



# **FRANKIE**

## **SERIOUS CASE REVIEW**

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## 1. INTRODUCTION

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### 1.1 The circumstances leading to this Review

1.2 This review was commissioned by Wandsworth Safeguarding Children Board (WSCB) following the death of a 3-year old, Frankie in July 2016. The child had been an inpatient in hospital for life threatening asthma in the days leading up to death and died within 24 hours of discharge. The London Ambulance Service was called to attend the child at the family home. Resuscitation attempts were made. Frankie was then transferred to hospital where despite ongoing resuscitation attempts, died. The cause of death is recorded as an “acute exacerbation of asthma.” The toxicology screen was negative. The child had a history of acute episodes of asthma with frequent admissions to hospital but also with some periods of stability. Frankie had required care on the Paediatric High Dependency Unit on several occasions and the asthma was considered by health professionals to be life threatening.

1.3 Frankie’s parents had been reluctant to fully comply with medical advice and prescribed medication for their child. They had a fear of steroids but declined or reduced numerous medications over the various admissions. This raised concerns with healthcare professionals.

1.4 Following the death, there was a Rapid Response meeting within the prescribed time where no safeguarding issues were identified. The family were not known to the Children's Social Services or the police and there were no apparent safeguarding concerns identified. The case was then reviewed by the Children’s Death Overview Panel (CDOP), but this was not until 10 months after the Rapid Response meeting. The death was brought to CDOP on 28<sup>th</sup> September 2016 but the case not ready for review (the full Postmortem was awaited). Then further delay occurred on 25<sup>th</sup> January 2017 when the CDOP review meeting cancelled as key members were unable to attend. On 22<sup>nd</sup> March 2017 Frankie’s death was reviewed and closed with a recommendation for the death to be raised at the Wandsworth Local Safeguarding Children Board Serious Case and Learning Sub-Committee.

1.5 At an extraordinary meeting of the Serious Case and Learning Sub-Committee on 2nd July 2017, it was agreed to recommend to the Independent Chair of the WSCB that a Learning and Improvement Review (LiR) be undertaken. This resulted in an Independent Chair and Report Author being commissioned and the learning review was formally commenced in February 2018 with an initial scoping meeting.

1.6 However after preliminary consideration of the case and in considering further information, the Independent Chair and report Author gave the view that the death merited a Serious Case Review (SCR). This view was raised formally to the WSCB on 4th May 2018. The matter was referred back to WSCB and after some deliberation a SCR was commissioned. The decision to proceed to a SCR was conveyed from WSCB to the Independent Chair and Author on 14th June 2018. A Serious Case review was then commenced.

1.7 The WSCB concluded that the case meets the criteria for a Serious Case Review (SCR), as outlined in Working Together to Safeguard Children 2015<sup>1</sup>, in that Frankie was a child at the time of death and there was information that:

- a) abuse or neglect of a child is known or suspected; and*
- b) either – (i) the child has died; or (ii) the child has been seriously harmed and there is cause for concern as to the way in which the authority, their Board partners or other relevant persons have worked together to safeguard the child.*

This criterion is now contained in the updated Working Together to Safeguard Children published in 2018.

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## 2. Purpose of the Review and Methodology

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2.1 The key purpose in undertaking this SCR is to ensure that learning can be identified following the death of this individual child. Most importantly the purpose is to ensure the Review achieves the fullest understanding possible both of what happened but also why, in order to identify improvements and contribute to the prevention of future similar tragedies. The review report will be published. It will support local and national learning.

2.2 Case reviews should be conducted in a way which:

- recognises the complex circumstances in which professionals work together to safeguard children;
- seeks to understand precisely who did what and the underlying reasons that led individuals and organisations to act as they did;
- seeks to understand practice from the viewpoint of the individuals and organisations involved at the time rather than using hindsight;
- is transparent about the way data is collected and analysed; and
- makes use of relevant research and case evidence to inform the findings.

2.3 A Review group was convened consisting of:

<b>Agency/Organisation</b>	<b>Role</b>
Wandsworth CCG	Chair
Independent	Report Author
Wandsworth Borough Council Children's Social Care	Head of Safeguarding Standards
Hospital A	Named Nurse
Wandsworth CCG	Named GP for safeguarding
Metropolitan Police	Specialist SCR Review Unit Officer

<sup>1</sup> Working Together: HM Govt March 2015

Central London Community Trust	Named nurse for safeguarding
Hospital A	Named Doctor
Hospital B	Consultant in Respiratory Medicine
Hospital B	Named nurse for acute services
Wandsworth Borough Council	Head of Education. Inclusion and Performance
Hospital B	Head of Safeguarding

2.4 The WSCB Business Manager supported and contributed to Review Team meetings as well as to the overall process of the Review.

2.5 Consideration was given at the outset, to inviting others who might bring a specialist knowledge, particularly in relation to asthma. The Review and practitioner group included clinicians with a knowledge of paediatric asthma and a specialist children's asthma nurse provided clinical expertise.

2.6 The Review Panel met on 6 occasions, and a practitioner meeting was also held to hear directly from frontline practitioners as to the interactions with this family and obtain more detailed information as to the issues which have emerged in looking at the care and management of this child across the agencies.

2.7 The Review began by gathering the necessary evidence which included the production of a multi-agency chronology involving all the services and agencies who had relevant contact with Frankie and family. All relevant voluntary sector and statutory agencies were contacted at the outset to check for any involvement with Frankie and family. As a result, full chronologies and individual management reviews (IMR's) were provided by the following agencies:

1. Hospital A
2. University Hospital B NHS Foundation Trust
3. The family's GP Practice
4. Wandsworth Children Social Care
5. Metropolitan Police

2.8 A report from Dr C a Consultant in Respiratory Medicine at Hospital 2 was also considered along with the Rapid response and CDOP records.

## 2.9 Equality and Diversity

Both parents were professionals. They employed a nanny to care for their two children. There are no known health or disability concerns for either parent. There is also a paternal grandmother though it is unclear how involved she was with Frankie or the family more generally.

The review adheres to the Equality Act 2010. All nine protected characteristics were considered by the Review group. The practices of agencies were carefully considered

to ascertain if they were sensitive to the nine protected characteristics of the Equality Act 2010, i.e. age, disability, gender re-assignment, marriage and civil partnerships, pregnancy and maternity, race, religion and belief, sex or sexual orientation.

The review panel considered all equality aspects and there is no information or inference in any records or other information to indicate that any incidents were motivated by ethnicity, faith, sexual orientation, gender, linguistic or other diversity factors. This should however be seen in the context that the family have declined to be part of this review, so it has not been possible to ask the family direct if there are any equality factors, they feel relevant.

Although not one of the nine protected characteristics, the review panel did note that the social class of the parents was likely to have contributed to this situation. The approach that professionals adopted towards the parents in considering their opinions and position in relation to the treatment of their child's condition was overly deferential and lacked robust challenge. It is the view of the panel that this is less likely to be seen when dealing with families without similar educational and employment backgrounds, where there is less likelihood of recourse to complaints systems and litigation.

2.10 The review examines the responses of all the relevant agencies that had contact with Frankie and family and considers whether there were gaps in services or wider learning about safeguarding children. The main timeframe for the review begins with the birth of Frankie in November 2012 and includes after death in July 2016 to consider the actions and decisions of the Rapid Response and CDOP process.

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### 3. THE CIRCUMSTANCES OF FRANKIE'S DEATH

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3.1 Frankie's parents (Mr and Mrs F) moved to the UK in 2009. Frankie was born in November 2012 at 38 weeks gestation at a London hospital and the birth was uneventful. Frankie was low weight at birth but did not require any hospitalisation after birth. Frankie had one older sibling at the time of death.

3.2 The family were registered with a GP in 2010 and Frankie was seen for routine 8-week new-born check where a marked deformity of the left 4th toe was noticed. This was referred for a paediatric orthopaedic opinion aged 1. The rest of the physical examination was normal. Frankie was seen regularly by the GP throughout the first four months of infancy with viral illnesses of cough and coryza<sup>2</sup> but these were all self-limiting and managed with advice and support. The first episode of this was at two months.

3.3 Frankie was next seen at 15 months of age when Mr and Mrs F presented to the GP with a further viral upper respiratory tract infection. At this consultation of note is that Mr F stated that both children had not had any immunisations as he had been warned about side effects and had read about the MMR and autism controversy. A discussion took place with the GP discussing the benefits of immunisation, explaining

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<sup>2</sup> **Rhinitis**, also known as coryza is irritation and inflammation of the mucous membrane inside the nose .

the falsified evidence around MMR and autism and discussing the risks of not protecting Frankie with immunisations. At that time Mr F agreed to discuss with his wife and come for review in two weeks. The parents did not attend as planned. The GP informed the Health Visitor and asked them to contact the family to encourage immunisation which they did but the parents would not engage. It should be noted that due to adverse research and publicity against MMR immunisations (which was later discredited) there was a backlash against immunisations due to the fear that there was possibly a link to autism. This proposition was widely profiled on social media platforms and despite evidence to the contrary some parents have remained to this day reluctant not to have their children immunised.

3.4 This was the first consultation of many where the GP's at the practice tried to discuss immunisation with both parents. The children remained unimmunised.

3.5 Frankie continued to be taken to the GP with recurrent upper respiratory tract infections and wheeze. Frankie was brought to the GP aged 18 months in June 2014 by the nanny. This was the first discussion the GP had about wheeze and "distress in breathing" (DIB) The GP advised the nanny to attend the Emergency Department (ED) if Frankie's breathing worsened.

3.6 On 24<sup>th</sup> August 2014, Frankie attended the ED with serious breathing difficulties and had been seen by the GP 6 days prior and antibiotics had been prescribed but the parents had not administered, it is not known why they did not administer. Frankie had a prolonged admission at this time at Hospital 1 (and required high dependency care. At this point was referred to the respiratory team led by Dr C; an experienced Respiratory Consultant based at the Hospital 2, but he was a visiting consultant at Hospital 1. Frankie was discharged home on inhaled steroids and oral Leukotriene antagonists (Montelukast) after a diagnosis of infantile asthma with severe wheezing was made. Frankie was subsequently seen by Dr C as an outpatient. It should be noted that neither Hospital 1 nor Hospital 2 are within Wandsworth Borough.

3.7 A letter from Dr C to the GP and copied to the Health Visitor in August 2014 communicated some of the difficulties with the parent's compliance with Frankie's asthma management. Dr C saw Frankie within a month after discharge and wrote to the GP stating the parents had reduced the fluticasone inhaler and that they were not giving Frankie Montelukast as they were concerned about its side effects, namely growth restriction. They had started Frankie on homeopathic alternatives. Dr C states clearly in his letter dated 14<sup>th</sup> August 2014 that he had a long conversation with Mr and Mrs F parents at this time about the importance of inhaled steroids and discussed the issue of side effects in detail. He was specific in guiding them that long term high/medium dose could possibly lead to a 1-2cm reduction in final height. He stated:

*'this must be countered however by the fact that inflammation that is unrestrained within the airways will reduce growth and some children die from asthma and it is usually those who are not receiving the inhaled steroid treatment they need.'*

3.8 Dr C was explicit to the parents that Frankie had a life-threatening asthma and optimal medical treatment was imperative. The plan was for Frankie to undergo some further investigations including a CT scan at Hospital 2 as clinical presentation was

quite unusual for a child of this young age. Dr C explained that depending on the result it was likely Frankie would need other investigations.

3.9 A CT scan was performed but no further correspondence around any other investigations was received at this time. It is not documented whether these were declined by Mr and Mrs F.

3.10 At this time a flag was put on Frankie's GP notes of suffering with severe asthma.

3.11 Frankie was also under the care of a Health Visitor for the first year of life but then moved to a health visiting "corporate caseload" (i.e. universal services) at the age of one as was not deemed to require any enhanced services. Frankie was seen twice at home by the health visitor. The first visit was a new birth visit in November 2012 (before the GP visit at 8 weeks when the toe deformity was discovered by the GP) and a follow up home visit in December 2012 which raised no concerns.

3.12 Frankie was not seen for the two-year developmental check milestone as the parents did not bring Frankie. This was not pursued and was not seen as obligatory nor necessitating any action under a "Did Not Attend" policy. This failure to attend was not seen as concerning by professionals. Frankie was not attending any early year's provision so had no contact with professionals there. Therefore, it is not possible to say if Frankie was meeting the two-year developmental milestones.

3.13 Frankie had twelve hospital admissions to Hospital 1 from the age of 20 months until death -all associated with severe asthma.

3.14 On six of these admissions Frankie required admission to the Paediatric High Dependency Unit. Frankie required resuscitation on at least three occasions. Frankie had also previously stopped breathing at home, and last admission to hospital had been on 3 July 2016 when acutely unwell and was found limp and foaming at the mouth. Frankie had become unwell at around 2am and an ambulance was called some hours later and was treated at the hospital and then discharged on 7 July 2016 with a defined plan of medication. On discharge Mr F did not want the oral steroids prescribed despite medical staff explaining to the parents that Frankie's had a life-threatening asthma.

3.15 There are numerous instances recorded where the parents declined or unilaterally reduced or stopped medication to Frankie for the asthma. There are periods when reported to be stable at home. The asthma was generally worse in the summer. The noncompliance of the parents to administer medication as advised did raise concerns but this was not referred for any safeguarding consideration. The parents had been advised that Frankie had a life-threatening condition and required medication. It is unclear what medication was being administered to Frankie at the time of death at home or whether alternative therapies were being administered.

3.16 When leaving the hospital on 7<sup>th</sup> July Mr F was clear that he would not accept steroids or other medication for Frankie based on possible side effects of which both parents were fearful. This was despite the concerns raised by the discharging doctor that Frankie had a life-threatening condition. No safeguarding concerns were raised at this point and Frankie was discharged back into the care of the parents. Frankie

returned the next day having had deteriorated at home overnight and could not be saved.

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## 4. CHRONOLOGY OF KEY EVENTS

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4.1 IMR's were provided by all the agencies known to be involved with the family but agency contact was limited largely to the GP, health visitor and hospital. The most pertinent timeline is around hospital admissions and this gives the review the richest information around the management of Frankie's asthma by practitioners and parents. This is a key aspect of this review.

4.2 The timeline is not an exhaustive list of contacts but centres around the main agency who by far had the most contact with Frankie and family- the hospital. For ease of reference the main exchanges with Frankie's parents are in italics. The timeline commences when Frankie's asthma starts to lead to hospital admissions as this reflects when risk to wellbeing appears to be increasing. It should be noted that two last entries in the medical records have been written retrospectively after the child's death and are not contemporaneous.

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## 5. CONTRIBUTION OF FRANKIE'S FAMILY AND FRIENDS

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5.1 Frankie's parents have declined to be part of this review which is their choice and one which must be respected. A face to face meeting was offered at the start of the review. The parents did initially agree to participate, and answer questions posed to them in writing. A letter was sent to the parents on this basis by the Chair of the SCR, but this has not elicited any response. Further contacts have been made to encourage involvement, but this has not been fruitful.

5.2 However, this means that our understanding of what was, or was not, happening within the family home is greatly limited and leaves many unanswered questions and a lack of wider family perspective other than is recorded in records. This also impedes understanding parental choices made; their rationale and what may have informed that including social class, cultural and faith aspects. It has not been possible through the parents to identify other family members who may have been able to contribute or the nanny who looked after Frankie for a period of time.

5.3 Understanding Frankie's lived experience is also limited by the fact that no professional observed Frankie in the home setting following the Health Visitor visit in December 2012. Frankie had one older sibling but is too young to participate in this review. The sibling was home educated at the salient time.

5.4 The experience of Frankie who was very young and unable to understand the illness and the restrictions this will have placed at times should not be underestimated. Frankie's condition would have been disruptive to routine and early learning as well as play. Frankie had repeated admissions to hospital as the condition was largely uncontrolled and had a high number of admissions where breathing was severely compromised. The potential negative psychological, physical and emotional impacts of hospitalisation upon a child is well researched and that play interventions

is key to assisting a child. <sup>3</sup> It is not possible to ascertain Frankie's quality of life at home or what medication was being administered to help but in the short life will have experienced the obvious stress a child will experience being admitted to a hospital which to even a young child is an alien environment. The review team and those clinical experts advising into the review are left wondering whether with better management of the condition such repeated admissions could have been avoided.

5.5 By 3 and a half years old a child should be able to verbally communicate and be understood by people outside the family. Three-year old's meeting their developmental goals are mobile and active; playful and engaging. They enjoy books, music, storytelling, swimming, role play and learning about colours and numbers and exploring their world. However, the majority of time Frankie was in hospital was seriously ill, and the focus was on parental choice and we can only speculate whether Frankie sensed the contention and tension between the parents and those professionals seeking to care. Play workers did engage with Frankie but at times was simply too ill to play. Frankie required high dependency care on more than one occasion and must have been extremely stressful.

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## 6. ANALYSIS AND APPRAISAL OF AGENCIES' PRACTICE

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6.1 The loss of a child is always a tragedy and the review panel do not underestimate what a great loss this will represent to Frankie's parents and the wider family. This review however is tasked to capture any learning that can be gained by Frankie's story and to that extent the review must approach the review from the child's perspective and ascertain how agencies and practitioners worked around the child and the family to safeguard where necessary.

6.2 The crux of this review has been to what extent does parental responsibility and choice override the welfare and health of a child who has an identified life-threatening condition. Furthermore, when does noncompliance of a child's parents to provide the child with optimal medical care become medical neglect? "Working Together to Safeguard Children A guide to inter-agency working to safeguard and promote the welfare of children (July 2018) defines neglect as:

*A persistent failure to meet a child's basic physical and/or psychological needs, likely to result in the serious impairment of the child's health or development. Neglect may occur during pregnancy as a result of maternal substance abuse. Once a child is born, neglect may involve a parent or carer failing to:*

1. *Provide adequate food, clothing and shelter (including exclusion from home or abandonment)*
2. *Protect a child from physical and emotional harm or danger*
3. *Ensure adequate supervision (including the use of inadequate care-givers)*

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<sup>3</sup> Play interventions to reduce anxiety and negative emotions in hospitalized children

• William H. C. L., Joyce Oi Kwan Chung, Ka Yan Ho and Blondi Ming Chau Kwok  
*BMC Pediatrics* BMC series – open, inclusive and trusted 2016

#### 4. *Ensure access to appropriate medical care or treatment*

*It may also include neglect of, or unresponsiveness to, a child's basic emotional needs.*

6.3 Under the Children Act 1989 as amended, the term “**parental responsibility**” is defined as “*all the rights, duties, powers, responsibilities and authority which by law a parent of a child has in relation to the child and his property*”. This is a qualified right and in some instances the courts must intervene to protect a child where parental responsibility is not exercised in a way that meets the best interest of the child and puts them in harm's way. There can be complex reasons why a parent may act in this way but the law is clear that if the child is suffering or likely to suffer significant or serious harm due to acts or omissions of a parent or indeed others all agencies and professionals have a duty to act to protect the child. This will inevitably require the expertise of safeguarding professionals to support professionals and families to work together to find an agreed way forward for an appropriate and safe care plan for the child. Some cases have attracted the attention of both High Court and Family Courts where medical care and attention has been impeded by parents and this has been to the detriment of the child and caused unnecessary suffering and /or harm. In some cases, children have required special guardianship or care orders. Asthma is not an uncommon condition amongst children and can be life threatening. There is a clear care pathway supported by National Institute of Clinical Excellence (NICE) and the British Thoracic Society<sup>4</sup> and the care pathway represents evidenced based practice.

6.4 What this review has clearly highlighted is that practitioners are much more comfortable in recognising the first three categories of neglect but consideration of the fourth pertaining to medical neglect presents a much greater challenge. When professional practice around Frankie was appraised it was found that there were several contributory factors for this.

6.5 The primary factor was that professionals felt unable to fully challenge parental responsibility and choice being exercised in the face of affluent, well educated, researched and assertive parents who willingly brought their child to medical attention but then sought to control what treatment the child was given. This was despite the parents having been advised of the real importance of asthma treatment judged to be safe and appropriate by numerous health professionals. This included a consultant expert in the field, Dr C. He was clear that those children who die of asthma are those that are not receiving treatment as prescribed and advised. Asthma is a condition that requires preventative and maintenance medications to stave off acute episodes and improve quality of life of the child. When the parents did comply as soon as there was improvement in Frankie's condition they would unilaterally stop or reduce medication which will have increased the risk of serious and acute stages and caused the child more breathing difficulties than was necessary. The parents were open on their actions around stopping and reducing medication, but this did not trigger any safeguarding consideration. The child's experience and wider impact of ill health appears to have been lost and yet there were other possible signs of failing to thrive such as weight loss and the child's nanny describing Frankie as lethargic.

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<sup>4</sup> <https://www.brit-thoracic.org.uk/.../guidelines/asthma/btssign-asthma-guideline-2014/>

6.6 This review has found that the assertion from the parents around not giving medication was powerful even when the child was deteriorating. On numerous occasions professionals were held back by the parents from treating in the best interest of the child. The parents stated repeatedly said they had researched the suggested treatment regime and medications on the internet and posed their research and their findings as more authoritative than advice being given by experienced professionals. Clinical governance and sound medicine management mean that prescribed medicines should be administered to the child unless there is a clinically based rationale not to do so.

6.7 Without speaking to the parents direct and gaining their perspective it is impossible to fully understand their rationale for their approach or reasoning and whether the non-acceptance of conventional medicine and their preference for alternative therapies comes from fear/ cultural/religious/inherent lack of trust for professionals or any other factors. The information gained by the parents was used by them to counter treatment and over emphasise possible side effects despite reassurances from most senior health staff that such side effects were minimal if they materialised and that the child's survival was the paramount issue. When the child had natural remissions from the acute nature of this condition and was not in hospital professionals were understandably reassured of a possibly stabilising condition.

6.8 Another factor is that practitioners managing Frankie lacked an understanding that parental responsibility does not extend to a degree that permits medical neglect. While it cannot be denied that the parents brought the child to medical attention the fact that they would then persistently fail to fully comply with the best evidenced treatment for Frankie and a well-recognised care pathway meant that they acted against their own child's best interests. This relates to care in the acute phases of illness but in all probability also inconsistent maintenance treatment at home to prevent further acute and life-threatening episodes. Even during the last discharge, the day before the death, parental noncompliance was apparent.

6.9 Practitioners did not recognise the safeguarding significance of medical neglect in the form of a parent consistently and persistently withholding consent to medical treatment for a child who had a life-threatening condition.

6.10 Therefore the parents who are well educated, well informed and confident with strong beliefs around alternatives therapy felt they had superior knowledge. They were able to disrupt a well evidenced medical care pathway and at times coerce modifications away from optimal treatment. This happened even on occasions where Frankie was seriously unwell. This disempowered the medical professionals. Both parents presented as confident, well-educated and were challenging the wisdom of professional judgements with research they had sought from the internet focussing upon side effects of conventional medications not seemingly accepting that such medications have in themselves an evidence base as an established care pathway for asthma. Both Mr and Mrs F were persistent and strong in their held beliefs and their social class and demeanour in this regard led professionals away from the basic premise that the child's welfare is paramount. The child being so young was unable to voice a view

6.11 The admirable ethos of wishing to work in partnership with families which is embedded culturally appears to have been a barrier in this case to practitioners having a more challenging discussion with the parents around the safeguarding aspects of their decisions. The parents therefore drew practitioners away from their safeguarding duty to the child.

6.12 The child's welfare is paramount<sup>5</sup> and the duty of care to the child became lost in the episodic exchanges with the parents permitting the parents to lead the medical care not medical professionals.

6.13 There was a professional over optimism around medical care being provided at home combined with no monitoring or support to the family in the community.

6.14 Parental challenge around medication is seen as a common problem and there may be desensitisation in that asthma is also a common condition though the severity of Frankie's asthma was recognised.

6.15 Practitioners in the hospital also stated anecdotally that past experience meant that if practitioners had referred to children's safeguarding this would not have met the requisite threshold or elicited action. The hospital works with numerous local authorities and this is their experience. However, Frankie was not discussed with any internal safeguarding professionals e.g. Designated and Named Professionals. These professionals could have usefully and if necessary, supported the health professionals speaking to the parents in safeguarding terms. The hospital concerned had /has clear safeguarding policy and designated professionals from whom advice could have been sought.

6.16 As it was the parents' behaviours around their assertions on asthma treatment permitted them to keep to an approach that they knew best and put them central rather than Frankie. This was compounded by inconsistent clinical leadership and supervision to assess and oversee the accumulative impact upon Frankie of parental noncompliance. The lead consultant was based in another hospital. As the child had repeated admissions understandably, was seen by many different doctors and nurses of numerous grades, experience and expertise. The lead consultant had neither the detail of the challenges being faced by nurses on the wards in trying to administer care or the holistic oversight.

6.17 During the very many admissions, professionals who had contact with Frankie's parents, strove to educate and impress upon them the importance of administering medication as prescribed and not to reduce or stop the treatment unless advised. It is impossible to ascertain without the parents participating in this review how much medication was being administered within the home or indeed what other substances were being given. The consultant did not see alternative therapies as a problem providing Frankie was also receiving inhalers and other prescribed medication. Dr C an experienced consultant wrote to the parents and their GP and this was copied to the Health Visitor. This letter set out the life-threatening risk to Frankie if the

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<sup>5</sup> The Children Act 1989

<https://www.brit-thoracic.org.uk/.../guidelines/asthma/btssign-asthma-guideline-2014/>

medication regime was not followed and monitored. The thread of this was then lost once expressed and so any opportunity to escalate to safeguarding was not utilised.

6.18 Frankie was also seen regularly by the GP. There were many opportunities for the GP's involved with Frankie's care to ask specifically about compliance with medication regimes communicated and prescribed by the respiratory team and lead consultant. On several occasions conversations around this were documented but there were many opportunities to explore and challenge some of the non-compliance further by GPs. Dr C's letters to the GP each mention his explicit communication about the risk of non-compliance to Frankie. Dr C's view expressed to the review into the review was that the death was avoidable with consistent and cooperative management. On balance he states that Frankie should possibly not have been discharged on 7<sup>th</sup> July 2016 but qualifies this by saying that view does include a hindsight bias. It was notable also that in the practitioner's event that professionals referred to other children with serious conditions with equally challenging parents so this would tend to indicate this is not an isolated case. This merits a safeguarding audit by Hospital A. There is a complex case meeting in the hospital but noncompliance by parents in this case was not seen as so worrying to merit the case being brought to that meeting. There are no formal terms of reference for the complex meetings and it would be helpful for these to be developed and medical neglect concerns around noncompliance be added as a factor that may bring a case to wider discussion.

6.19 The review was also able to have the benefit of a specialist asthma nurse to input into this review bringing her expertise and wealth of experience. She raises concerns around multiple documented occasions where Mr and Mrs F displayed obstructive behaviour and lack of engagement, even when their child was extremely unwell.

6.20 This extended to multiple reports of Mr and Mrs F's fears around orthodox and evidence-based treatment and their resulting refusal to administer such treatment coupled with obstructive behaviour in hospital, even when their child was seriously unwell. This presented a paradox that though Mr and Mrs F reported they had done much research around asthma medication, homeopathic remedies employed by them lacked any robust evidence compared to orthodox medication for asthma.

6.21 Further Frankie would have benefitted from being considered by the "Difficult Asthma Team." Usually if child is under care of Difficult Asthma Team, there would have been a more multi-disciplinary team involved and a home visit performed by an Asthma Specialist Nurse. Frankie was not "fully" under the care of the Hospital 2 and was just seen in the outreach clinic.

*"There is no universally agreed definition of difficult asthma in children or adults, and specifically at what level of treatment prescription or asthma attack frequency the term difficult asthma should apply"*<sup>6</sup>

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<sup>6</sup> *BTS/SIGN Asthma Guideline 2016*

6.22 However, generally children attending a designated Difficult Asthma Clinic have been prescribed high dose therapies, which was not the case with Frankie.

**In any event, the fact that:**

- the calibre of Frankie's asthma was designated as life-threatening by a Respiratory Consultant very early on
- this was explained to parents on more than once occasion
- that if inhaled steroids not given risk increased of death
- multiple episodes of hospitalisation for severe wheeze occurred likely due to "neglectful non-compliance"
- parents persisted in not doing as recommended as they felt they knew better

This should have triggered a local safeguarding team involvement and a referral to the local authority being made as the child's best interests were not being met.

6.23 It may be that significant factor in a safeguarding discussion not being triggered was the range and volume of health professionals of health professionals involved in Frankie's care with no single Consultant/team based at the hospital to take overall responsibility. Also, difficulties existed around the assertiveness of Mr and Mrs F. However, the safeguarding team could have been instrumental in helping to overcome such difficulties.

6.24 The GP IMR author suggests if Dr C and the hospital team had used the phrase neglectful non-compliance whether Frankie's health journey may have been different. That IMR states that if members of the health agency who dealt with Frankie had perhaps met to have a Team around the Child (TAC) meeting with the family as a whole it might have helped the parents to reconcile some of the advice being given.

6.25 This IMR goes on to give a view that ultimately Frankie's death may have been prevented by a more rigorous compliance to treatment, but it may also not have been as Frankie had an atypical presentation of early severe childhood asthma. There was potential for more rigorous review in primary care and it may have helped for the family to have always seen the same GP and to continue to build a rapport and trust around Frankie's treatment. This is always an aim when caring for any child with a severe chronic illness and indeed the surgery did very well in ensuring as much continuity of care as possible and each member of the team being aware of his case. Unfortunately, due to the pressure on GPs within the NHS having to manage 10-minute appointments in often understaffed circumstances continuity of care is not always possible.

6.26 There were opportunities for a multi-agency approach to supporting Frankie and parents complying with the management and treatment regimes. These opportunities were not taken despite good written liaison between secondary and primary care. No attempt was made to have a Team around the Child (TAC) or Team around the Family (TAF) meeting. This should have been arranged.

6.27 A thorough review of Frankie's GP notes and case has been discussed at practice level amongst the doctors who cared for Frankie. They have discussed

methods of monitoring compliance in addition to regular face to face review (e.g.; underfilling repeat prescriptions).

6.28 GP's should be confident to challenge parents when thinking about the best interests of a child. This was noted to be very difficult in practice, particularly when parents are highly educated and are presenting well thought out (although not evidence-based) arguments about not agreeing to medications or immunisations. However, all GP's are children safeguarding trained and so this should always be a consideration when they are seeing children and families.

6.29 There is helpful research which sets out the challenges for practitioners when working with affluent, resistant parents. It is set in a social work setting but has resonance for this review.<sup>7</sup> and emphasizes keeping the child central.

*“One of the most frequently discussed issues was that affluent parents’ confidence and sense of entitlement meant that they felt they could diagnose their own needs, expected children’s social care to accommodate them, and felt that they had a right to challenge those in authority. Practitioners reported that active engagement techniques, such as having a formal signed agreement and goal setting, often did not work with affluent parents”*

*“the thinking was on the importance on holding the child as a central focus of the assessment, so that the parents’ interests did not outweigh consideration of what was in the child’s best interest”*

6.30 The review explored what was available to protect Frankie and support the child in the community. Frankie was seen at home twice as per regime post birth but was never immunised and did not attend the two-year developmental check. Given children’s social care was not involved at any level and there was no social worker involved to drive forward a TAC although any agency can trigger that process. The health visiting service was more limited after the child past one year as the delivery model had been changed to accommodate resource issues by the commissioning body at the time. The same model of delivery dictated that unless a child was within safeguarding there would be no consideration of enhanced services or support. The health visiting service acknowledges that they would have received letters every time Frankie was admitted to hospital but states that health visitors now come from a wider pool of skills e.g. midwifery, mental health nursing. The IMR from the organisation that commissioned the service at the time states *“new health visitors would not necessarily have a full working knowledge of the medical/ acute setting terminology used in a discharge summary”*.

6.31 Asthma is stated to be a well-managed condition though the health visiting service did acknowledge that the condition could cause death. The issue of noncompliance was not appreciated by the health visiting service at the time because the direction from the GP was more around the child having not been immunised. It is unclear if the letter from Dr C to the GP explaining the concerns of noncompliance

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<sup>7</sup> An Exploration of How Social Workers Engage Neglectful Parents from Affluent Backgrounds in the Child Protection System 2017 Professor Claudia Bernard Goldsmiths, University of London

by the parents and the implications of that was ever actually seen by the health visitor.

6.32 The review was told that paediatric community services did not extend to an asthma nurse outreach into the community for children. It cannot be assumed of course that the parents would have engaged with the health visiting service under an enhanced service and there is evidence that the parents liked to keep professionals at arm's length.

6.33. It is a difficult judgement now to make whether Frankie should have been discharged on 7<sup>th</sup> July and whether this constituted a safe discharge. Frankie's deterioration appears to have been rapid that night and the fullest details are not known as to what the parents did to manage the condition at this point. It is also important to note that Frankie did have periods of stability and that in any circumstance given the severity of the asthma may have always presented some risk of death. However from a safeguarding perspective this meant that the stakes were higher in ensuring the best interests were met with medical care required and in a consistent manner that would have allowed the medical professionals to have accurate information and parameters on which to base their clinical decisions while the child was in and out of hospital. The parent's suspicious approach toward the care and treatment and fixed belief that they knew best in terms of diagnosis and treatment was the biggest risk factor of all to Frankie. As a result of the matter not being referred to safeguarding Designated or Named professionals or referred to the Local Authority Children services the option of working with the family from that perspective was not used. That is not to say that this matter would have reached threshold<sup>8</sup> to trigger a s47 child protection response but the important factor is one of a consideration in these circumstances.

6.34 The matter was referred to Rapid Response after Frankie died but those deliberating appear to have continued the lack of due consideration of the safeguarding aspects. This was largely informed by the medical history and lack of safeguarding response when Frankie was alive rather than a more independent consideration. This then took 10 months to reach CDOP for legitimate reasons stated in this report's introduction.

6.35 On discussion with children's social care in the context of some health professional's perception that had they referred Frankie this would not have elicited a response, the review was advised that there have been previous cases where children's social care have sought intervention in similar circumstances and that medical neglect is a recognised category of neglect in that service.<sup>9</sup> It needs also to

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Wandsworth Safeguarding Children Board Thresholds for Intervention March 2018

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Wandsworth Safeguarding Children Board Neglect Strategy April 2017  
Multi-Agency Neglect Strategy and Practice Guidance  
Wandsworth Safeguarding Children Board  
Multi-Agency Neglect Strategy and Practice Guidance  
2017-2019

be acknowledged that this was a tertiary hospital that deals with multiple local authorities where there is potential for differing applications of thresholds. Further professionals in all agencies can resolve differing professional viewpoints and interpretations of risk by using the escalation policy<sup>10</sup>. There is a recognition that social workers can also be challenged by affluent, well-educated and well-informed parents who challenge professional judgements. Also, at the time of Frankie's death the "front door" of children's social care and the referral gateway had been strengthened to support professionals accessing a consultation with a manager. safeguarding.

6.36 There were no concerns raised around the older sibling though it is not clear if the sibling was ever seen by any agencies as was home educated. The responsibility for a child's education rests with the parents, and while education is compulsory school is not. A parent's right to educate their child/ren at home is upheld by Section 7(b) of the Education Act 1996. Once the decision to home educate has been notified, there is a lack of a strong, mandatory framework to monitor, assess or inspect the quality of home education provision. Moreover, there is no agreed route for the children involved to formally express their views as to where they wish to be educated, or to give feedback on their experiences of being educated at home. There is no statutory requirement for a local authority to maintain a register of pupils being educated at home, the authority cannot insist on regular contact with parents, and the latter are under no obligation to accept home visits.

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## 7. Findings

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7.1 This review has highlighted several findings:

1. That the parents, not the child became central to clinical decision making around the child. The child's welfare is paramount<sup>11</sup> and the duty of care to the child became lost, as did authoritative practice. The child's voice was not being heard.
2. As a form of neglect, medical neglect is less understood across all agencies and within the health system. This represents a serious weakness in the multi-agency children safeguarding system.
3. Professional practice around how a parent exercises their powers under parental responsibility and when this might cross into neglect was not

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<sup>10</sup>

INTER-AGENCY ESCALATION POLICY The Resolution of Professional Inter-Agency Disagreements about Safeguarding Children Revised March 2018

<sup>11</sup> The Children Act 1989

<https://www.brit-thoracic.org.uk/.../guidelines/asthma/btssign-asthma-guideline-2014/>

considered. Nor was the impact of social class upon the relationship with health professionals. There was an unconscious bias at play.

4. Persistent and wilful parental noncompliance of a potentially lifesaving care pathway to a child was not considered as a safeguarding matter nor appropriate expertise sought.
5. Consistent and reflective clinical leadership and supervision was missing. This is key to meet the medical duty of care to the child and avoid disruption of a care plan to treat a life-threatening illness. In this case professionals were successfully coerced away from a well evidenced medical care pathway which at times prevented optimal treatment being given to the child.
6. There was a professional over optimism around medical care being provided at home combined with no monitoring or support to the family in the community.
7. Parental challenge around medication is seen as a common problem but there does not appear to be a robust strategy to manage this in the hospital.
8. Some professionals were unfamiliar with the escalation process for safeguarding within Hospital A.
9. The internal forum for complex cases was not used in this case missing an opportunity for clinical oversight; safeguarding and information sharing around the child and family.
10. The absence of other categories of neglect appear to have reassured practitioners.
11. Currently there is no system to identify children who are regular attenders at the hospital with life threatening and acute illness rather than suspected non accidental injuries.

7.2 Previous SCRs nationally have included children who were the subject of serious case reviews involving possible medical neglect<sup>12</sup>.

These highlight in the main undue professional optimism suggesting that medical professionals may be overly optimistic that families will be able to care for a child with a long-term illness even when there is evidence to the contrary.

7.3 Another theme has been around non-compliant parents, with some SCR's suggesting professionals did not appropriately challenge parental behaviours in order to safeguard the child. There is however some ongoing learning to be achieved across agencies to identify, manage and act upon situations where this may be a factor. That is not to say that all cases of concern brought to safeguarding will conclude medical neglect is present but it is the objective and thorough consideration within the safeguarding system that is key to make those deliberations and work with families to enable them to understand that the impact of withholding care to a child (intentional or not) may amount to significant harm or even in some cases death.

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<sup>12</sup> [Neglect and Serious Case Reviews](#)

A report from the University of East Anglia commissioned by NSPCC  
Marian Brandon, Sue Bailey, Pippa Belderson and Birgit Larsson  
University of East Anglia/NSPCC  
January 2013

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## 8. RECOMMENDATIONS

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8.1 The report made 8 recommendations which were challenged by the partnership in terms of their feasibility as they related to both health's service contractual arrangements and national commissioning issues, both primary and specialist care. A new set of recommendations with action plans were drafted and progressed. However, given the concerns raised an independent critique of the report was also commissioned. The critique of the report was accepted fully by the partnership and key findings to ensure effective learning are:

1. All Lead Directors for providers submitting IMR's must have oversight and sign off the reports to ensure that they are of good quality and to enable learning to be taken forward in a timely way.
2. Hospitals to explore how clinical teams manage parent consent for emergency treatment.
3. Hospitals must review how it manages severe illness in children when a parent favours alternative therapy.
4. Hospitals must review how ward staff act when there has been an incident of a parent administering medication, on the ward, to a child outside of the treatment plan.
5. The paediatricians at hospitals must undertake a reflective session to consider in what circumstances they would seek legal advice regarding parents who do not consent, and who would make the decision to escalate.
6. Acute Trust Boards must review how the clinical teams are supported in their decision-making regarding treatment when the parents do not agree with the treatment plan.
7. GPs and Health Visitors must have an agreed plan when following up issues of concern with families.
8. All services must be able to evidence how their workforce participates in **reflective** safeguarding supervision which supports their learning and development.
9. All children on the severe asthma pathway must have a management plan and names lead professional who has oversight of their care.

**Independent Critique Reviewer: Nicola Brownjohn**

**RN(Adult), SCPHN (School Nurse), MA (Professional Practice Safeguarding Children)**

### **Further Research**

Since this death Health London Partnership have developed asthma standards as a key priority for improving the health of London Children and Young People.

### **Healthy London Partnership**

*Asthma is the most common long-term medical condition affecting children and young people. 1 in 10 children and young people are affected by the condition, meaning 240,000 have asthma in London. Many have badly managed asthma- to the extent that 4,000 are admitted to hospital with asthma every year and 170 have such a severe episode that they require admission to intensive care.*

At the worst end of the spectrum around 12 children and young people die of this disease in the capital every year.

### **Healthy London Partnership Asthma Standards**

In 2016 Healthy London Partnership (HLP) developed London asthma standards for children and young people. These standards support the identification of those who are high risk. This includes 'children who have had more than one admission or admission to PHDU or two or more ED attendances in the last year. This would also target those with 80% or less uptake of repeat preventer prescriptions.'

The HLP have also developed a discharge standard to 'ensure safe discharge and transfer between providers.' This includes the need for discharge information to be sent to the GP and community teams electronically within 24 hours and for each hospital attendance to be followed up within 2 days of discharge.'

'Every child with asthma should have a Named professional and access to a named set of professionals working in a network who will ensure that they receive holistic integrated care which must include their physical, mental and social health needs.'

#### **Reviewer Note 9**

All CCGs/providers should now have established the HLP standards, for any children with severe asthma, to ensure that all have:

- A clear management plan
- Had follow up within 48 hours post admission /attendance at hospital
- A named professional leading their care
- A network of named professionals who meet to review the effectiveness of the management plan

Healthy London Partnership (2016) London Asthma Standards for Children and Young People – <https://www.healthylondon.org>  
:accessed 30 March 2020