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Dear Dr ~~Radcliffe~~ Shirley

Re: Regulation 28 Report to Prevent Future Deaths - Michael URIELY (died 25.08.15)

Thank you for your Regulation 28 Report which was received on Wednesday 29 March 2017 following the inquest into the sad death of Michael Uriely. I would like to express my deep sympathy to Michael's family.

Asthma deaths in children and young people are rare and have reduced substantially over the years. Nonetheless, each individual case is a tragic loss and often associated with preventable factors. In this particular case, it appears Michael's condition was not managed in accordance with the published asthma guidelines, specifically to treat asthma as a as a long term condition rather than a series of episodic incidents. Sadly this case has many similarities to the death of Tamara Mills as you have also noted in your report. We will endeavour to do all we can to prevent any further asthma related death, especially in children and young people, and to ensure that the NHS appropriately manages asthma care across England.

As you are aware, most asthma care is delivered in Primary Care by General Practitioners (GPs). Most Clinical Commissioning Groups (CCGs) have been delegated the exercise of primary medical services by NHS England so that they can commission care according to the need of their population. GPs and other Doctors who treat asthma have a professional responsibility to have regard to set clinical guidelines and to refer to a respiratory specialist where deemed appropriate.

Apart from the recommendations of the 2014 National Review of Asthma Deaths, there are established evidence-based asthma guidelines from BTS/ SIGN[1] which have recently been updated. These are promoted to primary care through the Primary Care Respiratory Society (PCRS). NICE has produced a Quality Standard

[1] https://www.brit-thoracic.org.uk/standards-of-care/guidelines/btssign-british-guideline-on-the-management-of-asthma/

(QS25[2]) and is in the process of developing guidelines for the Diagnosis and Monitoring of Asthma and also for the Management of Stable Asthma in Adults and Children. It is expected that these will be published later this year.

NHS England is actively working to improve asthma care in children. We have listed below some of the on-going key areas of work in response to the matters of concern listed in your report and to also serve as an update on the actions we set out in response to the death of Tamara Mills.

1. In 2014 NHS England set up **National Paediatric Asthma Collaborative** (NPAC)[3], partly in response to NRAD, to bring together a wide range of clinicians, commissioners and voluntary sector organisations to work together on improving care and support for children with asthma. It was successful in reviewing existing services and their effectiveness, highlighting and sharing good practice, and outlining deficiencies at a national level. This work has been beneficial to a wide range of subsequent workstreams listed below.

2. NHS England commissioned Health Quality Improvement Partnership (HQIP) to scope a national audit on asthma. As a result, HQIP have taken forward the **National Asthma Audit Development Project**[4], delivered by the Royal College of Physicians. This is a study to assess whether or not a National Asthma Audit would be feasible, what could be included and how it could be organised. There are some pre-set aims for the feasibility study, one of which is to ensure the scope considers both children and adults.

3. The development of the e-learning pack, **E-asthma**[5] was commissioned from Education for Health via Health Education England (HEE) and NHS England/ NPAC. This is an interactive asthma education resource for healthcare professionals of all disciplines. It aims to help to improve the diagnosis and management of asthma as a long-term condition for both children and adults. It is an entry level program which is free for all healthcare professionals and has been designed so that it can be audited by a health care provider, such as a hospital or CCG.

4. NHS England has supported the development of a **severe paediatric asthma database** to collect vital information that will help support improvements in severe asthma care in the future. This has helped develop the Paediatric Severe Asthma CQUIN.

5. Launched in December 2016 **the Paediatric Severe Asthma CQUIN** was designed to support services at a tertiary level and to mirror the adult provision of care that had been achieved through central commissioning. The CQUIN is currently being trialled in London across the 5 larger secondary and tertiary care units as well as several other tertiary centres and managed by Dr Louise Fleming at the Royal Brompton Hospital.

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[2] https://www.nice.org.uk/guidance/qs25

[3] http://www.respiratoryfutures.org.uk/programmes/national-paediatric-asthma-collaborative/

[4] https://www.rcplondon.ac.uk/projects/national-asthma-audit-development-project

[5] http://learning.wm.hee.nhs.uk/node/163

6. We have developed a **Quality Payments Scheme for community pharmacy**[6] to encourage community pharmacists to systematically identify patients who receive more than six bronchodilator inhalers in six months without any corticosteroid inhaler and refer them for asthma review. There are over 11,600 pharmacies in England and we will be evaluating this scheme to look at the impact. This element of the Quality Payments scheme was incorporated as a direct result of the NRAD recommendations.

7. We continue to explore with clinicians how a **Best Practice Tariff** would help incentivise the provision of best practice care for children with asthma. A best practice tariff (BPT) is where, rather than setting the price for a service at the average price, we link the payment a provider receives to the achievement of best clinical practice. Our initial assessment is that the information needed to enable us to link payment to the characteristics of best clinical practice is not currently collected centrally. However, we are still pursuing the possibility of a BPT and working with NHS Digital to ensure we can collect the appropriate data.

8. Through the **NHS RightCare**[7] programme we have included an indicator on emergency admissions to hospital for children with asthma in the asthma pathway within the 'Where to Look pack'. This pack is a comprehensive intelligence data pack which aims to give CCGs and local health economies practical support in where to focus their efforts in order to improve care and reduce unwarranted variation. As part of this work we are actively supporting and working with 38 CCGs across the country directly on respiratory conditions some of which are asthma specific.

Sharing and coordinating care records for all illnesses within a complex NHS has always been a challenge. As the NHS responds to these challenges we are finding more and more A&E departments can access primary care records. To change and improve asthma care across organisations, NHS England is also working in partnership with CCGs in London to transform care via the Healthy London Partnership Collaborative (HLP)[8]. This collaborative brings together health, social care, local government and other partners to transform care across the capital. Specifically for asthma the following work has been undertaken by HLP;

- The development of **London Paediatric Asthma Standards**[9] was published in 2015 and sets out a minimum standard of asthma care for children and young people across London. They have been developed around 11 key areas including primary, secondary and tertiary care, pharmacy, schools and transition.

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[6] https://www.england.nhs.uk/commissioning/primary-care-comm/pharmacy/framework-1618/pqp/.
[7] https://www.england.nhs.uk/rightcare/
[8] https://www.myhealth.london.nhs.uk/healthy-london-partnership
[9] http://www.londonscn.nhs.uk/wp-content/uploads/2015/07/cyp-asthma-stds-062015.pdf –

9. **The London paediatric asthma toolkit**[10] has been created to support healthcare professionals, schools, parents, carers and children and young people to improve care across the system. It advises on access, evidence, defines roles and responsibilities, techniques, plans and pathways. It also includes an online learning hub for pharmacists' to assess support including actively promoting good inhaler techniques, which can support direct referral from primary care into community pharmacy and to enable care reviews. The tool has been endorsed by the Royal College of General Practitioners (RCGP), Royal College of Paediatrics Child Health (RCPCH) and by Asthma UK.

10. **A public awareness campaign**. As you have noted in your report, clearer messaging on the management of asthma to patients, parents, carers and health professionals is vital. This need was also identified in the Healthy London Partnerships (HLP) work. They are currently working on a simple public awareness campaign. This will be trailed and assessed in London with the view to roll this out national if successful.

11. The development of a hand held **patient app.** Although still in the design and development stage, this app may enhance the existing system and allow care records to be shared more easily.

In addition, within your letter you also ask about the possibility of paediatric asthma death being classified as a 'Never Event'. This was reviewed by the National Clinical Lead for children and young people and by clinical advisers with in the HLPs. They concluded that in its strictest definition, not all asthma deaths are preventable and therefore 'Never Event' status would be medically incorrect. For the NHS a 'Never Event' relates to serious incidents that are wholly preventable as guidance or safety recommendations provide strong systemic protective barriers which are available at a national level and should have been implemented by all healthcare providers. Never Events include incidents such as; wrong site surgery, retained instrument post operation or, for example, wrong route administration of chemotherapy.

However, we strongly support the principle that each paediatric asthma death should be a Serious Incident and have a multi-level cross system review. NHS England has undertaken a review of children and young people deaths in London as a result of asthma. This is a collaborative piece of work with the Child Death Overview Panels (CDOP)[11] - which bring together a wide range of local bodies such as local authorities, the police, social care, health with the purpose of reviewing each child death - to produce a systematic template for asthma deaths (akin to an asthma death proforma), to provide clinical expertise to investigate all asthma deaths in future. Our aim is that the learning from this review will be shared and implemented across the country.

With regards to GP training, NHS England is unable to amend the content of the GP training curricula, but we will relay these concerns to Health Education England (HEE) to ensure that professional routes are used to advise GPs and other doctors

[10] https://www.myhealth.london.nhs.uk/healthy-london/children-and-young-people/london-asthma-toolkit

[11] https://www.gov.uk/government/publications/working-together-to-safeguard-children--2

delivering against Asthma care guidelines. We will also advise CCGs to make all GPs aware of the free E-asthmas training program as mentioned above and any asthma related practice software add-ons such as the PRIMIS Asthma Care Quality Improvement Tool[12] to alert them to patients who might be at risk from over prescription of bronchodilators.

NHS England will continue do more to ensure that CCGs and GPs are aware of the clinical and quality guidelines around asthma care especially for children and young people. To support this we will:

1. **Share learning and support tools** developed by the Healthy London Partnership collaborative and others, such as the E-asthma toolkit, standards and clearer messaging. These will be shared across the whole of the NHS commissioning landscape to ensure CCGs take active measures in asthma management.

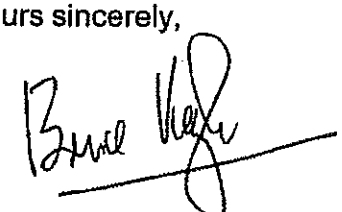
2. **Communicate to CCGs & GPs** on using the most up to date asthma guidelines and recommendations from the NRAD to aid the development of appropriate asthma patient care pathways. We will also advise CCGs to encourage GPs to take up available free asthma risk alert software.

3. **Continue to explore commissioning mechanisms**, such as the implementing a Best Practice Tariff, CQUIN development and RightCare programme initiatives to better incentivise improved commissioning of asthma care.

I note that your Regulation 28 report was also issued to HEE and to NICE. I shall liaise with both organisations in relation to implementing asthma guidelines so that the NHS minimises the risk of future deaths in this area of healthcare. I will also contact the NHS Trust in question to understand better their lessons learnt and ensure that this shared regionally.

Thank you for bringing this important patient safety issue to my attention and please do not hesitate to contact me should you need any further information.

Yours sincerely,



Professor Sir Bruce Keogh KBE, MD, DSc, FRCS, FRCP
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[12] http://www.nottingham.ac.uk/primis/tools-audits/tools-audits/asthma.aspx