



March 2024 exceptional surveillance of suspected cancer: recognition and referral (NICE guideline NG12) and suspected neurological conditions: recognition and referral (NICE guideline NG127)

Surveillance report

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Surveillance decision

We will amend the wording from absent red reflex to absent fundal ('red') reflex in [recommendation 1.12.2 in NICE's guideline on suspected cancer](#) and [recommendation 1.30.1 in NICE's guideline on suspected neurological conditions](#).

Reason for the exceptional review

[NICE's quality standard on suspected cancer](#) is currently being updated and was consulted on in August 2023. It is based on NICE's guideline on suspected cancer. During the quality standard consultation, 3 stakeholders raised objections to the wording of the guideline's recommendation 1.12.2 on referral for suspected retinoblastoma in children due to absent red reflex. Although this recommendation was not part of the quality standard update, it was referred to the guideline development team responsible for the cancer suite for investigation. Recommendation 1.12.2 was published with the guideline in 2015 and was not identified for subsequent updates in 2019 or 2021.

Methods

The exceptional surveillance process consisted of:

- Considering the new information that triggered the exceptional review.
- Determining whether any other guidelines beyond the NICE guideline on suspected cancer were affected.
- Seeking clinical advice on the proposed amendments to recommendations.

Information considered in this exceptional surveillance review

Summary of stakeholder comments

Barts NHS Trust, the University of St Andrew's and the Childhood Eye Cancer Trust have all objected to using the term red reflex on the basis that this colour is seen predominantly

in white populations and varies significantly among other ethnicities. The absence specifically of a red reflex (as opposed to other colours) in non-white populations can be considered normal because their reflex will be a different colour (brown, white, orange). However, because the recommendation in the suspected cancer guideline only states red reflex, this is leading to the over-referral of healthy non-white children and confusion when delivering training to clinicians working in areas with higher non-white populations. Stakeholders have suggested amending the wording to fundal reflex or absent fundal 'red' reflex; the latter recommended as transitional wording until the phrase fundal reflex becomes more widely recognised. The fundus is the interior surface of the eye opposite the lens and hence, fundal reflex means the reaction of this part of the eye during this test.

Rationale for the original recommendation in the suspected cancer guideline

No evidence on the diagnostic accuracy of tests for, or signs and symptoms of, retinoblastoma in children in primary care was identified by reviewers in [NICE's 2015 full guideline](#) (section 18.3, pages 299 to 301). The guideline committee noted that from clinical experience however, an absent red reflex could be a symptom of retinoblastoma and should prompt an urgent referral to an ophthalmologist. No other tests or symptoms were identified by the committee to prompt referral.

Equality considerations

The guideline committee discussed a 'variation' in red reflex among different ethnic groups and that this may mean a 'higher rate of referral for children in certain ethnic groups'. This was not considered by the committee to be a health inequality however, because they felt a higher referral rate was 'unlikely to disadvantage these children'.

This issue was not flagged in the [equalities impact assessment](#) or raised by stakeholders when this guideline was consulted on (see the [guideline consultation table](#)).

Summary of studies and guidance highlighted by stakeholders

- [The role of education in the promotion of red reflex assessments](#) (Muen et al. 2010)

The study contains an audit of referrals for abnormal red reflex following a poster campaign in GP practices and hospitals in east London. The author notes that 'darkly

pigmented races' often have duller red reflex, which can be a common cause of misdiagnosis; this is an anecdotal opinion from the author and not connected to the research itself.

- [Public Health England's Newborn and infant physical examination \(NIPE\) screening programme handbook \(April 2021\)](#)

The handbook contains a section on how to conduct the 'red reflex examination', not referred to as the fundal reflex but acknowledges that 'the reflex can be less bright and appear magnolia in colour in black, Asian or minority ethnic babies' and recommends assessing their parents as an indicator of what could be considered normal.

- [World Health Organization \(WHO\) recommendations on maternal and newborn care for a positive postnatal experience \(2022\)](#)

WHO guidance on screening for abnormalities at birth and referred to as red reflex. Red reflex is the term used throughout.

- [Red reflex examination in reproductive and child health clinics for early detection of paediatric cataract and ocular media disorders \(Mndeme et al. 2021\)](#)

A diagnostic accuracy study assessing the accuracy of different tools for detecting red reflex. There does not appear to be any information about variability of red reflex in people from different ethnic groups.

Expert advice

We consulted with an ophthalmologist registered on the NICE expert adviser panel for a clinical perspective on changing the wording. They agreed that it was not red in all children, but the clinical community were used to describing it this way. As a compromise, they suggested the wording be amended to absent fundal ('red') reflex, which was also suggested by 1 of the stakeholders who raised the issue. They also requested the wording be amended to absent or abnormal as the reflex is frequently abnormal, which would also warrant further investigation. They flagged that the same wording should also be used in recommendation 1.30.1 in NICE's guideline on suspected neurological conditions, which also references red reflex.

NICE clinical adviser input

NICE's clinical adviser noted that the purpose of the 2 guidelines is to improve efficiency of NHS referrals, not to ensure that 100% of all abnormal cases are referred. Because the addition of 'abnormal' has been suggested by only 1 person, and because it could reduce the efficiency of referrals, their view was that the recommendation wording should be amended to absent fundal ('red') reflex.

Conclusion

There appears to be broad consensus that 'red' reflex is an inaccurate description for the reflex found in non-white populations. The original guideline committee refer to this variability in reflex colour among people from different ethnic groups; however, they concluded that referring to it as red reflex did not create a health inequality and higher referral rates were not an issue. Stakeholders have subsequently noted that this is a health inequality issue and that over-referral of people in this population is leading to extra worry and stress for these children and their families, aside from being an unnecessary extra burden on services. The evidence highlighted by stakeholders so far appears to be anecdotal; however, St Andrew's University have conducted research that is currently undergoing peer review and awaiting publication, and the topic expert we consulted agreed with the stakeholder consensus views.

Overall decision

The wording should be amended from absent red reflex to absent fundal ('red') reflex in recommendation 1.12.2 in NICE's guideline on suspected cancer and recommendation 1.30.1 in NICE's guideline on suspected neurological conditions.

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