Perceptions and experiences of health care service use during the pandemic for children with uveitis: UNICORNS-C19 study

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PURPOSE:

Children newly diagnosed with rare chronic complex disorders such as uveitis are particularly vulnerable to pandemic related disruptions.

We aimed to describe the impact of the pandemic on the experiences and perceptions of care use for families of children newly diagnosed with uveitis.

METHODS:

UNICORNS-C19 is a cross-sectional study embedded within the currently underway Uveitis in Childhood National Prospective Cohort Study (UNICORNS), which is recruiting UK children with non-infectious uveitis.

We distributed a modified Health Foundation / Ipsos Mori survey on health and social care. Quantitative data were analysed using descriptive statistics, free text responses were analysed using qualitative thematic analysis. A framework was developed to index and chart data into themes through an iterative process.

CONCLUSIONS:

UNICORNS is well placed to provide useful data on patient experience for those starting a rare, chronic childhood disease care pathway. Our findings suggest that primary and secondary care teams require additional support in delivering / co-ordinating care for those with rare disease.

UNICORN C-19 findings will inform recommendations for future service planning for vulnerable patient groups during disruptive times.

RESULTS: Responses from 51 families diagnosed during the pandemic: 61% expressed concern over the impact of the pandemic on their health, with a third (31%) expressing difficulties in accessing essential medication, and 61% finding it harder to get basic food stuffs. Despite this, the majority expressed a positive experience with NHS services, with 74% being comfortable using their specialist hospital during the pandemic. **Key themes were**:

Safety procedures



"We already there monthly. Everyone is taking the right precautions to make the appointments covid safe "

Positive experience of health policy

Adoption of digital health tools (across 1° to 4° care)



"Very good solutions blending face to face appointments with virtual appointments. Diagnosis, treatment and care were not compromised"

Positive experience of changing practice

Challenges co-ordinating care



"Frustrating as they told us to go to the A&E for 'eye problem' and after waiting there we were sent to eye hospital"

Need for tools to support delivery of co-ordinated care

Challenges in delivering of synchronous telemedicine for rare disease



"May have to see different staff to usual which often means to tell the whole story again!"

Need for tools to support non-specialists co-managing rare disease

Use of immunosuppression



'With his immune system compromised due to the medication its scary as effects of covid will be greater should he catch it'

Need for improved dissemination of research findings amongst families

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