privileged to have access to. I share these more widely and publically to facilitate a more public discussion.

I write this in the context of a Non-Executive Board to HSSIB being appointed with no one on it with a harmed patient family perspective experience and role.

And I write this because I cannot ignore the context of various concerns myself and other panel members have, as well as whistleblowers, Kings Fund reports and other reports shared in the public domain, and the views of other patient and family subjects expressed in the public domain (most recently the Channel 4 programmes on the maternity side of HSIB) .

Further, I do not have enough assurance at all that many, indeed any, of these serious sources of concern have been responded to by HSIB adequately, seriously, respectfully and intelligently enough. HSSIB needs to work out how to model the opposite to the 'reputation first' dynamic that so many NHS trusts, like private sector bodies, demonstrate in the face of serious criticism,

**end**