Provision and Supervision of Low Protein Food in Schools: How Safe is it for Children with PKU?

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Background
• PKU has a practical, social and psychological impact on daily life, with issues such as social exclusion1.
• Children with PKU need access to the same opportunities as their peers and support to manage treatment safely at school2.
• In the UK, schools have a duty to support children with medical conditions and are expected to cater for children on special diets3.
• Individual Healthcare Plans (IHCP) outline the needs of each child with a medical condition and how these will be met, however these are not mandatory3.

Aim: To explore food experiences at school for children with PKU, from the perspective of their parents / caregivers.

Methods
• Online questionnaire hosted on the UK National Society for PKU (NSPKU) website
• 18 multiple choice and open questions
• Open from March-August 2020
• Completed by parents (n=159) of pre-school (aged 3-5y) (n=22) and school aged children (aged 5-16y) (n=137) with PKU

Results
• Uptake of school meals is lower amongst children with PKU than the general population. Work is needed to overcome some of the barriers to improve this.
• There is a need for better PKU training for school staff to ensure children are supported safely and appropriately.
• Some parents reported school catering services refused to provide for a low phenylalanine diet, resulting in children not having access to the same opportunities as their peers.
• Provision, supervision and staff training was poorer in children without an IHCP. It is important that every child with PKU has one in place.
• There are disparities in experiences across the UK. Clearer legislation and guidance would ameliorate this.

Table 1. Barriers and facilitators to better provision of school food

<table>
<thead>
<tr>
<th>Barriers</th>
<th>Facilitators</th>
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<tbody>
<tr>
<td>Rigidity of outsourced catering providers</td>
<td>In-house catering where school cooks prepare and cook all meals</td>
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<td>School’s fear of mistakes leading to reluctance / refusal to provide for a low phenylalanine diet</td>
<td>Education of school staff about PKU and a low phenylalanine diet by a dietitian</td>
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<td>School’s lack of knowledge / experience of PKU and a low phenylalanine diet</td>
<td>Communication between nursery and school during transition</td>
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<td>Lack of forward planning by school staff for trips and activities</td>
<td>Regular feedback from school to parents</td>
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<td>Requirement for low protein ingredients to be provided by parents</td>
<td>Direct communication between parent and school cook</td>
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<td>Lack of trust in school not to make mistakes</td>
<td>One-to-one staff support for child</td>
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Discussion
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References: