We have considered whether this can be attributed to Hashimoto's encephalopathy as a post-inflammatory neurological manifestation of SARS-CoV-2.

British Association of Perinatal Medicine and Neonatal Society

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RETINOPATHY OF PREMATURITY: READABILITY ASSESSMENT OF ONLINE PATIENT INFORMATION

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Background Retinopathy of Prematurity (ROP) is one of the leading causes of childhood blindness with increasing incidence as survival rates of premature infants improve over the years. Parents and families are increasingly using the internet to access health information to supplement information and confirm their understanding from healthcare professionals and with rather extensive conditions associated with prematurity, it is important that information accessed is accurate, easy to read and comprehend.

Objectives We aim to evaluate the readability of online health information regarding ROP.

Methods Readability assessment of online ROP information was evaluated using two validated readability instruments by two independent reviewers: Flesch-Kincaid grade level (FKGL) and Simple Measure of Gobbledygook (SMOG). Top 20 websites returned by a Google.co.uk search were analysed and only relevant body texts or bullet point texts related to parental information were analysed. Webpages intended for healthcare professionals were excluded. These scores were then compared to the U.S Department of Health and Human Services (USDHHS) reading-level categories: easy to read (below 6th grade level), average difficulty (7th to 9th grade level), and difficult (above 9th grade level).

Results 17 websites were analysed. More than 60% of the websites were classified as difficult to read for both FKGL and SMOG scores. Less than 10% of the websites were easy to read for both FKGL and SMOG scores. The median FKGL scores of were 9.9 and 9.8 for reviewers 1 and 2 respectively and the median SMOG scores were 9.3 and 9.7 for reviewers 1 and 2 respectively. Intraclass correlation coefficient for both scores were 0.99 (high).

Conclusions The World Wide Web has revolutionized parental education and when presented effectively, is a powerful tool that has great potential for health professionals to increase health literacy among the general population. The readability of online patient-oriented material for ROP is not consistent with the average public reading capability which could potentially result in confusion, poor understanding and misinterpretation. This could lead to suboptimal adherence to follow-up appointments and refusal of treatment. We recommend that health professionals should consider using readability scores when producing patient information resources. We also suggest that recommendations, guidance and standards for publishing

of patient-oriented literature on the Web ought to be put in place to ensure that the targeted audience could comprehend and act upon the contents.

British Association for Paediatric Nephrology

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COVID-19: EXPERIENCES OF LOCKDOWN AND SUPPORT NEEDS IN CHILDREN AND YOUNG ADULTS WITH KIDNEY CONDITIONS

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Background During the initial COVID-19 pandemic, young United Kingdom (UK) kidney patients underwent lockdown and those with increased vulnerabilities socially isolated or 'shielded' at home. The experiences, information needs, decision-making and support needs of children and young adult (CYA) patients or their parents during this period is not well known.

Objectives To understand the concerns and decision-making in CYA during the first lockdown, and perform subgroup analysis on shielded vs non-shielded patients

Methods UK wide online survey co-produced with patients was conducted in May 2020 among CYA aged 12–30, or parents of children aged <18 years with any degree of chronic kidney disease. Participants answered qualitative open text alongside quantitative closed questions. Thematic content analysis using a three-stage coding process was conducted.

Results 118 CYA (median age 21) and 197 parents of children (median age 10) responded. Predominant concerns from CYA were heightened vigilance about viral (68%) and kidney symptoms (77%) and detrimental impact on education or work opportunities (70%). Parents feared the virus more than CYA (71% vs 40%), that their child would catch the virus from them (64%) and adverse impact on other children at home (65%). CYA thematic analysis revealed: strong belief of becoming seriously ill if they contract COVID-19, lost educational opportunities, socialisation, and career development, and frustration at public for not following social distancing rules. Positive outcomes included improved family relationships and community cohesion. Only a minority (14–21% CYA and 20–31% parents, merged questions) desired more support. Subgroup analysis identified greater negative psychological impact in the shielded group.

Conclusions This is the first study specifically surveying CYA with kidney conditions and their parents' experience of the COVID-19 pandemic during lockdown. We found substantial concern and need for accurate tailored advice for CYA based on individualised risks to improve shared decision making.