Local Child Safeguarding Practice Review

Learning for the system in the management of asthma in children informed by "David"

REVIEW REPORT

Independent Reviewer: Alex Walters

REPORT- V6

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1. Introduction

1.1. Kent Safeguarding Children Multi- Agency Partnership (KSCMP) undertook a Rapid Review process as required by Working Together 2018 following notification of a serious incident in January 2023. The outcome was a decision to undertake a Local Child Safeguarding Practice Review (LCSPR), agreed by the National Child Safeguarding Practice Review Panel. It was felt that the circumstances met the criteria for an LCSPR because a child had died and neglect was suspected and it was recognised that there were opportunities for further agency and system learning.

1.2 David[1] had sadly died following an asthma attack in 2022. He had an asthma diagnosis and was prescribed regular medication but at the time of the incident, it was unclear what medication he was taking regularly, where it was sourced and how his asthma was being monitored. His mother was subsequently arrested for neglect but later refused charge.

1.3. The time period covered by this LCSPR includes the period of the Covid 19 pandemic and the national lockdowns from March 2020. This context is important as many of the processes used by agencies became virtual and will have impacted on the practitioners and family. The pandemic also impacted on overall recruitment and retention in agencies and for some practitioners, access to supervision and covering for absent colleagues resulted in increased demand/higher caseloads.

1.4 The purpose of a LCSPR, as confirmed in the current statutory guidance, "Working Together to safeguard children 2018": Chapter 4 is clear that the focus is on learning for agencies, systems and practice to secure improvement and not to hold individuals or agencies to account.

2. Process/methodology for conducting the LCSPR

2.1. KSCMP recognised the criteria for undertaking a LCSPR were met and there was potential further learning to address the main finding from the Rapid Review, using David's experience as a window on the wider system. This finding identified that the lack of a coordinated multi-agency approach to the management of David's asthma, coupled with factors linked to parenting, meant this very manageable medical condition became critical. Additional findings with potential learning identified through the Rapid Review process were considered but were being addressed in other LCSPRs already underway/recently completed by KSCMP.

2.2 KSCMP had agreed that the key focus of the LCSPR would be on how learning from the experience of this child and the response of agencies to their medical condition can enable better understanding and multi-agency co-ownership by the wider system. This is to ensure that children are not only well supported with their medical needs, but emerging neglect can be identified and acted upon if it is also a feature.

2.3 In May 2023, KSCMP commissioned an Independent Reviewer, Alex Walters, an independent safeguarding consultant, experienced Partnership Chair and Serious Case Review (SCR)/LCSPR Independent Reviewer, fully independent of KSCMP and its partner agencies. The first Panel meeting was held in June 2023 and included the relevant senior leads from the statutory partners.

[1] David is a pseudonym used in this report to protect the child's identity.

2.4 The Panel agreed the scope and the Terms of Reference of the LCSPR, which widened the review's remit to consider asthma and allergy conditions. Importantly and to address the Terms of Reference it was agreed that the methodology utilised would be to focus on the systemic issue of the management and coordination of services to children with these medical conditions, to identify the potential challenges and to make recommendations for improvement.

2.5 The agreed methodology did not require management reports as the Rapid Review reports were very detailed. It was agreed the review would be undertaken in four stages. The first stage of the review involved research by the Independent Reviewer into other published SCRs/LCSPRs where children had died following asthma attacks and to consider the issues and learning identified in these reviews, to identify similarities and any progress made on the response to their recommendations.

2.6 The second stage of the review involved the Independent Reviewer identifying and considering key national research and guidance published by NHS England and NHS Improvement (NHSE/I), National Institute for Health and Care Excellence (NICE), Healthcare Safety Investigation Branch (HSIB) as well as the LONDON Healthy Partnership on best practice standards around asthma care for children.

2.7 The third stage then involved developing a survey, which was distributed via various networks to parents and to children to consider their perspectives and experiences of asthma and allergy care. There was a particular focus on the interface between primary, secondary and tertiary health providers, pharmacies and schools.

2.8 The fourth stage involved a well-attended facilitated workshop with a wide range of professionals from all the key agencies and the voluntary sector, which presented the learning from the research undertaken by the Independent Reviewer and the results from the survey. Professionals then considered a number of key issues, which identified both challenges in the system and potential improvements.

2.9 The contribution of family members is a highly important part of the review process. It was agreed that both parents would be informed of the LCSPR process and offered the opportunity to contribute by meeting with the Independent Reviewer. This was undertaken but unfortunately no response was received from either parent.

2.10 This practice review has been undertaken in a proportionate way to ensure the key learning is identified to support improvements in policy, practice and systems. It is, therefore, deliberately not detailed but provides a summary of the family and key agencies' engagement with the family.

3. Brief history/chronology of the family

3.1 David had been living with his sibling and their mother who were all White British. Another child – Child A who was the subject of a Child Arrangements Order had lived with the family, but this had broken down in late 2022. David's male parent was co-parenting but not living in the family home and had suffered with serious mental health issues from the summer of 2022.

3.2 David, sibling and child A had all been home educated since late 2021 and had reduced prior school attendance in 2020/21, due partly to the Covid pandemic. There had been one home visit by the LA EHE team in early 2022 but further attempts at contact were refused/rescheduled by Mother. Mother had apparently been previously employed within the NHS and was described by the GP surgery as a foster carer (rather than a Private Foster Carer) for

Child A, which may have reinforced the perception that Mother was a professional carer with greater professional oversight and had a professional background. Children's Social Care were not involved with the family at the time of the serious incident but there had been a Child in Need Plan in 2016 and Early Help involvement ending in 2017.

3.3 Following a hospital admission in February 2020, David "was not brought" to 9 of 14 medical appointments with the GP, the Hospital Paediatric Clinic and Hospital Allergy Clinic over a 2.5-year period. Of those 5 appointments that were attended, 4 were undertaken by telephone due initially to Covid restrictions and then at Mother's request. From August 2021, Mother rescheduled appointments with both the hospital paediatric clinic and the GP surgery for David's annual asthma reviews and this coincided with him becoming home educated. David was hospitalised in July 22 for 2 days and was not seen again by any professional in the 5 months prior to his death. The GP surgery was not aware that the Hospital Paediatric Clinic had discharged David prior to their latest hospital admission or that Mother was not routinely collecting prescriptions from the Pharmacy.

4. Learning from other published SCRs/LCSPRs

4.1. In reviewing the SCR/LCSPRs involving other child deaths as a result of asthma over the last five years, there were some clear similarities in the learning identified. The following are a summary of the key learning themes that resonated with David.

4.2 SCR published September 2022- 8-year-old male child died in 2017.

- There is a need for professionals to become more aware of the correlation between poor parental management of medication for children with chronic health conditions such as asthma, and wider childhood neglect. A reliance on parental self-disclosure may not always be best practice.
- For GPs and other medical staff, there must also be an expectation that all children with asthma have a personalised asthma action plan which includes structured education on the medications prescribed and how they should be given, how to recognise an asthma attack, when to seek help and how to prevent a relapse. This plan must be shared with families, hospital, GPs, school nurses and any other relevant professionals.
- It is essential that where children have had hospital admissions for chronic conditions there is a robust discharge plan that includes identifying if any other agencies are involved.
- There is also a need for pharmacists to have specific safeguarding training that addresses the wider safeguarding issues that by parents continuously requesting emergency medicine they may be unable to plan or meet the basic needs of their children.

4.3 LCSPR published November 2020- death of 14-year-old male child.

- There is a reliance on parental self-reporting to support the ethos of people as experts of their own health. Whilst this ethos is important there is a difficult balance to strike and there is a need for professionals to be curious to consider if there are questions around risk management.
- The communication systems between universal and acute and specialist health services did not support the lead consultant to explore what risks were being presented by the current management of his asthma.
- There were additional challenges brought by a pattern of cancelling and rescheduling appointments by father, which meant there were periods of time when he was not brought to appointments.

4.4 LCSPR published July 2020- death of a 3-year-old child.

- The parents, not the child became central to clinical decision making around the child. The child's welfare is paramount and the duty of care to the child became lost, as did authoritative practice. The child's voice was not being heard.
- 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.
- Professional practice around how a parent exercises their powers under parental responsibility and when this might cross into neglect was not considered. Nor was the impact of social class upon the relationship with health professionals. There was an unconscious bias at play.
- The absence of other categories of neglect appears to have reassured practitioners.

5. FINDINGS AND ANALYSIS

KEY PRACTICE THEMES:

5.1 To understand the current system and based on the learning from the Rapid Review Process and other LCSPRs, a facilitated workshop was held involving the following practitioners representing Health- Tertiary, Secondary Care, Primary Care and Community services, Education, Children's Social Care, Public Health and the Voluntary sector.

- Consultant Paediatrician and Kent and Medway Integrated Care Board (ICB) Designated Doctor
- Named GP, Kent and Medway ICB
- Specialist Asthma Nurse Kent Community Health NHS Foundation Trust
- Named Nurse Safeguarding Children, Kent Community Health NHS Foundation Trust
- Associate Director for Medicines, Governance and Pharmacy Education, Kent and Medway ICB
- Paediatric Asthma Nurse Specialist, Evelina London Children's Hospital
- Children's Allergy Clinical Nurse Specialist, East Kent Hospitals University Foundation Trust
- Consultant Paediatrician, Dartford and Gravesham Trust
- Senior Area Safeguarding Advisor, Education Safeguarding Service
- Helpline Manager, Allergy UK
- Public Health Specialist, Kent County Council Public Health
- Social Work Standards Officer, Kent Integrated Children's Services
- Headteacher, St Alphege Infant School and Sunbeams Nursery
- Asthma Nurse, Community Children's Asthma Team, Kent Community Health NHS Foundation Trust
- Consultant Paediatrician and Designated Doctor, Kent and Medway ICB

5.2 The focussed discussion covered the following 5 practice themes identified through David's case and Stages 1,2 and 3 of the review. The practitioners were asked to identify their views on the current challenges and then suggest opportunities for improvement. KSCMP is very grateful for the time and commitment evidenced by practitioners attending the event.

5.3 **Practice Theme One- Medical neglect** What are the signs the health issue is worsening and/or neglect is emerging? How is this responded to?

Challenges

- In discussion with practitioners at the workshop, it was clear that medical neglect, particularly at a lower level is frequently recognised by health professionals but is difficult to escalate/refer to Children's Social Care (CSC) or Early Help as consent of the parent for referral is required and the safeguarding "threshold" for support may not be met for dispensing with consent. There are frequently instances of disguised compliance by parents who appear to be engaging and it is therefore not clear-cut. This is particularly apparent if the child is not already known within the system and there are no other obvious signs of neglect. The issue of parental consent was a consistent theme. Parents are able to refuse to have Midwifery, Health Visitor involvement, to not send their child to nursery and to home educate their child if they are of school age, which has negated the involvement of school nursing.
- When there is an Asthma Action Plan in place, parental consent is needed by health practitioners to share this with the child's school. The majority of parents will consent but this is not always the case and school SENCOs cannot insist on receiving a copy from a medical professional. There is a perception that a child with a potential life-threatening medical condition could be considered a safeguarding issue to override consent, but there is concern in the system of the potential impact, and this has not been tested.
- Recognition that there is increased challenge when children are in their teenage years and may be managing their own conditions.

Proposals

- Raised awareness of medical neglect with the wider children's workforce and increased emphasis on the recognition/understanding of impact on a child particularly with chronic medical conditions which are potentially life threatening.
- Asthma and Allergy Action Plan forms to have an embedded message to reinforce the expectation they will be shared routinely with other key agencies: the GP, School, Children's Social Care as appropriate.

5.4 **Practice Theme Two- "Was Not Brought" (WNB) Policies** What is the understanding and expectation of agencies?

Challenges

- Most secondary/specialist hospitals do have "Was Not Brought" policies but the evidence from practitioners was that these policies are not clearly embedded or consistently used. Some described 3 hospital admissions for asthma would be an automatic referral to the Hospital Safeguarding Team but there are different application thresholds.
- If secondary care discharge as a result of non-attendance, the discharge letters to GP should identify next steps. GP surgeries will make every effort to engage with families and understand the reason for non-attendance and will refer to Children's Social Care if concerned. However, for David, this was affected by the assumption of the hospital clinic having the overview of care combined with a parental presentation where appointments were not cancelled but continually rescheduled, so a pattern of non-attendance is difficult to identify and can be classified in hindsight as disguised compliance.

Proposals

- Health/Education (including LA services for children electively home educated) professionals to endeavour to have direct multi-disciplinary conversations to share concerns around WNB/medical neglect through the sharing of Care Plans.

- If a Request for Support (RFS) however is made under "WNB" policy to Kent's Front Door Service (FDS), the concerns regarding potential impact are clear and in the referral.
- If No Further Action (NFA) is the outcome decision of FDS then this must be communicated to the referrer so they are aware.
- KSCMP Escalation policy to be reinforced and used by health/school professionals if concerns remain.
- Quality Assurance activity to continue to be undertaken routinely on all NFA decisions by Kent's FDS.

5.5 **Practice Theme Three- Secondary and primary/community interface** What are the plans/templates in current use for children with asthma/allergies? Who is responsible for completing them? How are they reviewed and monitored? How are they disseminated/understood?

Challenges

- There are a number of different care/action plan formats used by practitioners and there are also a number of different names used for these forms including: Asthma Management Plan; Personal Asthma Action Plan; Asthma Care Plan.
- Although the GP surgery is the lead for undertaking these annual reviews and completing the care plan, they can be undertaken/completed by the school and by specialist providers i.e., Asthma clinics.
- The recognition that GPs need to be provided with sufficient resource to ensure that there is routine checks/follow up on all communications from tertiary/specialist provision to ensure potential risk is understood.
- There is not equity of access to specialist community provision within the Kent area. In East Kent there is a community asthma team who will lead on the asthma engagement with families and the asthma care plan. This does not exist in other areas of Kent.

Proposals

- Adoption of standard Asthma and Allergy Care Plan templates and accompanying clear guidance by Kent to ensure one name and one form for asthma and allergy plans for all children. The consensus of professionals at the event was that the Asthma and Lung UK template should be used for asthma and BSACI template for allergies.[2]

- Promotion of digital copy use (Evelina Hospital are piloting this)

- The Kent and Medway ICB need to review their current commissioning strategies for asthma and allergy services to ensure there is equity of access to specialist community services for asthma and allergy conditions.

5.6 **Practice Theme Four- Engagement of wider professionals (pharmacies/schools/public health)** What oversight is there of medication being prescribed? How are schools and school nursing engaged in oversight of medication and planning?

[2] childrens-asthma-plan_may22_cc_editab BSACIAllergyActionPlan2019EpiPen-1 1.

Challenges

- The Asthma and Allergy Action Plans are not routinely shared with schools by Health practitioners without clear parental consent.
- The Asthma and Allergy Action Plans need to be written in a way that can be understood by all practitioners and is proportionate in its use of medical terminology.
- School staff do not feel confident or trained to respond to asthma/allergy conditions.
- The perceived reduction in school nursing capacity has meant services are targeted at children with the highest medical need and cannot meet the need of children with lower levels concerns.
- There is a challenge that parents may use different pharmacies to have their prescriptions dispensed and receive their children's medications, so it is difficult to pick up an overall picture of use.

Proposals

- The standardised Asthma and Allergy Action Plan templates used by practitioners to include question on educational status (to identify if child EHE) and on expected consent for information sharing within the child's network.
- KSCMP to recommend the implementation of the national training package for mainstream schools on asthma and allergy care for children recognising the different governance structures
- KSCMP to review what quality assurance systems exist in current regulation S.175 processes and in Ofsted inspections on how schools understand and manage children with asthma/allergies and how this can be enhanced to provide assurance.

5.7 **Practice Theme Five-Engagement with families**. How are families supported to ensure they understand the asthma or allergy plan/medication?

- There were 194 responses from parents and 5 from children to the KSCMP survey. 71% of responses stated that children had an asthma management plan, 76% of those said it was clear what to do in an emergency but less clear on how to prevent health episodes. 79% stated they have regular asthma reviews although the question did not ask if reviews had been offered.

- 56.8% of respondents felt the prescription of medication process worked well with 24% feeling it is effective some of the time. The survey free text responses demonstrated some excellent support for families from health practitioners and schools but also some very real challenges in understanding, communication, support and access for families to information and services.

- There was recognition of the challenges with older children who are competent to advocate for themselves and how their views and wishes are considered and they are supported.

6. National Guidance on management of asthma in children

6.1 Included in the Review methodology, the Independent Reviewer considered the national guidance around asthma care. There are numerous documents/research studies and guidance. It is known that asthma is the most common long-term condition among children with 1.1 million

children diagnosed with the condition. In 2018, more than 1,400 adults and children died from asthma attacks in England and Wales, an 8% increase compared to 2017.

6.2 **The National Review of Asthma Deaths (2014)** highlighted that children are still dying unnecessarily. The UK has the highest asthma mortality and morbidity in Europe among this demographic. The effectiveness of asthma management is particularly challenging in those patients whose care fall between hospital and general practice, where responsibility for monitoring the condition is not clearly defined.

6.3 The Review also highlighted some avoidable factors which have a role to play in three quarters of asthma-associated deaths. One of the most important factors that the NICE guidelines highlight is ensuring that there is an appropriate clinical review carried out by primary care, when a child's asthma becomes problematic, or within two working days of receiving treatment in hospital or via the out of hour's service for an acute exacerbation.

NHSE/I Guidance -updated September 2021

6.4 NHS England and Improvement (NHSE/I) published the "**National Bundle of Care**" for children and young people with asthma with clear expected standards. Phase 1 of this national plan seeks to provide support for the new Integrated Care Systems (ICS) in delivering high quality asthma care. These standards incorporated the recommendations from the HSIB investigation report of May 2021 following the near fatal death of a 5-year-old-child.

6.5 The following standards are particularly relevant to this Review:

Organisation of Care (OC) standards

"Lack of leadership, accountability of pathways adversely impacts CYP with suspected or diagnosed asthma. The implementation of Integrated Care Systems provides the NHS with a real opportunity to improve the outcomes for CYP with suspected or diagnosed asthma by integrating care across different organisations and settings. In addition to the specific standards around each element of the patient journey, the National Bundle of Care for CYP with Asthma sets out the following standards for organisations:

OC 1- All organisations/services; including Primary Care Networks (PCN), secondary and tertiary services as well as places of education, must have a named lead with asthma expertise who is responsible and accountable for the dissemination and implementation of asthma standards and good asthma practice which includes CYP.
OC 2- Each Integrated Care System (ICS) should have a paediatric asthma network with an identified lead in paediatric asthma who interfaces with place-based systems and PCNs, secondary care, pharmacy, schools, community and severe asthma services. This network should integrate and transition with adult services.
OC 3 - Each ICS should develop and maintain a pathway of referral and ensure responsibilities between primary, secondary and tertiary care. This should include safeguarding at all levels of care.

Effective Preventative Medicine (EPM) standards

EPM 5 – All CYP with asthma should have a Personalised Asthma Action Plan that is developed collaboratively with them and their significant others. ICS' should ensure these tools are made available to healthcare professionals working with CYP with asthma.

EPM 6 - All CYP with asthma should undergo a structured review at least annually. Adherence should be discussed as part of this review and inhaler technique should be assessed and where necessary extra training provided. Healthcare professionals should also signpost CYP to useful inhaler technique resources. ICS' should ensure these tools are made available to healthcare professionals working with CYP with asthma. The review should include an assessment of risk and severity and recent asthma control. Where loss of control is identified, immediate action is required. This should include escalation of responsibility, treatment changes, conversations about adherence and arrangements for follow-up.

Healthy London Partnership Asthma Standards –December 2021

6.6 Healthy London Partnership (HLP) were commissioned by NHSE/I to develop London asthma standards for children. Development of these standards was informed through an extensive literature review and included the NHSE/I Bundle of Care standards and wide engagement including primary and secondary care clinicians, managers, and commissioners from across London, views from professional bodies, and voluntary sector organisations.

6.7 This resulted in the development 49 standards covering the whole system including schools and pharmacies. These standards are a comprehensive, clear document which sets out the evidence to achieve them for ICBs.

6.8 Standard 23 sets out "Clear effective partnership arrangements are in place between health, education and local authorities for management of CYP with asthma within primary and secondary schools. Appropriately trained school nurses should play a key role. This includes the implementation of government policy on emergency inhalers and early years settings such as children's centres having access to education programmes for wheezers. This should include after school care/clubs that take place on school sites. Education about asthma should also be provided."

6.9 The standards cover the following ten areas of focus:

- Organisation of Care
- Patient and Family Support
- Diagnosis and chronic care
- Schools
- Acute Care
- Integration and Care coordination
- Discharge and Care Planning
- Transition
- Effective and consistent prescribing
- Workforce education and training

7. Conclusion and Recommendations

7.1 David sadly died as a result of an asthma attack and had not been seen by a Health Professional for the preceding 5 months following a hospital admission. This was due to cancelled appointments by Mother at Paediatric Clinics and the GP surgery for the annual asthma review. David was home educated and therefore had not been seen at school over this period.

7.2 It was proposed and agreed through the Rapid Review process that this review focus specifically on the learning from David's experience to examine more widely how effective the

system is in managing the potentially life threatening medical conditions in an integrated multi-disciplinary manner and not to focus on the child's EHE status.

7.3 This Review concludes with recommendations to the KSCMP and partner agencies, which build on the learning from the research phase and the robust process of practitioner discussion.

Theme One-Medical neglect

1. KSCMP reinforce the need for the current KSCMP Neglect Strategy and associated training to emphasise the impact of medical neglect relating to chronic, potentially life threatening conditions on children with the wider children's workforce.

2. Kent and Medway ICB support the adoption of the standard templates for asthma and allergy plans by Asthma and Lung UK and BASCI and provide clear guidance on expectations and responsibilities and ensure there is one name and one form for Asthma and Allergy Plans for all children.

3. Kent and Medway ICB to support the approach that the guidance incorporates the expectation in principle that asthma/allergy management plans will be shared with other key agencies to support the management of the child's asthma/allergy.

4. Health and Education professionals to be encouraged to explain/discuss the expectation with parents that asthma/allergy care plans are shared with other key professionals and the impact of any subsequent refusal of consent on the child is considered.

5. Public Health consider the remit of the school nursing service including consideration of this service being available for children with chronic medical conditions who become Electively Home Educated.

Theme Two- Was Not Brought Policies

6. Kent and Medway ICB facilitate and support all health providers, including GP practices, to routinely review and audit their "Was not Brought" policies to measure compliance and effectiveness and report to the ICB and to KSCMP.

7. Kent FDS and Health agencies undertake an audit of referrals for support from health practitioners under "Was not Brought" procedures to assess the quality of the referral and the response by FDS and report to KSCMP.

8. Kent and Medway ICB review the actions undertaken by the GP surgery in response to the learning from David in relation to improving the identification and monitoring of children with asthma/allergies who are "Was Not Brought" and consider how this learning is shared more widely within Primary Care Networks.

9. KSCMP ensure that the Kent professional escalation procedure is understood and used by all agencies and is routinely monitored.

Theme Three- Secondary/Primary/Community interface

10. Kent and Medway ICB update KSCMP on work already undertaken under the CYP Transformation programme and specifically undertake a benchmarking exercise and develop an Action Plan in response to both the NHSE/I "Bundle of Care" standards and the London Healthy Partnership standards for the management of childhood asthma.

11. Kent and Medway ICB to work with the GP Safeguarding Forums to ensure Asthma Management Pathways are discussed and the learning for GP practices is widely disseminated.

12. Kent and Medway ICB review their current commissioning arrangements for community specialist asthma care services to address concerns that this is not equitable to the wider population of children in Kent and report to KSCMP.

Theme Four – Wider engagement of professionals

13 KSCMP highlight to schools the national training package for mainstream schools on asthma and allergy care for children to support and manage risk to children with life threatening conditions.

14. Kent Local Authority review how the local school arrangements to support and manage risk around children with life threatening medical conditions are quality assured through regulation/S.175 processes and Ofsted inspections and if a national recommendation is appropriate.

15. KSCMP ensure the learning from this Review is shared with the wider school sector through the Education Safeguarding sub-group.

16. Kent and Medway ICB encourage pharmacist's engagement in single and multi-agency safeguarding training provision and provide any additional support if required.

17. KSCMP request Asthma and Lung UK and BSACI consider the inclusion within the Asthma and Allergy Plan templates a question relating to the educational status of the child to support identification of children who are EHE.

18. KSCMP to consider any additional learning from the National Child Mortality Database thematic analysis on deaths caused by asthma and anaphylaxis to be undertaken in 2024.

Theme Five- Engagement of Family

19. KSCMP consider how the views and experience of children and their parents routinely inform the development of service provision within all agencies and how they are used in established quality assurance activity.

Alex Walters – 21/2/2024