NICE National Institute for Health and Care Excellence

Adrenal insufficiency: acute and long-term management

Consultation on draft scope
Stakeholder comments table

01/02/2022 to 01/03/2022

Stakeholder	Page no.	Line no.	Comments	Developer's response
British Society of Paediatric Endocrinology and Diabetes	001	008	Inadequate corticotrophin releasing hormone production - this could be clearer	Thank you for your comment. We have used this as it is the widely used description of tertiary adrenal insufficiency and is sufficient for this introductory section of the scope
British Society of Paediatric Endocrinology and Diabetes	001	014	Addison's is the not the most common in infants/children. Could add in Congenital Adrenal Hyperplasia here?	Thank you for your comment. Edited as suggested.
Sheffield Teaching Hospitals NHS Foundation Trust	001	014	Could consider adding that the commonest cause of adrenal insufficiency in children is congenital adrenal hyperplasia?	Thank you for your comment. Edited as suggested.
Diurnal Ltd	001	014	We feel it would be helpful to clarify that congenital adrenal hyperplasia (CAH) is in scope as it is the most common cause of adrenal insufficiency in the paediatric population and is a challenging condition to manage throughout life.	Thank you for your comment. Edited as suggested.
British Society of Paediatric Endocrinology and Diabetes	001	015	1. A much more common cause of secondary AI is prolonged steroid use and could be added here. 2. Mentioned line 18 but maybe better to have as separate heading 3. The term 'tertiary AI' are not really used in the context of AI	Thank you for your comment. We have added a statement to say exogenous steroids are a common cause of tertiary adrenal insufficiency Thank you for your comment. We have used this term as it is used in the research literature and by health professionals.
Sheffield Teaching Hospitals NHS Foundation Trust	001	021	Could consider opioids as a cause of tertiary adrenal insufficiency?	Thank you for your comment. We have not included all causes of adrenal insufficiency but have added now a section on drug causes
Addison's Disease Self Help Group	001	022	We welcome the addition of text that highlights the likelihood of effects on daily living	Thank you for your comment.
Society for Endocrinology	002	003	(and mineralocorticoid preparations in cases of primary adrenal insufficiency)	Thank you for your comment. Edited as suggested.

Adrenal insufficiency: acute and long-term management

Consultation on draft scope
Stakeholder comments table

01/02/2022 to 01/03/2022

Stakeholder	Page no.	Line no.	Comments	Developer's response
British Society of Paediatric Endocrinology and Diabetes	002	006	1) This intramuscular dose does not apply to all (children will have lower doses). Could just leave it as IM hydrocortisone needs to be given, 2) Generally treatment is not as easy as stated and not necessary at this stage other than to say needs to be carefully thought through as part of review.	Thank you for your comment. We have removed dose and left in IV and IM. This introductory text explains the main principle of treatment. The complexities will be covered by the key area 4. Managing adrenal insufficiency.
Society for Endocrinology	002	007	crystalloid fluid (suggest changing to: adequate intravenous fluid hydration with crystalloid)	Thank you for your comment. Edited as suggested.
Addison's Disease Self Help Group	002	008	We welcome the text that highlights the role of medication in maintaining a good quality of life	Thank you for your comment.
City, University of London	002	008 – 009	It should also be added here that although small numbers of people die each year from adrenal crisis, the prevalence of potentially preventable hospital admissions due to adrenal crisis is significant with 1 in 6 patients experiencing at least one hospital admission per year.	Thank you for your comment. We agree with your comment and the prevention of adrenal crisis through the provision of information and support, effective routine management and preventing adrenal crisis during periods of physiological and psychological stress are included in the scope.
British Society of Paediatric Endocrinology and Diabetes	002	011	1) NHS steroid emergency card. The link does not link to the actual card. 2) Card needs a lot of work as fluid recommendation for adults is not safe without knowing what plasma sodium is	Thank you for your comment. We have amended the link. Corrections to the steroid emergency card is not within NICE's remit.
Society for Endocrinology	002	012	prompt and appropriate	Thank you for your comment. Edited as suggested.
City, University of London	002	017 – 018	Self-management should also be added here, i.e. to enable active engagement of patients in their self-management by supporting them with relevant and accessible information and resources.	Thank you for your comment. Self-management is included in section 3.3.1
NHS England and Improvement	003	001	We welcome the information and support guidance for people suspected/diagnosed with adrenal insufficiency	Thank you for your comment.

Comments received in the course of consultations carried out by NICE are published in the interests of openness and transparency, and to promote understanding of how recommendations are developed. The comments are published as a record of the submissions that NICE has received, and are not endorsed by NICE, its officers or advisory committees.

Adrenal insufficiency: acute and long-term management

Consultation on draft scope
Stakeholder comments table

01/02/2022 to 01/03/2022

Stakeholder	Page no.	Line no.	Comments	Developer's response
City, University of London	003	002 – 007	The link "an equality impact assessment" is unfortunately not active. Another inequality that may be relevant to this guideline is variable access to specialist services for patients with adrenal insufficiency, where some patients receive care in highly specialist tertiary centres and others are managed by their GP. There is evidence, though limited, to show the poor level of understanding of this condition by non-endocrine specialists.	Thank you for your comment. We are sorry you were unable to access the equality impact assessment. We have added where a person lives in relation to specialist services to the equality impact assessment. We hope that this guideline will improve the understanding of adrenal insufficiency among non-endocrine specialists.
Diurnal Ltd	003	007	As some forms of adrenal insufficiency (such as CAH) are genetic diseases with a higher incidence in certain populations we feel it would be helpful to consider how these populations will have access to, and support to engage with, appropriate healthcare resources (Khalid et al., Arch Dis Child . 2012 Feb;97(2):101-6).	Thank you for your comment. The reference discusses the potential benefit of newborn screening for CAH. Screening is outside of the remit of a NICE guideline. Please see the National Screening Committee https://www.gov.uk/government/organisations/uk-national-screening-committee
NHS England and Improvement	003	007	should it be wider than the 3 stated groups? e.g. include travellers, BAME communities etc.	Thank you for your comment. We have added Gypsy, Roma and Travellers to the groups mentioned under 'equality considerations' as they may find it difficult to access specialist services. We are unaware of any issues specific to adrenal insufficiency in people from BAME communities.
Diurnal Ltd	003	012	We feel it would be helpful to clarify that CAH will be in scope especially given the specific consideration of babies and children.	Thank you for your comment. We now mention CAH as a primary cause in the introduction. This guideline will focus on the management of the adrenal insufficiency as a consequence of CAH but not the management of CAH itself.
NHS England and Improvement	003	022	When exploring the information that is given to patients and their families, it would be good to make reference to the need for accessible, health literate information to	Thank you for your comment. This guideline will cross-refer to the NICE guideline on patient experience in adult NHS services https://www.nice.org.uk/guidance/cg138 which

Comments received in the course of consultations carried out by NICE are published in the interests of openness and transparency, and to promote understanding of how recommendations are developed. The comments are published as a record of the submissions that NICE has received, and are not endorsed by NICE, its officers or advisory committees.

Stakeholder	Page no.	Line no.	Comments	Developer's response
			prepare patients for the decisions they will need to make about the treatment and ongoing management of their condition.	makes general recommendations on providing information and support. This guideline will also be making recommendations on information and support to be provided (see section 3.5)
NHS England and Improvement	004	001	We welcome the guidance including identification and management of adrenal crisis	Thank you for your comment.
City, University of London	004	005 – 007	It would also be useful to acknowledge and give consideration to individual requirements for treatment and variations between the type of adrenal insufficiency but also individual-specific variations, e.g. a 3 times/day regime may not be suitable for all patients with primary adrenal insufficiency.	Thank you for your comment. This is covered in 3.3.4
Diurnal Ltd	004	006	We feel it would be helpful to clarify that CAH will be considered specifically in this context	Thank you for your comment. We now mention CAH as a primary cause in the introduction. This guideline will focus on the management of the adrenal insufficiency as a consequence of CAH but not the management of CAH itself.
Addison's Disease Self Help Group	004	013	We welcome the scope element covering crisis prevention during periods of psychological stress	Thank you for your comment.
British Society of Paediatric Endocrinology and Diabetes	004	013	'Preventing adrenal crisis during periods of psychological stress' - this may be contentious. Might be better to phrase this as 'advising'	Thank you for your comment. We acknowledge this may be contentious and the recommendations from the review of managing psychological stress may be advisory. Psychological stress is quoted as a cause of needing to increase glucocorticoid replacement hence why it is included in this scope.
Society for Endocrinology	004	015	As this is a chronic condition, the guideline should include recommendation on standard for patient education,	Thank you for your comment. This guideline will cross-refer to the NICE guideline on patient experience in adult NHS services https://www.nice.org.uk/guidance/cg138 which

Comments received in the course of consultations carried out by NICE are published in the interests of openness and transparency, and to promote understanding of how recommendations are developed. The comments are published as a record of the submissions that NICE has received, and are not endorsed by NICE, its officers or advisory committees.

Stakeholder	Page no.	Line no.	Comments	Developer's response
			engagement and empowerment and promoting effective self-management.	makes general recommendations on providing information and support. This guideline will also be making recommendations on information and support specific to the needs of people with adrenal insufficiency (see section 3.3.1 and 3.5 information and support)
Diurnal Ltd	004	017	Use of medicines outside of their licensed indication, for example due to manipulation at home or provision of an unlicensed special, is common in this area, especially in paediatric adrenal insufficiency patients. We feel it would be helpful to clarify in which situations, if any, this approach might be recommended over a licensed preparation.	Thank you for your comment. Use of a medicine outside its licensed indication (off-label use) may be considered in some circumstances; for example, if this use is common practice in the UK, if there is good evidence for this use, and there is no other medicine licensed for the indication (see also the section on recommendations on medicines, including off-label use of licensed medicines). Medicines with no UK marketing authorisation for any indication will not usually be considered in a guideline because there is no UK assessment of safety and efficacy to support their use.
British Society of Paediatric Endocrinology and Diabetes	004	023	Not addressing diagnosis so how does that square with page 4 lines 22-27?	Thank you for your comment. How to diagnose adrenal insufficiency is excluded from the scope but the draft questions in section 3.5 are included because they are under the key area 'Initial identification of people with suspected adrenal insufficiency who may benefit from referral for specialist investigation and care'.
NHS England and Improvement	004	023	Including 'diagnosing adrenal insufficiency' would be useful	Thank you for your comment. At the stakeholder workshop it was agreed that there is wide agreement on how adrenal insufficiency is diagnosed and therefore it is not area where a NICE guideline can add value i.e., an area where there is variation in practice or uncertainty as to what to do.

Comments received in the course of consultations carried out by NICE are published in the interests of openness and transparency, and to promote understanding of how recommendations are developed. The comments are published as a record of the submissions that NICE has received, and are not endorsed by NICE, its officers or advisory committees.

Adrenal insufficiency: acute and long-term management

Consultation on draft scope
Stakeholder comments table

01/02/2022 to 01/03/2022

Stakeholder	Page no.	Line no.	Comments	Developer's response
British Society of Paediatric Endocrinology and Diabetes	004	024	Again if we don't state what treatment should be then hard to follow on with page 6 line 28 through to Page 7 line 3	Thank you for your comment. This guideline will be making recommendations on treatment (key area 4 managing adrenal insufficiency)
Addison's Disease Self Help Group	004	025	Should the 's' at the end of the word 'causes' be removed?	Thank you for your comment. Edited as suggested.
Diurnal Ltd	004	025	Cause rather than causes	Thank you for your comment. Edited as suggested.
British Society of Paediatric Endocrinology and Diabetes	004	026	Don't understand logic as weaning is weaning. Surely it applies to anyone on glucocorticoids for any condition where weaning is possible	Thank you for your comment. We have edited to the scope and now include the prevention of adrenal insufficiency due to steroid withdrawal as a key area.
Sheffield Teaching Hospitals NHS Foundation Trust	004	026	We believe this is an important area as the majority of patients with adrenal insufficiency/suppression are patients who have been on steroids not prescribed for adrenal insufficiency. Non endocrine specialists still have difficulty with weaning their patients off steroids and a number of misconceptions do exist. Guidance on this aspect of care for their patients would be valuable and could be considered.	Thank you for your comment. We have edited to the scope and now include the prevention of adrenal insufficiency due to steroid withdrawal as a key area.
Society for Endocrinology	004	027	It would be good to cover recommended preparations of glucocorticoid for the management of adrenal insufficiency	Thank you for your comment. These will be covered under section 3.3.3
NHS England and Improvement	006	010	As with the above comment	See response above.
City, University of London	006	010 – 016	In addition to what information and support do people with adrenal insufficiency need, it is important to also consider how this could be delivered, how often and by whom, e.g. guidelines from the Society for Endocrinology recommend patient education on an annual basis and recent evidence from Germany and Netherlands supports nurse-led group	Thank you for your comment. We will be making recommendations on what information and support should be provided but not on who should provide this or how often it should be provided. This guideline will cross-refer to the NICE guideline on patient experience in adult NHS services

Comments received in the course of consultations carried out by NICE are published in the interests of openness and transparency, and to promote understanding of how recommendations are developed. The comments are published as a record of the submissions that NICE has received, and are not endorsed by NICE, its officers or advisory committees.

Stakeholder	Page no.	Line no.	Comments	Developer's response
			education for patients with adrenal insufficiency. Delivering face-to-face patient education by endocrine specialist nurses to all patients on an annual basis would have significant cost-effectiveness and economic implications. At the same time, many patients do not receive any form of (or very limited) patient education and have to rely on information they access from the internet which can often be inaccurate.	https://www.nice.org.uk/guidance/cg138 which makes general recommendations on providing information and support, and to the NICE guideline on shared decision making https://www.nice.org.uk/guidance/ng197.
Addison's Disease Self Help Group	006	011	We welcome the scope elements that relate to managing health during situations like travel, exercising, working non-standard hours and fasting	Thank you for your comment
Addison's Disease Self Help Group	006	017	Can we assume that Sick Day Rules education might be covered under this section please?	Thank you for your comment. These will be included in the guideline where appropriate, for example information and support
NHS England and Improvement	006	017	As with the above comment	See response above.
Sheffield Teaching Hospitals NHS Foundation Trust	006	026	Is there scope to mention groups of patients who should be screened for adrenal insufficiency and what criteria should be satisfied to screen? (e.g patients on steroid inhalers, intramuscular steroid injections, intermittent oral steroids, opioids)	Thank you for your comment. Screening is outside of the remit of a NICE guideline. Please see the National Screening Committee https://www.gov.uk/government/organisations/uk-national-screening-committee. We will be making recommendations on when to refer for specialist advice and advising on management of adrenal insufficiency related to exogenous steroids.
Sheffield Teaching Hospitals NHS Foundation Trust	006	031	Should one mention both conventional treatment and novel technologies?	Thank you for your comment. NICE guidelines investigate the clinical and cost effectiveness of existing treatments. Treatments with no UK marketing authorisation for any

Comments received in the course of consultations carried out by NICE are published in the interests of openness and transparency, and to promote understanding of how recommendations are developed. The comments are published as a record of the submissions that NICE has received, and are not endorsed by NICE, its officers or advisory committees.

Stakeholder	Page no.	Line no.	Comments	Developer's response
				indication will not usually be considered in a guideline because there is no UK assessment of safety and efficacy to support their use. The committee are able to make research recommendations to inform future guidance.
Diurnal Ltd	006	031	We feel it would be helpful to clarify that CAH will be considered specifically with this question. We also believe it would be useful to consider age groups such as babies, children, adolescents with the aim of recommending the most appropriate treatment for each group.	Thank you for your comment. The management of adrenal insufficiency in people with CAH will be included (we now refer to CAH as an example of primary adrenal insufficiency in the introduction). These age groups will be covered as stated in section 3.1
Sheffield Teaching Hospitals NHS Foundation Trust	007	001	Should one mention both conventional treatment and novel technologies?	Thank you for your comment. NICE guidelines investigate the clinical and cost effectiveness of existing treatments. Treatments with no UK marketing authorisation for any indication will not usually be considered in a guideline because there is no UK assessment of safety and efficacy to support their use The committee are able to make research recommendations to inform future guidance.
Diurnal Ltd	007	003	We believe it would be useful to consider age groups such as babies, children, adolescents with the aim of recommending the most appropriate treatment for each group.	Thank you for your comment. The committee will define the evidence review protocol, including whether to use strata based on age. This may enable recommendations to be made based on age.
Diurnal Ltd	007	003	We believe it would be helpful to add a question about how best to support innovation in the therapy area and ensure adoption of new beneficial treatments. It may be helpful to consider how the guideline scope would address new treatments for AI which become licensed during the guideline development period.	Thank you for your comment. NICE guidelines investigate the clinical and cost effectiveness of existing treatments. Treatments with no UK marketing authorisation for any indication will not usually be considered in a guideline because there is no UK assessment of safety and efficacy to support their use. The committee are able to make research recommendations to inform future guidance. The

Comments received in the course of consultations carried out by NICE are published in the interests of openness and transparency, and to promote understanding of how recommendations are developed. The comments are published as a record of the submissions that NICE has received, and are not endorsed by NICE, its officers or advisory committees.

Adrenal insufficiency: acute and long-term management

Consultation on draft scope
Stakeholder comments table

01/02/2022 to 01/03/2022

Stakeholder	Page no.	Line no.	Comments	Developer's response
				literature searches are re-run towards the end of development so that any new studies meeting the evidence review criteria published during development can be included.
City, University of London	007	023	An additional question can be: 1: What are the factors beyond the patient's control that can influence prevention and management of adrenal crisis and how can these be addressed? Although this overlaps with earlier questions, it is important to address the wider factors such as management of a patient presenting in A&E with adrenal crisis but is being refused urgent triaging due to lack of awareness of the condition. This would include clinical and cost-effectiveness of how best to use preventative non-pharmacological strategies, such as the steroid card or red alerts in patient's records, to inform relevant clinicians and other healthcare professionals of the need to administer immediate parenteral hydrocortisone.	Thank you for your comment. The scope includes a draft review question (2.1) on when adrenal crisis should be suspected, which would include people presenting to A and E. Implementation is beyond scope of this guideline and is highlighted by the National Patient Safety Alert (NHSE/I 2021).
British Society of Paediatric Endocrinology and Diabetes	007	024	As in comment 9 above	See response above
NHS England and Improvement	007	024	It would be useful to explore the use of a personalised care and support plan (PCSP) as part of the ongoing management of the person's adrenal insufficiency, including planning for deterioration and crisis. The PCSP could act as a pivotal source of information for the patient and all the services involved in their care, avoiding the	Thank you for your comment. Your comment will be made available to the committee when defining the review protocols on information and support.

Comments received in the course of consultations carried out by NICE are published in the interests of openness and transparency, and to promote understanding of how recommendations are developed. The comments are published as a record of the submissions that NICE has received, and are not endorsed by NICE, its officers or advisory committees.

Adrenal insufficiency: acute and long-term management

Consultation on draft scope
Stakeholder comments table

01/02/2022 to 01/03/2022

Stakeholder	Page no.	Line no.	Comments	Developer's response
			need for the person to keep repeating their story time and time again with different services.	
NHS England and Improvement	007	025 - 026	There may something around offering PIFU (patient-initiated follow-up) for those patients, who after a SDM conversation, are deemed suitable to go on to a PIFU pathway. This would allow those patients to follow up as and when needed with any concerns or issues.	Thank you for your comment. Your comment will be made available to the committee when defining the review protocols on ongoing care and monitoring.
Diurnal Ltd	007	026	We believe it would be useful to consider monitoring of the long-term effects of glucocorticoid therapy such as bone mineral density, diabetes, obesity, and cardiovascular risk. In addition some focus on mental health, fatigue and quality of life might be considered here.	Thank you for your comment. The outcomes will be decided by the committee when defining the review protocol. We will make the committee aware of your comment.
Society for Endocrinology	029	007	Would be good to include: Ongoing care of people at risk of adrenal insufficiency (e.g. those who have been exposed to high dose glucocorticoid within 12 months) including the duration of monitoring for ongoing risk of adrenal insufficiency	Thank you for your comment. This is included in the scope under the key area ongoing care and monitoring
Pituitary Foundation	General	General	One comment re dealing with emotional stress in adrenal insufficiency - emotional stress can be a challenge for ALL with AI and so we feel that all diagnosed AI patient should have this considered. Comments around diverse and unsafe practice- our patient feedback testifies to the difficulties people face when presenting at A&E to ambulance services, and then when trying to maintain adequate steroid cover if admitted to wards. We feel the consultation should consider	Thank you for your comment. The scope includes draft reviews questions (1.1 and 1.2) on information and support which will include psychological factors. The scope includes a draft review question on when adrenal crisis should be suspected, which would include people presenting to A and E. The scope includes a draft review question (1.2) on information and support for the prevention and emergency care of an adrenal crisis.

Comments received in the course of consultations carried out by NICE are published in the interests of openness and transparency, and to promote understanding of how recommendations are developed. The comments are published as a record of the submissions that NICE has received, and are not endorsed by NICE, its officers or advisory committees.

Stakeholder	Page no.	Line no.	Comments	Developer's response
			providing clear and definitive advice for all grades of staff in those areas to promote patient safety, rather than patients being allowed to collapse in A&E waiting rooms. Advice given to the patient should be accurate- we know of patients with secondary AI who are told they cannot have adrenal crisis, that they don't need to double dose or indeed that they are taking too much hydrocortisone and so reduce, only to suffer the adverse effects of this. Staff education across the grades and working areas is key- maybe adrenal crisis management should be included in annual update staff training- just as diabetes care, infection control etc. Provision of a link for the management of pan-hypopit patient admitted in crisis but also with diabetes insipidus (DI)- both need very careful management to avoid rapid deterioration of the patient. Agree that the prescribing of the daily replacement steroid should be for at least 2months with extra provision to cover sick days. Patient should have immediate access to emergency prescriptions for their steroid- not having to wait 3 days. Also, emphasise steroid replacements are not a 'course' as some patient are told -they should not be stopped without specialist advice and supervision.	Staff education is not included in the scope of this guideline, but we expect that this guideline will improve health professional knowledge of adrenal insufficiency. The committee will consider cross-referencing to the NICE guidelines on diabetes. The scope includes a draft review question on the pharmacological management of adrenal insufficiency (4.1 and 4.2) The scope includes a draft review question on pharmacological treatments for the emergency management of adrenal crisis (4.4) which would include emergency injection kits. The scope covers the management of adrenal insufficiency including in people with other medical conditions, but does not include the management of the latter. People taking immunotherapies has been added to scope in drug causes of adrenal insufficiency.

Adrenal insufficiency: acute and long-term management

Consultation on draft scope
Stakeholder comments table

01/02/2022 to 01/03/2022

Stakeholder	Page no.	Line no.	Comments	Developer's response
			Emergency injection kits should be readily available via prescription for patients and include the needles, syringes with which to give the injection. As many people as possible that are connected to the patient should be trained in their use. Maybe areas could consider working with volunteer organisations in the delivery of injection training? I didn't see mentioned those cancer patients treated with immunotherapies – can also result in AI and be a very rapid presentation, possibly aim guidance at oncology care for this patient group too – not much use eradicating a cancer to die from unrecognised adrenal crisis.	
Royal College of Paediatrics and Child Health	General	General	The scope doesn't address all the key/important areas of practice	Thank you for your comment. We have amended the scope based on stakeholder feedback.
Royal College of Paediatrics and Child Health	General	General	Does the scope exclude any important clinical groups? Yes. We all know the commonest cause of congenital adrenal insufficiency is congenital adrenal hyperplasia (CAH) that presents in different clinical and critical presentations: Disorders of Sex Development (DSDs), peripheral precocious puberty hirsutism added to that, acute complications in salt losing types, hypoglycaemia and adrenal crisis in stress conditions. Indeed, this issue is a medical and social challenge for patients, families, society and physicians.	Thank you for your comment. We have edited the introduction and now refer to congenital adrenal hyperplasia under primary adrenal insufficiency.

Comments received in the course of consultations carried out by NICE are published in the interests of openness and transparency, and to promote understanding of how recommendations are developed. The comments are published as a record of the submissions that NICE has received, and are not endorsed by NICE, its officers or advisory committees.

Adrenal insufficiency: acute and long-term management

Consultation on draft scope
Stakeholder comments table

01/02/2022 to 01/03/2022

Stakeholder	Page no.	Line no.	Comments	Developer's response
British Society of Paediatric Endocrinology and Diabetes	General	General	More focus on infants and children as there pathology and presentation can be different	Thank you for your comment. The scope includes infants and children, and young adults, and these will be considered as strata, where appropriate, so that specific recommendations can be made for these groups.
British Society of Paediatric Endocrinology and Diabetes	General	General	2) From comment above. There is no national NHS paediatric emergency card and this would be valuable output. 1) In fact why not a single card as adult dosing should be the same as paediatric!!	Thank you for your comment. This is outside the scope of this guideline as it is the responsibility of the NHS patient safety team https://www.england.nhs.uk/patient-safety/the-nhs-patient-safety-strategy/.
Sheffield Teaching Hospitals NHS Foundation Trust	General	General	Novel formulations and therapeutic strategies have been developed with published data for the use in adrenal insufficiency such as oral modified release hydrocortisone and subcutaneous hydrocortisone infusion pumps that provide more physiological replacement and could help with improvement in QOL and to reduce metabolic complications. We feel these could be considered for inclusion in the guidance.	Thank you for your comment. NICE guidelines investigate the clinical and cost effectiveness of existing treatments and may review evidence that is available including modified release drugs. Subcutaneous hydrocortisone pumps are not licensed for use in the UK. Recommendations for glucocorticoid replacement will be based on the published literature. Medicines with no UK marketing authorisation for any indication will not usually be considered in a guideline because there is no UK assessment of safety and efficacy to support their use.
NHS England and Improvement	General	General	We would welcome the inclusion of a section for primary care health care professionals on when to suspect adrenal insufficiency and the monitoring of treatment and repeat prescribing for this long-term condition.	Thank you for your comment. The section 'Initial identification of people with suspected adrenal insufficiency who may benefit from referral for specialist investigation and care' would include primary care health professionals. Similarly, ongoing care and monitoring may also include recommendations relevant to primary care. The section on pharmacological management includes longer term management.

Comments received in the course of consultations carried out by NICE are published in the interests of openness and transparency, and to promote understanding of how recommendations are developed. The comments are published as a record of the submissions that NICE has received, and are not endorsed by NICE, its officers or advisory committees.

Adrenal insufficiency: acute and long-term management

Consultation on draft scope
Stakeholder comments table

01/02/2022 to 01/03/2022

Stakeholder	Page no.	Line no.	Comments	Developer's response
Addison's Disease Self Help Group	Question 1	Question 1	1. Are there any cost saving interventions or examples of innovative approaches that should be considered for inclusion in this guideline? Patient support groups can provide or seek funding to provide solutions not within the budgetary reach of the NHS. Could partnerships with trusted charities be an option for things like emergency injection training and other types of patient education maybe?	Thank you for your comment. We will make the NICE implementation team aware of your comment for consideration where relevant support activity is being planned.
Royal College of Paediatrics and Child Health	Question 1	Question 1	Are there any cost saving interventions or examples of innovative approaches that should be considered for inclusion in this guideline? Application of neonatal screening programs for CAH as hypothyroidism and inborn error of metabolism	Thank you for your comment. Screening is outside of the remit of a NICE guideline. Please see the National Screening Committee https://www.gov.uk/government/organisations/uk-national-screening-committee.

Registered stakeholders

Comments received in the course of consultations carried out by NICE are published in the interests of openness and transparency, and to promote understanding of how recommendations are developed. The comments are published as a record of the submissions that NICE has received, and are not endorsed by NICE, its officers or advisory committees.