Bridging the gap. Launch of the PKU Compendium for late diagnosed adults

Metabolic Diseases Unit, Royal Melbourne Hospital, Parkville, Victoria, Australia

Summary
Achieving dietary adherence in individuals with late diagnosed Phenylketonuria (PKU) can be challenging due to external factors. Identified barriers to care led to the development of the PKU Carers’ Compendium. We describe the development and launch of the PKU Carers’ Compendium and the effectiveness of this project.