

05 April 2024

Alison Mutch  
HM Senior Coroner  
The Coroners Court  
1 Mount Tabor Street  
Stockport  
SK1 3AG

Dear Ms Mutch

**Re: Regulation 28 Prevention of Future Deaths Report (Michelle Louise Whitehead)**

I write in response to your regulation 28 report dated 14 February 2024 regarding the very sad death of Alfie Anthony Kevin Nicholls. I would like to express my sincere condolences to Alfie's family.

The patient safety leads at NICE have discussed the report and understand that your request is that we develop guidance on avoidant/restrictive food intake disorder, and in particular in medical emergencies in eating disorders (MEED), as is mentioned in paragraph 7 of the matters of concern.

We have concluded that the request is for such guidance to be directed to 'medical professionals in acute settings such as Emergency Departments and Paediatrics'.

Our conclusion is that NICE is not best placed to develop guidance in this area. ARFID was explicitly excluded from the scope of our [eating disorders guideline NG69](#) for the reason that it is a relatively new diagnostic category and one for which there is as yet little in the way of evidence on which to make recommendations. A recent literature review of the subject from University College London and the Maudsley Centre for Child and Adolescent Eating Disorders concluded that whilst ARFID is a common and impactful problem among young people with autism, it is currently under-researched. The authors stated that work is required to identify the prevalence of ARFID in children and young people with autism; to uncover the key drivers of ARFID in this population; to adapt currently available interventions for use with children and young people with autism; and to rigorously test these interventions

in clinical trials. Until this work is done, it is unlikely that NICE will be able to produce useful and usable guidance in this area.

There are, however, a number of resources available to healthcare practitioners and families and carers of people with ARFID, including the work of the charities 'Beat Eating Disorders UK' ([ARFID - Beat \(beateatingdisorders.org.uk\)](https://www.beateatingdisorders.org.uk)) and ARFID awareness UK ([ARFID Awareness UK](https://www.arfidawarenessuk.org)). The NHS [webpage on eating disorders](#) links to the Beat website in its section on ARFID. A [position paper](#) has been written by members of the ARFID Special Interest Group (ARFID SIG), which is part of the British Dietetic Association (BDA). Locally, a number of NHS trusts have produced guidance for parents and health care professionals, such as [this](#) from Cambridge. In 2021-22, the British Paediatric Surveillance Unit, part of the Royal College of Paediatrics and Child Health undertook a [surveillance study](#) in the UK and Republic of Ireland to establish incidence rates (number of new cases) of ARFID in children and young people presenting to secondary health care, and also to get information on ARFID, specifically on referral pathways, patterns of presentation, and clinical features (eating behaviours, medical complications and the types of medical or psychiatric presentations it is associated with). This study has not reported yet. A systematic review of the literature by the same authors published in 2023 concluded that 'The current literature on the epidemiology of ARFID in children and adolescents is limited. Studies are heterogeneous with regard to setting and sample characteristics, with a wide range of prevalence estimates. Further studies, especially using surveillance methodology, will help to better understand the nature of this disorder and estimate clinical service needs.'

We will refer this report to our surveillance team so that the inclusion of ARFID can be considered when our eating disorders guideline is next reviewed, or when the literature on ARFID has matured sufficiently to allow the development of reliable, evidence-based guidance. The NICE guideline surveillance team monitors and reviews new evidence to determine whether guidelines should be updated. An exceptional surveillance review is undertaken when we are alerted to new, significant evidence relevant to the topic.

In the meantime, the view of NICE is that clinicians should follow the information provided by specialist groups such as the British Dietetic Association and the Royal College of Paediatrics and Child Health as well as the specific charities.

I hope this information is helpful.

Yours sincerely,



Chief executive