Supporting treatment adherence in young people with Tyrosinemia: co-creation of a discussion guide for healthcare professionals (HCPs)

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Background

- Tyrosinemia (type 1) is a rare hereditary metabolic disease.
- Incidence of 1 in every 1000,000 births.
- If left untreated can lead to progressive liver and kidney damage.
- Requires lifelong adherence to a combination of medicine, protein supplements and a low-protein diet.
- Qualitative research undertaken to understand adherence challenges and patient support needs.
Summary of key research findings

- Adherence to treatment guidelines can be difficult for some patients, particularly for teenagers.
- Patients/ carers are less likely to comply with medication and treatment guidelines if they:
  - have doubts about the need for treatment
  - have concerns about taking the medication
  - have a poor understanding of treatment guidelines
  - perceive the condition to be asymptomatic
  - are unsure about the chronic nature of the condition
  - perceive greater practical barriers to treatment adherence
- Patients should be more involved in clinic consultations from a young age

1. Malik et al. (2014). Treatment adherence in Type 1 Hereditary Tryosinemia (HT1): a mixed-methods investigation into the beliefs, attitudes and behaviour of adolescent patients, their families and their healthcare team. In JMID Reports, 18, 13-22.
Development of a brief HCP-led intervention

- A brief booklet designed to support treatment adherence discussions between HCPs and their patients either alone or in collaboration with parents/carers.
Refining the discussion guide...

- An initial prototype of the discussion guide was developed and tested with HCPs (n=5) in a focus group.
- The discussion guide was positively received by HCPs who felt it would help to structure and support treatment discussions in the clinic.
- The process also identified a few key areas that needed further refinement:
  - Content around dietary and medicines non-adherence
  - Tips and strategies for communicating with teenage patients
  - Providing additional information to describe how the guide could be used in practice

**Next Steps:** Incorporating feedback from HCPs and piloting the discussion guide with patients in a clinic setting