

NATIONAL INSTITUTE FOR HEALTH AND CARE EXCELLENCE

EQUALITY IMPACT ASSESSMENT

NICE guidelines

Adrenal Insufficiency: identification and management

The impact on equality has been assessed during guidance development according to the principles of the NICE equality policy.

1.0 Checking for updates and scope: before scope consultation (to be completed by the Developer and submitted with the draft scope for consultation)

1.1 Is the proposed primary focus of the guideline a population with a specific communication or engagement need, related to disability, age, or other equality consideration? Y/N

If so, what is it and what action might be taken by NICE or the developer to meet this need? (For example, adjustments to committee processes, additional forms of consultation.)

No.

1.2 Have any potential equality issues been identified during the check for an update or during development of the draft scope, and, if so, what are they?

(Please specify if the issue has been highlighted by a stakeholder)

- Age: Treatment adherence in young people and particularly during transition to adult services.
- Disabilities: Treatment adherence due to difficulties arising from cognitive challenges. This includes people with learning disabilities and mental health conditions.
- Pregnancy and maternity care: Women with hypoadrenalism were noted as being particularly at risk of adrenal crisis during labour and c-sections.
- Socio-economic factors. People from lower socio-economic groups can face challenges accessing health care.

Other groups with definable characteristics who would impact treatment adherence and accessing services and medication are listed below:

- refugees
- asylum seekers
- migrant workers
- people who are homeless
- prisons and young offenders. Potential issues with access to medication particularly when in custody in police stations
- people in care homes. Potential issues with access to medication.

1.3 What is the preliminary view on the extent to which these potential equality issues need addressing by the Committee?

It is noted that the groups identified above are important to consider when making recommendations for the guideline. All will be included within the population covered by the reviews. Where appropriate they will be considered as subgroups when the protocols for specific review questions are set. Care will be taken to consider the needs and preferences of these patient groups when drafting recommendations, particularly when recommendations involve patients directly, such as patient engagement in shared decision making about medicines.

1.3 What is the preliminary view on the extent to which these potential equality issues need addressing by the Committee?

- This guideline will cross refer to guidelines on [Patient experience](#) (CG139), [Shared decision making](#) (NG197) and [Decision-making and mental capacity](#) (NG108) that address communication issues.
- The guideless that address access to services and issues around treatment adherence include: [Transition from children's to adults' services for young people using health or social care services](#) (NG43), [Care and support of people growing older with learning disabilities](#) (NG96), [Physical health of people in prison](#) (NG57) and Managing medicines in care homes (SC1).

Problems with access to healthcare for people from lower socio-economic groups, refugees, asylum seekers and people who are homeless relate to a wider issue than can be dealt with in this guideline

Completed by Developer: Sharon Swain

Date: 31 January 2022

Approved by NICE quality assurance lead: Simon Ellis

Date: 24 January 2022

2.0 Checking for updates and scope: after consultation (to be completed by the Developer and submitted with the revised scope)

2.1 Have any potential equality issues been identified during consultation, and, if so, what are they?

Access to specialist services - A stakeholder identified that some people live far away from specialist services, where some patients receive care in highly specialist tertiary centres and others are managed by their GP

Other groups that should be mentioned – A stakeholder identified that people from BAME communities and travellers should be specifically mentioned in the scope (no further detail provided)

2.2 Have any changes to the scope been made as a result of consultation to highlight potential equality issues?

The incidence of adrenal insufficiency is the same in people from BAME communities as the general population. No other equality issues specific to the areas in the scope were identified and therefore no changes were made.

Where a person lives in relation to specialist services is not an equality issue but may be considered by the committee when making their recommendations. Asylum seekers, refugees and Gypsy, Roma and Travellers may also find it difficult to access specialist services and these groups were added to the scope under 'equality considerations'. No changes will need to be made to review protocols, but these issues may be considered by the committee when they are making their recommendations.

2.3 Have any of the changes made led to a change in the primary focus of the guideline which would require consideration of a specific communication or engagement need, related to disability, age, or other equality consideration?

If so, what is it and what action might be taken by NICE or the developer to meet this need? (For example, adjustments to committee processes, additional forms of consultation)

No

Updated by Developer: Sharon Swain

Date: 22 March 2022

Approved by NICE quality assurance lead: Simon Ellis

Date: 12 April 2022

3.0 Guideline development: before consultation (to be completed by the Developer before consultation on the draft guideline)

3.1 Have the potential equality issues identified during the scoping process been addressed by the Committee, and, if so, how?

Age- A recommendation was made to review the information and support needs of children as they grow up and referred to NICE's guideline on Transition from children's to adult services for generic recommendations to ensure health and social care needs continue to be met.

Recommendations were made for alternative formulations of glucocorticoid medication such as modified-release hydrocortisone, for children and young people between 1 and 15 years who have difficulty adhering to standard regimens. See table 3.

The committee recognised that babies, children, and people under 16 years require more frequent monitoring than adults and highlighted in the recommendations the times and situations where more monitoring would be needed. This includes during periods of rapid growth, when transitioning from child to adult services, if adherence to medication is an issue, for vulnerable children or concerns with the child's condition not being managed by family or carers adequately.

Disabilities

The committee referred to NICE's guideline on decision making and capacity when working with people with adrenal insufficiency and learning disabilities.

In the pharmacological management of psychological stress, the committee recommended considering using intramuscular hydrocortisone rather than an oral preparation for people in severe mental health crises. The committee also referred to the recommendation on referral to NHS talking therapies or mental health services within the NICE guideline Managing anxiety and depression.

Pregnancy and maternity care

3.1 Have the potential equality issues identified during the scoping process been addressed by the Committee, and, if so, how?

Consensus recommendations have been made for counselling women and people with adrenal insufficiency planning pregnancy. The committee also made recommendations on advice for managing their medication during pregnancy, including modification of dosages during periods of physiological or psychological stress, and monitoring by healthcare professionals during a person's pregnancy. The committee referred to the steroid replacement recommendations within the NICE guideline on intrapartum care for women with existing medical conditions or obstetric complications and their babies. The committee also provided guidance on the dosage of glucocorticoid medication after the birth of the baby.

Access to health care - The committee made a recommendation to advise health care providers in other settings such as residential care and prisons on the needs of a person with adrenal insufficiency and provide them with a management plan.

The committee recognised some groups of people may require more frequent monitoring by health professionals and made a consensus recommendation for vulnerable adults. This could include people with disabilities, older people in residential care, and people in prison.

Asylum seekers, refugees and Gypsy, Roma and Travellers may find it difficult to access specialist services. In the recommendations on what information to provide to people with adrenal insufficiency the committee included the need to have a supply of medicines at all times including when travelling or moving between places of residence and how to obtain additional supplies of medication.

3.2 Have any **other** potential equality issues (in addition to those identified during the scoping process) been identified, and, if so, how has the Committee addressed them?

No additional equality issues were identified.

3.3 Have the Committee's considerations of equality issues been described in the guideline for consultation, and, if so, where?

Where equality issues have been identified these are discussed in the committee discussion sections of the following evidence reviews: (A)

3.3 Have the Committee's considerations of equality issues been described in the guideline for consultation, and, if so, where?

Information and support, (J) Pharmacological management of physiological stress, (N) Ongoing care and monitoring, (F) Routine pharmacological management of Primary AI, (G) Routine pharmacological management of secondary and tertiary AI, (K) Routine pharmacological management of psychological stress, (M) Non-pharmacological management of psychological stress.

3.4 Do the preliminary recommendations make it more difficult in practice for a specific group to access services compared with other groups? If so, what are the barriers to, or difficulties with, access for the specific group?

No barriers to access services were identified.

3.5 Is there potential for the preliminary recommendations to have an adverse impact on people with disabilities because of something that is a consequence of the disability?

No adverse impacts on people with disabilities have been identified.

3.6 Are there any recommendations or explanations that the Committee could make to remove or alleviate barriers to, or difficulties with, access to services identified in box 3.4, or otherwise fulfil NICE's obligation to advance equality?

N/a

Completed by Developer: Gill Ritchie

Date: 13 December 2023

Approved by NICE quality assurance lead: Rupert Franklin

Date: 12 March 2024

4.0 Final guideline (to be completed by the Developer before GE consideration of final guideline)

4.1 Have any additional potential equality issues been raised during the consultation, and, if so, how has the Committee addressed them?

- Age

The recommendation not to do cortisol tests at random times of the day does not apply to newborns and young infants as they do not have a circadian rhythm for several months, and therefore random cortisol can be performed as an initial investigation in suspected cases of adrenal insufficiency. A recommendation was added for babies under 1 year serum cortisol levels may be measured at any time of the day.

A recommendation to consider giving an emergency kit to people under 16 years old who are being treated for tertiary adrenal suppression who may be at more risk of adrenal crisis due to their underlying pathology and relative physical immaturity. This population would include children undergoing cancer treatment, or young people with Duchenne muscular dystrophy with multiple morbidities, who regularly undergo treatment with IV bisphosphonates where symptomatic AI including severe complications like HDU/ICU admissions have been known.

Disability

No new equality issues were identified

- Gender reassignment

No new equality issues were identified

- Pregnancy and maternity

Placing more emphasis on the safety of hydrocortisone in pregnancy was raised. Additional information was added to the rationale and impact section of the guideline advising women that hydrocortisone will not harm the baby as hydrocortisone is broken down and inactivated in the placenta.

- Race

Clinical features such as hyperpigmentation might be under recognised on different skin types. The committee added a recommendation and

4.1 Have any additional potential equality issues been raised during the consultation, and, if so, how has the Committee addressed them?

describes in the rationale and impact section that this feature may not be easily recognised in people with black or brown skin and that clinicians should inspect buccal mucosa or surgical scars and ask the person if they have noticed any change to their skin colour.

- Religion or belief

No new equality issues were identified

- Sex

No new equality issues were identified

- Sexual orientation

No new equality issues were identified

- Socio-economic factors

No new equality issues were identified

- Other definable characteristics (these are examples):

No new equality issues were identified

- refugees
- asylum seekers
- migrant workers
- looked-after children
- people who are homeless
- prisoners and young offenders
- any others identified

4.2 If the recommendations have changed after consultation, are there any recommendations that make it more difficult in practice for a specific group to access services compared with other groups? If so, what are the barriers to, or difficulties with, access for the specific group?

None were identified

4.3 If the recommendations have changed after consultation, is there potential for the recommendations to have an adverse impact on people with disabilities because of something that is a consequence of the disability?

No

4.4 If the recommendations have changed after consultation, are there any recommendations or explanations that the Committee could make to remove or alleviate barriers to, or difficulties with, access to services identified in question 4.2, or otherwise fulfil NICE's obligations to advance equality?

N/A

4.5 Have the Committee's considerations of equality issues been described in the final guideline, and, if so, where?

Where equality issues have been identified these are discussed in the rationale and impact sections of the guideline and in the committee discussion sections of the following evidence reviews: (D) Diagnostic tests and thresholds, (I) Emergency management of adrenal insufficiency, (J) Pharmacological management of physiological stress, (B) When to suspect adrenal insufficiency and (H): When to suspect adrenal crisis

Updated by Developer: Gill Ritchie

Date: 04 June 2024

Approved by NICE quality assurance lead: Sharon Swain

Date: 21 August 2024