Template for Hypoadrenalism Stakeholder subgroup 2 discussions **Date: 05/01/22 Time: 10am – 1pm** **City University of London, The University of Birmingham, Addison's Disease Self Help Group, Sheffield Teaching Hospitals, Leeds Teaching Hospitals NHS Trust**	
Guideline Title Hypoadrenalism: acute and long-term management Adrenal insufficiency is the more usual term. - NHSE/I and in the related NICE guidance. Should Hypoadrenalism be changed to Adrenal insufficiency?	SHs agree that the term 'hypoadrenalism' is not really used in clinical practice. All guidelines currently published refer to Adrenal insufficiency. They suggested the title be changed to Adrenal insufficiency: acute and long-term management.

3.1 Population:
3.1.1 Groups that will be covered:
 	
• Babies, children, young people and adults with suspected and diagnosed hypoadrenalism.
 	
Specific consideration will be given to babies and children.
	Is the population appropriate?
	
	• Are there any specific subgroups that have not been mentioned? The group's suggestions are listed below:
	
	  • Perhaps separate Preterm and term infants. Neonates would present very non-specifically. Any differences may need to be addressed, identified in this guideline and links provided to other existing NICE guidelines where possible.
	
	  • Young adults around transition. This population will be experiencing lots of physiological changes and coming to terms with what self-management entails.
	
	  • Learning difficulties, special needs, cognitive difficulties. It was thought that groups who cannot communicate, may be covered in equalities consideration, but there are specific additional carer needs for these groups.
	
	  • Women going into menopause. The group discussed the significant changes patients may be undergoing at this time in their lives. Lots of different symptoms, changes in cortisol levels, patients are muddling through so addressing this in this guideline may be timely and very useful. Group aware that there may not be much evidence in this area, but it is an issue commonly raised by patients. This is a good opportunity to develop and provide guidelines for these patients. Existing guidelines thought to be quite superficial.

	• Pregnancy: It was suggested that this should be edited to state pregnancy and intrapartum care. During discussions it was mentioned that that adrenal deficiency in pregnancy may be addressed in other NICE guidelines. • End of life care patients. Ethical dilemmas related to management of adrenal deficiency.
3.3.1 Key clinical issues that will be covered: 1 Information and support • for people with suspected and diagnosed hypoadrenalism (and their families and carers)	These are the key areas of clinical management that we propose covering in the guideline. Do you think this is appropriate, acknowledging we must prioritise areas for inclusion? **Information and support** To include information and support for prevention of adrenal crisis and for emergency care of adrenal crisis. Information on steroids ? • The group suggested that this section should include information for carers of people with cognitive/communication problems. Other suggestions included: • Signposting people and their carers to patient support groups and peer group. • Providing refresher education once per year as needed/ state what it entails. Education to avoid adrenal crisis. • Addressing pre-hospital care. Including: Hospitals, Admissions, Dentists, Ambulance. • Providing guidance to clinicians on what advice to give patient after someone has had a crisis. • Making the most of your appointments/patient-initiated follow ups.
2 Initial identification and referral for further investigation of suspected hypoadrenalism	**Initial identification and referral for further investigation of suspected hypoadrenalism** - Risk factors, signs and symptoms - What tests if any should be done before referral for diagnosis ? • More about identifying risk of adrenal insufficiency.
Managing hypoadrenalism • Adrenal crisis o identification of adrenal crisis o emergency management • Pharmacological treatment of primary adrenal insufficiency, and secondary and tertiary adrenal insufficiency • Management of intercurrent illness and periods of stress:	**Managing hypoadrenalism** Not just pharmacological also medical care , so questions are around strategies and not just pharmacological treatment. • The group agreed that a definition of adrenal crisis is needed. Currently there is too much variance. Information on Sick-day rules and how this is affected by adrenal crisis would be useful for patients and medics. Information for patients on when they need to be tested and helping them understanding blood pressure and what this means for levels of severity. • The group mentioned opioid induced adrenal insufficiency and acknowledged that this needs to be addressed but there is currently no data though a common issue.

○ physiological stressors, including minor (for example colds) and major illnesses (for example, severe infection, cardiac events) ○ planned and emergency invasive procedures ○ intrapartum care ○ psychological stressors	• Weaning that results in adrenal insufficiency. This was thought to be a significant problem in clinical practice and the most common reason for adrenal insufficiency. Supporting patients and helping them to deal with partial adrenal insufficiency. It was noted that there are patients on steroids for other conditions and this further complicates things. • Day to day management: considered to be covered by pharmacological treatments. The group thought this section should address: ○ sports/exercise ○ activities of daily living ○ night shift work ○ Ramadan ○ jet lag and travelling. • The group thought that a management guide was needed for patients which covers: ○ What to do once stabilised after having had a crisis. ○ When they need to adjust their medication dosing, and generally getting the dosing right. ○ Available technology that may assist with monitoring, including wearable tech that could help patient self-management (cortisol monitors). May not be enough robust evidence on this area. • Physiological stressors (include sports, competitive sports, consider the impact around drug testing) • Psychological stressors (include exams, PTSD) • Pharmacological treatment to cover: ○ Weight adjusted regimes for children/dosing in different age groups. Perhaps body-surface ranges? ○ Route of administration – oral/regular and slow release. ○ Indications for when other routes of administration should be considered, e.g., modified release should be considered. ○ Pumps not used in NHS. Used in private practice and in some research. Opportunity to look at this. Small number of patients. Guideline may be an opportunity to look at this. ○ Length of prescription. Pharmacy/GP guidance needed. To maybe cover intercurrent illness as a minimum. But not too much detail. Important as patient not able to access drug to cover sick days. • Emergency treatments were discussed, and group suggested the following: ○ Provision of an emergency kit. This could be covered under prehospital management. The guideline could address what the kit contains, where they can access the equipment. Access to syringes via pharmacies (the group were unaware if there is currently a policy in place for accessing this). They were unaware of the availability of evidence around emergency injections.

Ongoing care and monitoring • The frequency and content of monitoring of hypoadrenalism	**Ongoing care and monitoring** End of life care, deprescribing ? • Concerns expressed around: o Multimorbid patients: overlapping conditions. Diabetes, gastro conditions. (patients with difficulty absorbing). o Diabetes: adrenal crisis could be quite technical to manage. o Timeliness of pharma management. Self-management, timing of doses on hospital ward. Issues around empowering the patient. o Absorption issues of hydro cortisol. o Models of care – at what point do you refer for psychological support. Signposting perhaps to other guidelines? o Fatigue and brain fog. Patients think they have an invisible disability and that this is not recognised and acknowledge by others.
3.3.2 Key clinical issues that will not be covered: 1 Adrenal fatigue 2 Diagnosis of hypoadrenalism 3 Diagnosis, management and monitoring of underlying medical conditions that causes hypoadrenalism 4 Steroid weaning	No comments.
Further Questions:	
1. Are there any critical **clinical** issues that have been missed from the Scope that will make a difference to patient care?	
The following areas were identified by the group as important: • Psychological stressors: suggestion to include relationship between the emotional stress and Addison's disease. • PTSD from adrenal crisis. • Referral to Psychological treatment. • Patient education: patients facing no diagnosis but have fallen into adrenal crisis. • Of note, that psychological stressors could be affecting the effectiveness of medication and treatment.	
2. Are there any areas currently in the Scope that are **irrelevant** and should be deleted?	
None.	
3. Are there areas of **diverse or unsafe practice** or uncertainty that require address?	
There was thought to be diverse practice related to the following: • The use of electrolyte tests, and understanding how small drops in these levels could affect how patients feel. But group comments noted that this would be difficult to manage and generalise. • Salt replacement. It was thought that there may be confusion in medical profession and patients. Thought that this may come under monitoring and pharmacological support. Perhaps highlight differences for monitoring purposes. • Work adjustments:	

• Vaccinations are a grey area, unclear what the guidance is for patients. Inconsistent care provided.	
4. Which area of the scope is likely to have the most marked or biggest health implications for patients?	
The group mentioned patient information and support.	
5. Which practices will have the most marked/**biggest cost** implications for the NHS?	
No comment.	
6. Are there any **new practices** that might **save the NHS money** compared to existing practice?	
The following was highlighted in earlier discussions: • The use of wearable technology for monitoring cortisol levels etc.	
7. If you had to delete (or de prioritise) two areas from the Scope what would they be?	
No comments.	
8. As a group, if you had to rank the issues in the Scope in order of importance what would be your areas be?	
No comments.	
9. What are the top 5 outcomes? (scope currently has: - Mortality - Health related quality of life - Complications of hypoadrenalism - Fatigue ? - Adequacy of replacement steroid doses (how is this measured?) - Adrenal crisis - Complications of adrenal crisis - Treatment related adverse events No changes from the group.	
10. Any comments on guideline committee membership? 1. Patient Member (x2 minimum) 2. General practitionerx1 3. Endocrine Clinical Nurse Specialist (adult and paediatric) 4. Consultant Endocrinologist x1 5. Consultant Emergency medicine physician x1 6. Consultant Endocrinologist Paediatrician x1 7. General Paediatrician consultant x1 8. Pharmacist x2 community and secondary care <u>Other/Cooptees:</u> - Prehospital practitioner /paramedic - Obstetrician - Anaesthetist	The group suggested the addition of a school nurse to the list of cooptees.

- Dentist - General medical consultant x1 with an interest in adrenal insufficiency/non specialist	
11. Are there any areas that you think should be included for the purposes of the quality standard? Are there any service delivery or service configuration issues that you think are important?	
None	
12. Other issues raised during subgroup discussion for noting:	
None	
EIA discussion – refer to document	
The group suggested that people with cognitive difficulties/communication difficulties/dementia should be added as an equality consideration. .	