Classification: Official





**Stage One: Warning** *Risk of severe harm or death when desmopressin is omitted or delayed in patients with cranial diabetes insipidus* 8 February 2016

Alert reference number: NHS/PSA/W/2016/001 Alert stage: One - Warning

Cranial diabetes insipidus is a rare disorder of the pituitary gland characterised by an inability to produce antidiuretic hormone (ADH) [1]. This results in the production of large volumes of dilute urine. Cranial diabetes insipidus is the most common type of diabetes insipidus. It can be caused by damage to the hypothalamus or pituitary gland, for example, after an infection, operation, brain tumour or head injury. Left untreated, patients with cranial diabetes insipidus will develop life-threatening dehydration and hypernatraemia. Desmopressin is a synthetic form of ADH used to treat cranial diabetes insipidus and is considered a life sustaining medication in this situation. In the treatment of cranial diabetes insipidus, desmopressin is most commonly administered as an intranasal spray or oral tablets, but may also be given as an injection, which is useful in the treatment of acutely unwell or fasting patients. It is also available in sub-lingual tablet and oral liquid formulations.

The dose of desmopressin is different depending on the indication for use and formulation [2]. While 56 reported incidents to the National Reporting and Learning System (NRLS) identified dosing errors with resulting patient harm, NHS England is aware of four incidents in the past seven years where omission of desmopressin has resulted in severe dehydration and death. A further 76 incidents to the NRLS described omission or delay that had been detected and acted on before the patient became critically ill. An example incident reads:

This patient was admitted and had their drug chart written-up. The patient did not receive desmopressin for 48 hours and became profoundly hypernatraemic as a result. The patient is currently life-threateningly ill. (Patient subsequently died, reported harm death).

The main themes from reported incidents of desmopressin omission, confirmed by a short survey of nursing staff, included: a lack of awareness of the critical nature of desmopressin amongst medical, pharmacy and nursing staff; and poor availability of desmopressin within inpatient clinical areas where it was often not kept as a stock item. Other common reasons for desmopressin omission included nil-by-mouth status and patient refusal, which may be related to acute illness. There was also an assumption that desmopressin was a relatively low priority medication; in particular where the nasal spray formulation was prescribed as most other nasal sprays are used to treat minor symptoms (including where desmopressin is used for the treatment of nocturia). As the symptoms of omitted desmopressin can include confusion, agitation, hostile and un-cooperative behaviour, patients who would usually be aware of how vital their medication was were not always able to emphasise this to staff.

In many organisations, desmopressin, when indicated for the treatment of cranial diabetes insipidus, was not classed or recognised as a critical medicine as understood in the National Patient Safety Agency Rapid Response Report, NPSA/2010/RRR009 [3]. For organisations with alerts linked to electronic prescribing, warnings of the risks of desmopressin omission may not be in place.

# Actions

### Who:

All organisations providing NHS-funded care for treatment of cranial diabetes insipidus

## When:

As soon as possible and by no later than 21 March 2016

Identify if the omission of desmopressin for the treatment of cranial diabetes insipidus has or could occur in your organisation.

Consider if immediate action needs to be taken locally, and ensure that an action plan is underway if required, to reduce the risk of further incidents occurring.



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Circulate this alert to all relevant medical, nursing, pharmacy and other staff.

Share any learning from local investigations or locally developed good practice resources by emailing patientsafety.enquiries@ nhs.net

See page 2 for technical notes and references.

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### Technical notes

### NRLS search dates and terms

A SAS search was performed on 6/10/2015 of the NRLS for reported medication patient safety incidents occurring between 1/1/2009 and 1/10/2015 inclusive containing the terms 'desmo' or 'ddavp'.

The search returned 471 incidents. All harm incidents (94) and a search of no harm undertaken with key terms to identify further incidents (n=200) were thematically reviewed. Omission (76) and wrong dose (56) were the most common themes identified. An additional two fatal incidents were identified through inquest reports and direct information from the trust where they had occurred.

Five Medication Safety Officers in different acute trusts undertook an opportunistic survey of 25 ward-based registered nurses in October 2015. Apart from nurses working in specialist brain injury units, none were aware that desmopressin was a critical medication, and some were not aware that diabetes insipidus was a different condition from diabetes mellitus.

#### Stakeholder engagement

- Medical Specialties Patient Safety Expert Group
- Patient Safety Steering Group
- Medication Safety Officer Network

For details of the membership of the NHS England patient safety expert groups and steering group see http://www.england.nhs.uk/ourwork/patientsafety/patient-safety-groups/

#### References

- 1. NHS Choices, diabetes insipidus: http://www.nhs.uk/Conditions/Diabetes-insipidus/Pages/introduction.aspx
- 2. Summary of Product Characteristics http://www.mhra.gov.uk/spc-pil/?ldcService=SS\_GET\_ PAGE&nodeld=%3C%25%3D+nodeld+%25%3E&searchFiled=desmopressin&SubmitSearch=Search
- 3. National Patient Safety Agency. Reducing harm from omitted and delayed medicines in hospital. NPSA/2010/ RRR009 24 Feb 2010 http://www.nrls.npsa.nhs.uk/alerts/?entryid45=66720