The cost of implementing ketogenic diet therapy for children and young people with drug-resistant epilepsy in the UK

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Purpose

In 2021, within the National Institute for Health and Care Excellence (NICE) 'Epilepsies: diagnosis and management' (CG137) update, it was highlighted that there was no relevant cost or health economic data for ketogenic diet therapy (KDT) in the UK. This project aims to provide a nationally representative and robust estimate for the cost of implementing KDT for children and young people with drug-resistant epilepsy in the UK.

Method

To estimate the direct cost of implementing KDT in the National Health Service over a 2-year period, a step wise approach was used:

1. Determining a common patient pathway;
2. Estimating the quantity of the resource components;
3. Determining the unit cost of each resource component;
4. Combining values to estimate the total cost of KDT.

Results

The common patient pathway was determined by comparing services from across England and determining the sequence of clinical actions throughout a 2-year period for outpatient initiation of KDT (Figure 1).

The total average cost of implementing KD over a 2-year period was £13,130.59 ($16,352.38) per person (range £8,078.67 - £19,824.16).

For Comparison, different dietary types and age groups were analysed to highlight the variation in the cost of prescribed nutritional supplements (figure 2).

Figure 1 – Common Treatment pathway for KDT in the UK

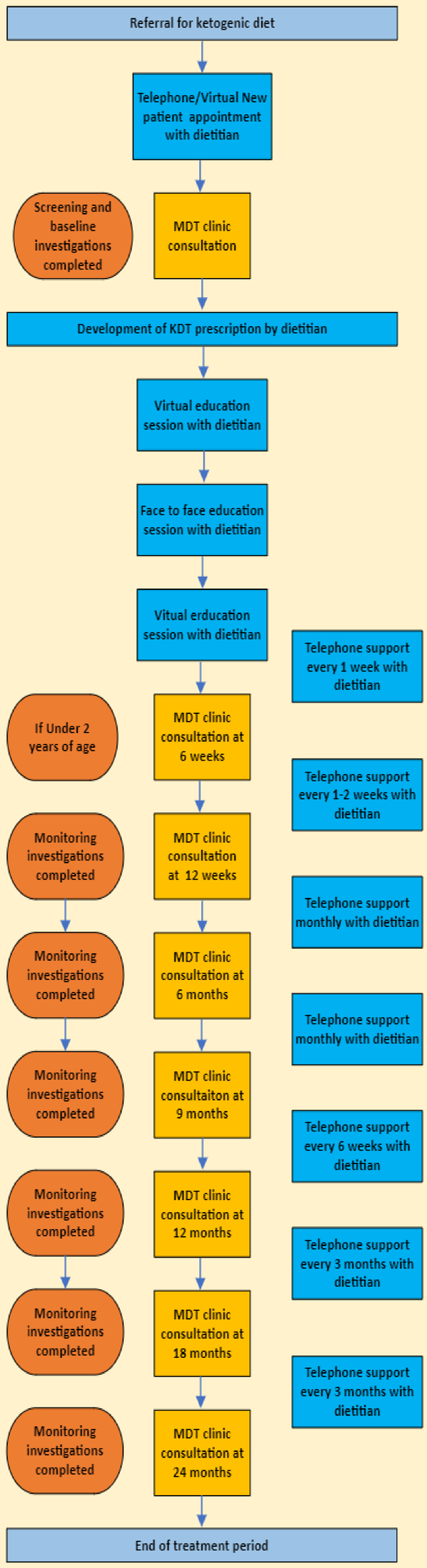
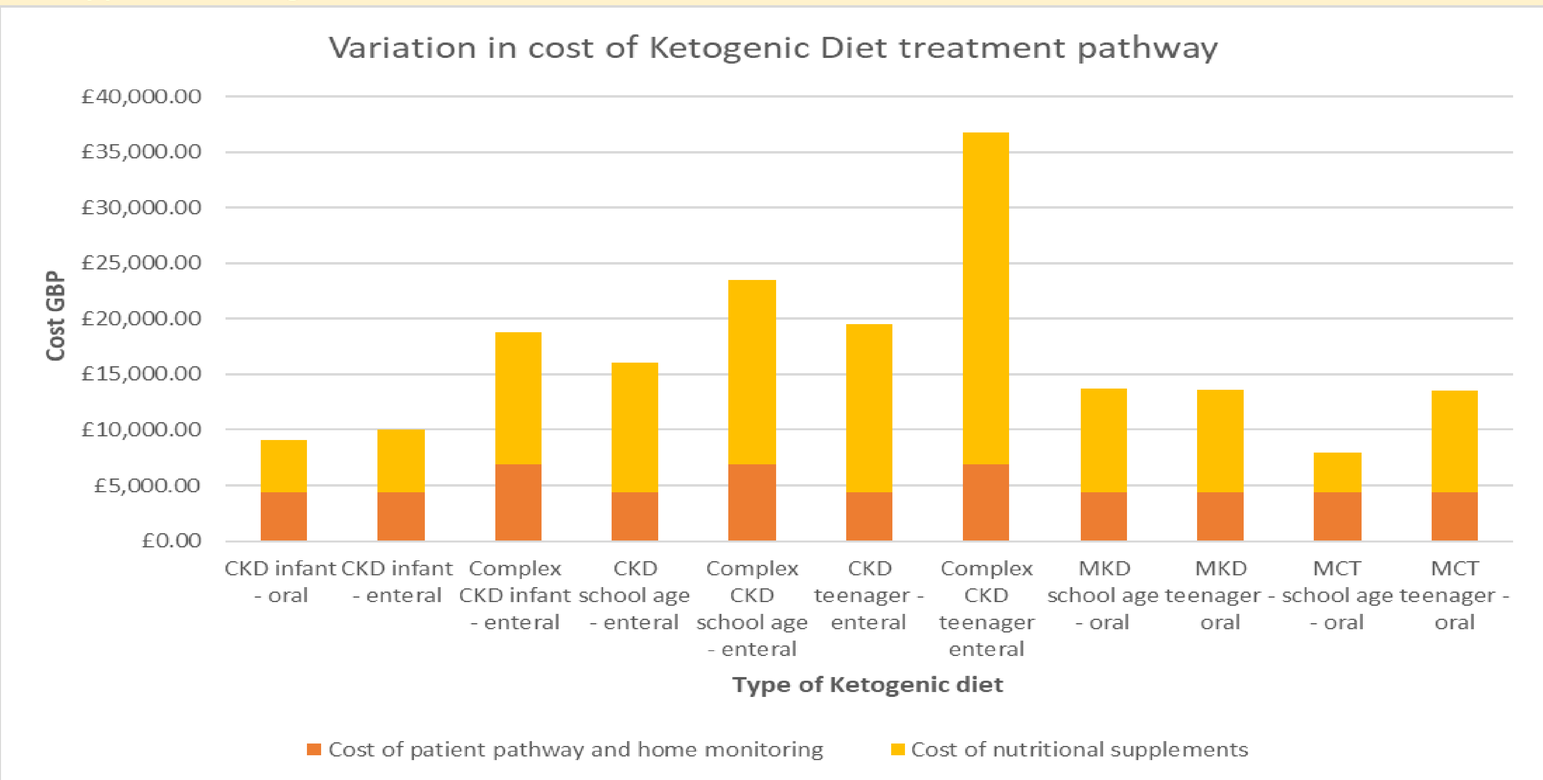


Figure 3 – Total cost of Ketogenic diet therapy comparing differences in dietary protocol and age



Results

The cost if the patient pathway over a 2-year period, including consultations, dietetic time, biochemical investigations and at-home monitoring was **£4,386.02** ($5,590.57) for 'routine' care and up to **£6,971.01** ($8,875.73) for those with complex medical backgrounds, requiring more intensive support.

The cost of prescribable items to support KDT cost on average £10,251.76 (range £3,690.65 - £15,436.14), with variations due to age, dietary plan and feeding route (Figure 2). This variable had the biggest impact on overall cost as highlighted in Figure 3.

Figure 2 – Quantity and cost of resource use was compared across the following age groups and KDT protocols

	Group 1 (under 2 years of age)	Group 2 (school age)	Group 3 (teenager)
CKD oral	X		
CKD enteral	X	X	X
CKD enteral milk free formula	X	X	X
MKD oral		X	X
Modified MCT KD oral		X	X

Conclusion

This is the first analysis of cost of implementing KDT for DRE in the UK. Costs are significant, but may be less than other non-pharmacological treatments with similar efficacy. These data will form part of a larger health economic analysis of KDT, which will be essential to inform nationwide service planning and evidence-based guidelines in the future.

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