Summary

This paper summarises information and guidance on best practice in identification and follow up of children deemed to be of low height. The Child Measurement Programme (CMP) is established as a population surveillance and not an individual screening programme, however it is recognised that clinical staff may identify new concerns during the measurement process. This paper is intended to provide advice and guidance to staff in school health teams who identify concerns about low height as part of the CMP.

While there is a professional consensus on the usefulness of identifying low height in children in the reception year age group and about the threshold at the 0.4\textsuperscript{th} centile, there is little information about how this should take place. However the UK National Screening Committee (UKNSC) supports the idea of a single measure of height taken at age 4 to 5 with referral of any child falling below the 0.4\textsuperscript{th} centile.

It is important for any child falling below this threshold to be referred on by the school health service with as much information as is available, including any previous growth measurements of the child and the reported height of both birth parents if available. It is also important to remember that even if children are above the 0.4\textsuperscript{th} threshold when they are measured, children of any height who are growing more slowly than expected may still have a growth disorder and will require further assessment.

Policy context

The Welsh government regulations\textsuperscript{1} allowing for the introduction of a child measurement programme in Wales allow for measurements of both height and weight. The CMP feasibility study\textsuperscript{2} carried out in 2009 prior to the regulations coming into force recommended that “The (UK) National Screening Committee guidance on
screening for short height should be implemented as part of any national programme, using the recommended threshold of the 0.4th centile for height.”

The Child Health sub-group of the UK National Screening Committee reported to the main committee in December 1999, and this recommendation was last reviewed in 2006. They recommended a number of actions including that "children should have their height and weight measured at around the time of school entry and the 0.4 cut-off for height should be used to initiate referral". The UKNSC suggested that “effective screening for short stature using the 0.4 centile should identify at least half of all previously missed cases of Growth Hormone Deficiency and of Turner’s Syndrome, the two main target disorders”. This recommendation has never been formalised in a national screening programme in the UK. However all children in England and Wales are weighed and measured in Reception Year as part of national surveillance programmes in school.

Background

During the first three years (2011/14) of the programme, there were 468 children who were identified as being of low height – that is their height was below the 0.4th centile for their age. This was 0.46% of the total number of 93,266 children who were measured across the three years. It is not known how many of these children were already known to health professionals because of concerns about their height, but it is known that some were: the data the Child Measurement Programme receives is anonymised, but checks were carried out on the 2011/12 information which showed that some of the children identified through the CMP as being of low height had previously been identified and referred. Therefore the number of new cases at health board level is predicted as small (Figure 1). However referral of any new children into the system will have cost implications for Local Health Boards.

Figure 1 – number of children by local health board who were identified as “low height” between 2011 and 2014

In terms of identification and treatment, the Welsh Paediatric society have published guidance on their website on the evaluation and assessment of children found to be
of short stature. The guidance states that “the vast majority of children referred for short stature have common variations of normal physiological growth. However, a few children may have an underlying pathology.” That guidance also provides much more comprehensive information about child growth including possible causes of short stature, medical investigation, and monitoring and assessment of children of short stature once they have been referred. One of the most common medical reasons for short stature which only occurs in girls is Turner Syndrome (TS) which occurs in one out of every 2,500 to 3,000 live female births. A second condition, Growth Hormone Deficiency (GHD) occurs in about one in every 3,800 births in the UK. These are the two main conditions where screening for low height could be justified, as most other conditions involving short stature will have other signs and symptoms that are noticeable at an earlier age, or may not be amenable to any intervention (e.g. skeletal dysplasia).

**Early identification of low height**

There is little UK guidance available on managing early identification and referral of low height, apart from the Child Growth Foundation’s Coventry Consensus\(^5\). While the main focus of the Consensus statement relates to babies and children under two, there are also recommendations about measuring children over 2, specifically for height (rather than weight) monitoring. A health technology assessment\(^6\) carried out for the National Institute for Health Research (NIHR) and updated in 2011 concluded that “there is a lack of evidence on appropriate referral strategies” and compared the Coventry Consensus to a monitoring strategy from the Netherlands, concluding that the UK strategy was both less effective and less cost-effective. However the Netherlands strategy included several elements including growth velocity, but the threshold for referral was also lower, which would lead to more children being referred unnecessarily, and could lead to parental anxiety.

The Coventry Consensus statement reiterates the need for careful measuring techniques using robust equipment, and states that in children over two “provided that the measurement is taken on suitable equipment with proper care and correctly plotted, a single measurement is, in principle, sufficiently precise to be a useful screening method”. The paper identifies that if the 0.4\(^{th}\) centile is used as the cut off, then in children identified as falling below that threshold there is a strong likelihood of there being an actual concern but that some children may be missed (specificity good / sensitivity fair). However increasing the threshold to the 2\(^{nd}\) centile (used in some other countries) would result in many more children being referred who did not actually need investigations, and could cause unnecessary anxiety in both parents and children. They rejected the suggestion that growth velocity should be measured (which would involve two or more measurements taken over time) as it is in the Netherlands, for several reasons which are explained in the full statement\(^7\).

**Evidence base**

Two evidence searches were carried out in relation to low height screening. The two questions posed were as below:

1. Are single height measurements useful for screening for growth disorders in children aged 4 to 5?
A number of relevant papers were identified, including several systematic reviews. One study actually carried out in Wales concluded that “The study shows poor coverage and compliance together with a lack of parental awareness that short stature could be a potential health problem even in asymptomatic children. For a low yield programme to be successful and cost effective at the national level, a near 100% coverage is required”. Currently participation in the CMP in reception year in Wales is 90.8%. The measurement programme in England which has been running for several years showed that participation has increased there year on year, and was 94% last year.

One systematic review which included 31 studies suggested that “growth monitoring is associated with health improvements” and concluded that their work had identified “the potential utility and cost-effectiveness of growth monitoring in terms of increased detection of stature-related disorders” but that more studies were needed and that “diagnostic accuracy studies would require long-term follow-up of both short and normal children to determine sensitivity and specificity of growth monitoring”. There was discussion in several of the papers about the threshold for identification, with the UK guidance (at below 0.4th centile) being one of the lowest. A study from the USA which used the 3rd centile as the threshold said that using this threshold meant that “nearly 99% of patients were diagnosed as possible variants of normal growth” so were unnecessarily identified. Using this approach could cause unnecessary anxiety to children and families.

2. Are low height disorders identified in children aged 4 to 5 amenable to treatment?

The two main disorders already referred to as being the most likely diagnosis in children of a short stature with a medical condition are Turner’s Syndrome and Growth Hormone Disorder. There is an ongoing debate about which treatments are most effective, however there appeared to be agreement that both conditions are amenable to treatment. The evidence search results suggested that the earlier treatment started, the more successful it was likely to be, from both physical and psychological perspectives. One of the papers identified in the evidence search highlighted the challenge of diagnosing Turner’s Syndrome after the age of 12 and challenges with treatment with growth hormone and with initiating artificial puberty after the age at which it should have commenced.

A number of other less common conditions were also mentioned, and their treatments discussed. These included Prader-Willi, chronic kidney disease, Noonan’s syndrome, HIV and inflammatory bowel disease. Some papers included economic modelling of height screening and early versus late treatment. At least one UK systematic review suggested that height screening is associated with health improvements, with the consensus being that cost per Quality Adjusted Life Year (QALY) fell well under the £30,000 cost per QALY adopted by the National Institute for Health and Care Excellence (NICE).

Conclusion and Recommendations

Despite the critique from the NIHR of the Coventry Consensus approach, there appears to be little reason to deviate from the UK National Screening Committee recommendation that “children should have their height and weight measured at around the time of school entry and the 0.4 cut-off for height should be used to initiate


referral”. Children in the UK have historically been weighed and measured at this age as part of the school-entry health check. With the introduction of the CMP in Wales the process of weighing and measuring children was made more robust through provision of additional equipment and training. School health teams provide annual assurance to the CMP Office on staff training and on calibration and maintenance of measuring equipment so any measurements should be regarded as reliable.

The school nurse making any referral should supply as much information as possible including information about the reported height of the birth parents (if available) and any previous height measurements for the child. It is not recommended that referral be delayed to allow for further measurements over time in order to specifically calculate growth velocity. There should be no additional costs to the school health services associated with provision of this guidance as there is no requirement to carry out additional measurements. There will be additional costs to any service the children are referred to in terms of a very small number of additional children being identified, but all of the children referred have a robust reason for referral and require further investigation.

Where there is local policy in place in health boards which dictates referral routes from school health teams then that local guidance should be adhered to. However where there is no local policy or guidance in place the local school health team will need to make a decision based on local knowledge about the most appropriate referral pathway, which in most circumstances will be the child’s GP or a community paediatrician. A proportion of the children identified will not have been previously identified so there will be additional costs to any services that children are referred into.

References

5 Hall, DMB. “Growth monitoring” Archives of Disease in Childhood 2000 82: 10-15

5