

# Patient Experience of the Paediatric Ketogenic Dietetic Service

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## Introduction

The ketogenic diet (KD) service is a small, highly specialist, regional service for infants and children with epilepsy. The KD can provide symptomatic relief in patients with poorly controlled seizures. The KD team aimed to evaluate the patient experience of this service.

## Methods

A questionnaire was devised with the support of the Patient Experience department. The questionnaire was sent to all patients in the service between December 2020 and February 2021.

## Findings:

- 13 responses from a case load of 20.
- 100% of questionnaires were completed by a parent.
- The majority of patients were first seen in a face to face (F2F) capacity with ongoing follow up via phone or email and again in F2F or phone clinics.
- The majority of respondents commented on being able to email and phone, in-between appointments, as a positive aspect of their care.
- All respondents commented on the importance of feeling supported by the dietitian and were positive about their experience around the level of support provided.

## Subsequent Changes to the Service:

- Creation of paediatric ketogenic diet service email address.
- Letters sent to all patients clarifying how to get in touch with dietetics (also advising when contacting via email is not appropriate e.g. in an emergency). These are also given out at pre-assessment appointment to new patients.
- Reviews and meetings with patients/community teams etc. via Teams are now offered.
- Confirmation of the need to keep communication open to parents e.g. they can contact dietetics during working hours (rather than waiting for an appointment), and which days the service is covered.
- Letter sent to parents when there are staff changes.

