

## Supplementary material: Full Questionnaire

**Title: Provision of school food for children with PKU: A parent's perspective**

**1. Are you a parent / carer of a child under the age of 18 who has PKU?**

- Yes
- No

**2. Which type of school does your child currently attend?**

- State school
- Private school
- Boarding school
- Other

If you selected other, please specify:

**3. Which year group is your child in?**

- Nursery/reception
- Primary school (years 1-3)
- Primary school (years 4-6)
- Secondary school (years 7-9)
- Secondary school (years 10-11)
- Other

If you selected other, please specify:

**4. Do you have an Individual Healthcare Plan or a written agreement about how your child's PKU should be managed at school?**

- Yes
- No
- Don't know

**5. Is your child entitled to free school lunches?**

- Yes
- No
- Don't know

**6. How many times per week, if any, does your child normally have lunch provided by the school?**

- 0
- 1
- 2-3
- 4-5

What are the reasons for this?

**6b. Would you like your child to have school lunches more often?**

- Yes
- No

If yes, what are the barriers to this?

**7. Does your child's school provide snacks for children at break time? (e.g. fruit or milk)**

- Yes
- No
- Don't know

**7a.. If yes, is the snack or drink provided suitable for a low protein diet?**

- Yes
- No

**7b** If no, what alternatives are in place for your child?

**8. To what extent are you satisfied or dissatisfied overall with the school lunch service provided for your child?**

**Please tick:**

- Very satisfied
- Fairly satisfied
- Neither satisfied nor dissatisfied
- Very dissatisfied

**9. For your child, are meals chosen from the same menu as the other children choose from, or are specific alternative meals made?**

- Meals are chosen from the same menu as the other children
- Specific alternative meals are made
- Other

If you selected other, please specify:

**10. Which of the following are included in the school lunch service at your child's school? Please tick all that apply.**

- Low protein bread
- Low protein pizza bases
- Low protein sausage/burger/fish mix
- Low protein pasta
- Low protein flour
- Low protein cake mix
- Low protein chocolate
- Quorn Fishless fingers
- Low protein cheese
- Low protein milk
- Low protein meal alternatives that have been prepared at the parents at home and need reheating
- None of the above

**10.a** What are the reasons given for this?

**10.b** Who provides the following low protein food?

- Low protein bread (Hospital/ Parents/ School catering/ Not applicable)
- Low protein pizza bases (Hospital/ Parents/ School catering/ Not applicable)

- Low protein sausage/burger/fish mix (Hospital/ Parents/ School catering/ Not applicable)
- Low protein pasta (Hospital/ Parents/ School catering/ Not applicable)
- Low protein flour (Hospital/ Parents/ School catering/ Not applicable)
- Low protein cake mix (Hospital/ Parents/ School catering/ Not applicable)
- Low protein chocolate (Hospital/ Parents/ School catering/ Not applicable)
- Quorn Fishless fingers (Hospital/ Parents/ School catering/ Not applicable)
- Low protein cheese (Hospital/ Parents/ School catering/ Not applicable)
- Low protein milk (Hospital/ Parents/ School catering/ Not applicable)
- Low protein meal alternatives that have been prepared at the parents at home (Hospital/ Parents/ School catering/ Not applicable) and need reheating
- None of the above (Hospital/ Parents/ School catering/ Not applicable)

**11. Do catering staff at your child's school measure/weigh exchange to meet your child's exchange allowance? (e.g. mashed potato)**

- Yes
- No
- Don't know

If no, what are the reasons given for this?

**12. Have the teachers at your child's school received training from a health professional about PKU and a low phenylalanine diet?**

- Yes
- No
- Don't know

**12.a. If yes, how long was this?**

- Less than 12 months ago
- 1-2 years ago
- 3-4 years ago
- Over 4 years ago

**12.b. If yes, who conducted the training?**

- Child's dietitian in person
- Child's dietitian by letter/information pack
- Child's nurse
- Hospital support worker
- Other

If you selected other, please specify:

**13. Have the catering team at your child's school received training from a health professional about PKU and a low phenylalanine diet?**

- Yes
- No
- Don't know

**13.a If yes, how long ago was this?**

- Less than 12 months ago
- 1-2 years ago

- 2-3 years ago
- Over 3 years ago
- 13.b. If yes, who conducted training?
- Child's dietitian in person
- Child's dietitian by letter/information pack
- Child's nurse
- Hospital support worker
- Other

13.b.i. If you selected other, please specify:

**14. Using the scale below, rate how knowledgeable you feel the staff in your child's school are about the dietary requirements of children with PKU?**

- Teachers (no knowledge/ very limited knowledge/ neither knowledgeable nor unknowledgeable/ fairly knowledgeable/ extremely knowledgeable/ Not applicable)
- Teaching assistants (no knowledge/ very limited knowledge/ neither knowledgeable nor unknowledgeable/ fairly knowledgeable/ extremely knowledgeable/ Not applicable)
- School cooks (no knowledge/ very limited knowledge/ neither knowledgeable nor unknowledgeable/ fairly knowledgeable/ extremely knowledgeable/ Not applicable)
- Lunch time supervisors (no knowledge/ very limited knowledge/ neither knowledgeable nor unknowledgeable/ fairly knowledgeable/ extremely knowledgeable/ Not applicable)

**15. Who supervises your child eating the following?**

- Lunch (Teacher/ Teaching assistant/ Catering staff/ Lunchtime supervisor/ Unsupervised/ Don't know/ Other)
  - If you selected other, please specify:
- Snack (Teacher/ Teaching assistant/ Catering staff/ Lunchtime supervisor/ Unsupervised/ Don't know/ Other)
  - If you selected Other, please specify:
- Protein substitute (Teacher/ Teaching assistant/ Catering staff/ Lunchtime supervisor/ Unsupervised/ Don't know/ Other)
  - If you selected other, please specify:

**16. Do you receive feedback in any format about what has been eaten by your child at school?**

- Yes
- No

**16.a If yes, what format do you receive this in?**

- Verbal feedback
- Written record
- Photographic record
- Online report
- Other

If you selected other, please specify:

**16.b** If yes, does this include feedback about protein substitute?

- Yes
- No
- Not applicable

**17. To your knowledge, has your child ever eaten foods which are not permitted as part of their PKU diet while at school?**

- Yes
- No
- Don't know
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**17.a** If yes, how many times had this happened in the last 6 months?

- 1
- 2-3
- 4-5
- Greater than 5

**17.b** Please give more details of what happened (e.g. where did it happen, what was eaten):

**17.c** Do you feel that you were adequately informed of the incident?

- Yes
- No

**17.c.i** If no, what do you feel could have been done better?

**17.d** Are there strategies in place at your child's school to avoid incidents like this happening?

- Yes
- No
- Don't know

**17.d.i** If yes, what are these?

**18. Please use the box below to make any additional comments about provision or supervision of food or protein substitute at your child's school.**

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