

Perceptions and experiences of health care service use for children newly diagnosed with uveitis: UNICORNS-C19 study

Introduction

COVID-19 has disrupted provision of and access to healthcare services. Patients newly diagnosed with uveitis, a rare chronic inflammatory disease which if untreated can lead to irreversible visual loss, are particularly vulnerable to these disruptions. We aimed to describe the impact of the pandemic on the experiences and perceptions of health care use of families of children newly diagnosed with uveitis.

Methods

UNICORNS-C19 is a cross-sectional study embedded within a multicentre inception cohort study, the Uveitis in Childhood Prospective National Cohort Study (UNICORNS), which is recruiting children with non-infectious uveitis diagnosed since March 2020 across 29 NHS Hospitals.

We distributed (postally and electronically) a modified Health Foundation survey, which comprises 13 questions around the different aspects of health and social care. Quantitative data were analysed using descriptive statistics and free text responses were analysed using exploratory thematic analysis. A framework was developed to index and chart data into main and sub-themes through an iterative process by two researchers.

Results

Response rate to date is 42 of the 95 UNICORNS families approached (44%), The majority (26/43 families, 61%) expressed concern over the impact of the pandemic on their health. However, the majority (31/43, 72%) were very comfortable using their specialist hospital for face-to-face visits during the pandemic, expressing a positive experience with NHS services across the UK. Key themes included positive and negative experiences and perceptions of safety procedures / services across different levels of care (primary to quaternary).

Conclusion

The UNICORNS study is well placed to provide useful data on patient experience for those starting a rare, chronic childhood disease care pathway during a global pandemic. Findings will inform recommendations for future service planning.