

**BIMDG Workshop: Reviewing the Sapropterin Pathway****Date:** 9 December**Venue:** Aston Business School, Birmingham

10.00 a.m. to 4.00 p.m.

Aim: Discuss experience of the PKU sapropterin responsiveness testing pathway to share best-practice and to guide review of the pathway.

Target attendees: Dietitians, Clinicians and Nurse Specialists managing paediatric and adult patients with PKU.

10.00	Welcome and introductions Aims and Objectives	Chair TBC
10.10	Background: Sapropterin testing pathway development and ongoing review/data collection	Rachel Skeath
10.30	NHSE commissioning perspective	TBC
10.40	Patient experience and perspective	NSPKU: John Skidmore
11.00	Real-world experience of implementing pathway: • Patient cohort numbers • Number tested through pathway • Proportion of responders • Specific challenges encountered	Short presentation (5mins) from each centre
12.30	Lunch break	
13.15	Introduction to group discussion remit	
13.20	Breakout group discussion: • What is working well? • What are the key challenges? • What have we learnt from implementation? • Suggested amendments.	Paediatric and adult healthcare professional groups with representation from multiple centres in each group.
14.20	Feedback from group discussion: each group to contribute	Chair TBC
15.00	Plenary discussion: common themes and agreed next steps	Chair TBC
16.00	Close	



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Registration Form

This BIMDG workshop is open to NHS healthcare professionals working with patients and families with phenylketonuria.

There is no registration fee.

Refreshments and lunch will be provided.

Name	
Email	
NHS Trust	
Job role	☐ Paediatric dietitian ☐ Adult dietitian ☐ Paediatric clinician ☐ Adult clinician ☐ Paediatric nurse specialist ☐ Adult nurse specialist ☐ Other (please state)
Specify any dietary requirements	
Specify any access requirements	

Please return this completed form to jamesdavison@nhs.net