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RESEARCH ARTICLE

# A critical analysis of UK media characterisations of Long Covid in children and young people

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# **Abstract**

Long Covid is the continuation or development of symptoms related to a SARSCoV2 infection. Those with Long Covid may face epistemic injustice, where they are unjustifiably viewed as unreliable evaluators of their own illness experiences. Media articles both reflect and influence perception and subsequently how people regard children and young people (CYP) with Long Covid, and may contribute to epistemic injustice. We aimed to explore how the UK media characterises Long Covid in CYP through examining three key actor groups: parents, healthcare professionals, and CYP with Long Covid, through the lens of epistemic injustice. A systematic search strategy resulted in the inclusion of 103 UK media articles. We used an adapted corpus-assisted Critical Discourse Analysis in tandem with thematic analysis. Specifically, we utilised search terms to locate concordances of key actor groups. In the corpus, parents highlighted minimisation of Long Covid, barriers to care, and experiences of personal attacks. Mothers were presented as also having Long Covid. Fathers were unmentioned. Healthcare professionals emphasised the rarity of Long Covid in CYP, avoided pathologising Long Covid, and overemphasised psychological components. CYP were rarely consulted in media articles but were presented as formerly very able. Manifestations of Long Covid in CYP were validated or invalidated in relation to adults. Media characterisations contributed to epistemic injustice. The disempowering portrayal of parents promotes stigma and barriers to care. Healthcare professionals' narratives often contributed to negative healthcare experiences and enacted testimonial injustice, where CYP and parents' credibility was diminished due to unfair identity prejudice, in their invalidation of Long Covid. Media characterisations reveal and maintain a lack of societal framework for understanding Long Covid in CYP. The findings of this study illustrate the discursive practices employed by journalists that contribute to experiences of epistemic injustice. Based on our findings, we propose recommendations for journalists.

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# Introduction

Long Covid in children and young people (CYP) occurs in those under 25 with a history of confirmed or probable SARS-CoV-2 infection, with symptoms lasting at least 2 months initially occurring within 3 months of an acute covid-19 infection [1,2]. Potential symptoms range widely and include cognitive difficulties, cough, dizziness, dyspnoea, joint pain, light sensitivity, loss of appetite, myalgia, palpitations, and sore eyes or throat, and can newly onset or persist from the initial infection. The World Health Organisation (WHO) definition of Long Covid in CYP was developed in February 2023 to align understanding of the condition and acknowledge that CYP have potentially different Long Covid presentations from adults [1].

Long Covid is the first illness to be socially constructed through afflicted individuals connecting online on social media [3]. Tweets initially aimed at urging the medical establishment to notice Long Covid, but morphed into co-experting, where people with Long Covid and professionals created knowledge together [4]. Some had both lived experiences of being ill with Long Covid and being health researchers or health professionals [5–7].

While the construction of Long Covid has more patient input than seen in other diseases, people with Long Covid nevertheless experience barriers to recognition of their experience and valuable perspectives [8]. Lokugamage and colleagues (2021) used the term "structural iatrogenesis" to describe how people with Long Covid are harmed by power imbalances within medicine, such as how the longstanding authority of healthcare professionals (HCP) overpowers and may lead to dismissal of the legitimate knowledge base within patients [8]. People with Long Covid have countered this through transforming their knowledge into traditionally accepted forms of information, such as scientific publications and epidemiological data. Despite data collection and advocacy by patients and HCPs, it took considerable effort for national agencies and governments to recognize Long Covid [9]. Patients coined the term "Long Covid" which obscures the biphasic disease pathway common in biomedical knowledge that separates the acute infection from the post-infection chronic condition [5,10,11]. In contrast, the NHS sometimes uses the term "post-covid syndrome" while the WHO has used the term "post-covid-19 condition", reimposing traditional understanding of temporality and disease [4,5,11].

In addition to the requirement of proof of SARS-CoV-2 infection, there are formidable barriers for those with Long Covid, especially CYP, to accessing adequate care [12–14]. Within the UK, Long Covid services often require a general practitioner (GP) referral [15,16], and many clinics continue to have a wait time of over 15 weeks [17]. In addition to the logistic barriers to care, CYP and adults with Long Covid face discrimination and stigma which hinders engagement with health services and can result in HCPs minimising the experience of people with Long Covid [12,13,15,16,18,19].

In the absence of an objective test for Long Covid, people with the condition are frequently dismissed or their illness accounts are met with scepticism [9,20]. An additional issue is that despite parents and caregivers reporting other illnesses in children being classically accepted by HCPs and society at large, this has been used to further minimise Long Covid in CYP—adding weight to the burden of stigma. In adults, Long Covid stigma primarily occurs through three mechanisms: enacted, internalised, and anticipated stigma [18]. Enacted stigma are overt experiences of discrimination (such as where a patient is disbelieved because a HCP does not believe Long Covid exists); internalised stigma occurs when people with Long Covid recognize negative associations with Long Covid (such as people with Long Covid are lazy exaggerators) and accept them as true of themselves; and anticipated stigma is the expectation of poor treatment by others (such as expecting a HCP to be biased against Long Covid accounts) [18]. In one survey, over 95% of people with Long Covid based in the UK reported experiencing at least one form of

stigma at least sometimes, and 75% report experiencing stigma often or always [18]. Much of what contributes to Long Covid stigma also leads to epistemic injustice [9].

Epistemic injustice occurs when people are unjustifiably discredited, as unreliable evaluators of their own illness experiences [21]. There are two main forms of epistemic injustice: testimonial and hermeneutical [22]. Testimonial injustice occurs when someone's credibility is diminished because of unfair identity prejudice [22]. This has been seen in Long Covid, where lived experiences are dismissed due to those living or describing them being negatively stereotyped [9]. These negative stereotypes can be influenced by aspects of a person's identity that unfairly diminish their perceived credibility, such as their race, gender, social class, health status, or age. Those that historically disproportionately experience testimonial injustice, such as women, people of colour, sexual minorities, and younger people report facing disbelief and dismissal over their Long Covid that may be exacerbated by their marginalised identities [23]. Negative stereotypes include beliefs that people with Long Covid are attention-seeking, making up or exaggerating symptoms, or that they only have an alternate mental health diagnosis [9]. Children with Long Covid have reported that they are valued less due to Long Covid, they are perceived as potentially lying, they are less respected, that others see Long Covid as a sign of weakness, and that others may judge them negatively due to their diagnosis [19]. When a person is perceived to have these negative attributes, their testimony is less likely to be believed, especially considering the validity of Long Covid is still being contested [24].

The other form of epistemic injustice is hermeneutic injustice, where a person is not able to articulate their experience because of a gap in collective interpretive resources [25]. The hermeneutic injustice in Long Covid stems from a societal lack of a framework for understanding and conceptualising the condition. There is still limited understanding of Long Covid partially due to its relatively recent emergence, and this hinders recognition of the condition. The predominance of the biomedical illness model for conceptualising disease in countries such as the UK privileges diseases diagnosable by an "objective" test over diseases that are predominately diagnosed via symptom presentation [9]. There is still no biomarker that can offer sensitive and specific diagnosis of Long Covid. As a result, Long Covid suffers low disease prestige and those afflicted are disadvantaged by this [9].

Systemic power and social structures influence the characterisation of Long Covid [22]. The media play a large role in the knowledge construction of certain chronic diseases and the epistemic (in)justice in representing various actors involved [22]. Media articles both reflect and influence perception of the condition and subsequently how people regard and behave towards CYP with Long Covid. It is especially important to understand how the media characterises CYP with Long Covid, as these individuals are at higher risk of being misunderstood and may be disproportionately negatively affected by scepticism towards their condition and experiences [25]. Most research and media coverage on Long Covid has focused on adults which hinders understanding of the condition in CYP [14]. Additionally, CYP may be less able to access care and resources [26,27]. Key actors such as HCPs, parents of children with Long Covid, and affected CYP are frequently represented in media articles reporting on Long Covid in CYP. In the articles, the actors share their knowledge and are also discussed by others. There is currently a lack of research analysing media coverage of Long Covid. We aimed to examine how the UK media characterise Long Covid in CYP using a modified Critical Discourse Analysis approach.

#### Methods

# Data sources and systematic search strategy

This study analyses media articles about Long Covid in CYP published in national newspapers in the UK between January 1st, 2020 and June 7th, 2023. National articles included articles

Table 1. Inclusion and exclusion criteria for media articles.

Inclusion criteria	Exclusion criteria
UK based Published after January 1st, 2020 Media article on Long Covid in CYP Media article published by a national publisher (including England, Scotland, Northern Ireland, Wales)	Non-UK based Published before January 1st, 2020 Media article not both on Long Covid in CYP On Long Covid generally On pandemic effects on children Media article published by a nonnational publisher CYP Local, regional, or international Published by individuals not affiliated with a publisher

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from publishers specific to the UK or any of the four nations within the UK. Restricting regional articles made it feasible to analyse the full systematic search and avoided skewing results towards less widely read articles from publishers that may not broadly impact public perception and discourse. Articles were collected through the search engine LexisNexis using search terms related to Long Covid and CYP. After duplicates were removed and all articles were reviewed for relevance according to the inclusion criteria (Table 1), 103 articles were included for analysis. The adapted PRISMA diagram is presented in Fig 1. For the full systematic search strategy, a list of included/excluded publishers, descriptive data including a demographic breakdown of the included articles (style and political leaning of publisher, date published), refer to S1 and S2 Tables, S1–S3 Figs. For the characterisation of each publisher, refer to S3 Table. Articles were labelled as duplicates if they were published within 48 hours with the same author(s), with an identical or nearly identical text body. Articles with repeated text but significantly different lengths (as assessed by the primary researcher) were not considered duplicates.

All included articles were manually converted into plain text format using Notepad, and text not related to the body (such as suggestions for further reading) were removed if spotted at the beginning or the end of the text file. All media articles were loaded into the corpus tool ANTconc [28], which was utilised to facilitate the analyses.

# Data analysis

We used a modified social actor theory approach [29] to Critical Discourse Analysis (CDA) in determining how media articles (re)produce knowledge of Long Covid in CYP within existing power structures. In CDA, discourse is viewed as an inherently social practice that is both reflective of and influential on public perception and power structures [30,31]. Our approach to CDA maintains the fundamental purpose of producing systematic and reproducible problem-oriented investigation [31] but focuses on a craftsmen perspective of methodology [32,33] in integrating elements of thematic analysis. The critical angle taken is informed by the conceptual framework of epistemic injustice [21].

Each article was examined using ANTconc [28] to locate various actors: parents of CYP with Long Covid, HCPs, and CYP with Long Covid. HCPs were defined as medical clinicians as well as scientists and researchers addressed as doctors. Actors were identified in the text via KeyWord in Context search (KWIC) (for the list of search terms used and results yielded, refer to \$4 Table). As a result, the articles were not read in full. Focusing on the overall representation of actors as opposed to individual articles provided a broad overview and allowed the researcher to identify key information and common themes through cross-referencing. Each line was read and coded thematically and linguistically.

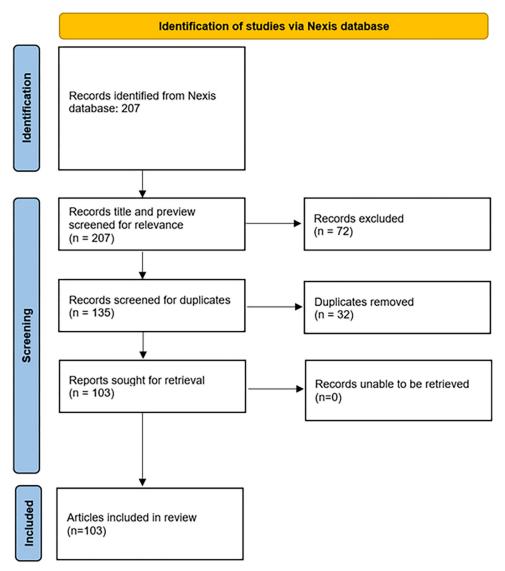


Fig 1. Adapted PRISMA diagram of media articles identified for inclusion.

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Themes were derived based on Braun and Clarke's steps for thematic analysis [34]. The discursive elements of the research were conducted based on Baker's corpus-driven approach to discourse analysis [35]. The thematic diagram was iteratively constructed for each actor based on the developing understanding of identified themes. When beneficial, the significance or uniqueness of findings were evaluated against the BE06, a reference corpus. The BE06 is a publicly available, one-million-word corpus of published written British English and is intended to be used as a representative sample [36]. For a detailed explanation of each step undertaken in the analysis and the rationale behind each step, refer to \$5 Table.

#### Patient and public involvement (PPI)

PPI helped to gain insight into stakeholder perspectives. The founder of a patient advocacy group for CYP with Long Covid which is now a leading charity is a PPI co-author on this paper (SM). She shared her experience in that role, as a person with Long Covid, and as a

parent seeking care for her child. The research co-production process involved a review of potential research questions as well as an overview of the public contributor's lived experience. The methodology and focus of the research were modified in light of this.

#### **Ethical considerations**

We analysed publicly available media articles. Names referenced in quotes from the published media articles were redacted.

# Quality assurance

The data were initially single-coded manually by the primary researcher and then reviewed a second time, as recommended to enhance credibility [37]. Coding of lines was reviewed against the final codebook to ensure strict adherence to the definitions of codes. Single coding likely allowed for greater consistency in the coding process, as there was no potential for interrater coding discrepancy. As a result, reliability is high, but validity is weakened with a single coder. To enhance validity, the data for all codes and themes included in the results were carefully reviewed by a second author (DC) to ensure that the data were well represented by these themes. DC reviewed each line, provided input on the accuracy of the coding classifications as well as on the quotes to highlight as examples. The coding manual and comprehensive thematic maps are included to allow the reader to determine validity and the degree of confidence to be placed in the findings (S6 Table and S4–S6 Figs). Rigour for the study was evaluated according to Lincoln and Guba's criteria for trustworthiness in qualitative research [38]. Our adherence to Lincoln and Guba's four criteria of credibility, transferability, dependability, confirmability are documented in detail in S7 Table. Initial themes were discussed with the other co-authors to enhance trustworthiness in findings.

#### Results

Themes selected for inclusion in the results section below were based on saliency, relevance to the research question, and alignment with the theoretical framework of epistemic injustice.

#### **Parents**

**Parents versus mothers.** Of the 181 times the actor parents were identified via the KWIC tool, 57 instances referred explicitly to the mother. No instances were found where the father of the CYP was specifically referenced. To determine if this is unique to the corpus created for this research, the search terms used were replicated in the BE06. The BE06 identified 1684 references to parents via the KWIC tool, of which instances referring explicitly to the mother and father were exactly equal. This indicates that the absence of fathers in this corpus is atypical. The presented themes collate mothers and parents, with specifications when themes between mothers and parents differed.

# Knowledge produced by parents

**Parents providing information.** The primary function of parents in the corpus was to recount symptoms or the experience of CYP with Long Covid. Often parents reported CYP's symptoms in the context of contributing to research. Sometimes parent-reported symptoms were regarded neutrally, but they were frequently framed as a research limitation or a source lacking credibility. Parents' reporting of CYP's symptoms were devalued when they were seen as subjective and potentially exaggerated. Of note, symptoms are inherently subjective [39], so

the criticism may more accurately reflect criticism of the diagnostic criteria which is based on symptoms and not biomedical markers.

Parents highlighting a lack of support and experiencing personal attacks. The media articles heavily featured parents highlighting a lack of support for themselves and CYP with Long Covid. Within the theme of a lack of support, parents reported minimisation of Long Covid in CYP. In addition, parents cited numerous barriers to care and a lack of available services. Parents also reported experiencing personal attacks in seeking support for their CYP with Long Covid. In many of these attacks, the credibility of the parent was questioned.

The media articles primarily presented lack of support and experiences of personal attacks through quotations and reporting of parents' perception. Media articles did not present parents experience as factual. As a result, the responsibility for the accuracy of the claims lies within the referenced parents as opposed to the journalist. This created an opportunity to devalue parental accounts. For example, in writing "[redacted CYP name] and her mother [redacted parent name] feel the illness hasn't been taken seriously [40]," using the word "feel" highlights their subjective perspectives as opposed to contextualising their experiences within evidence that Long Covid is indeed not taken seriously [41]. In another example, "parents of children with the condition claim nothing has been done to help them [42]," the word "claim" alongside the extreme "nothing" implies that parents' statements may be unreliable.

Parents describing gaps in collective understanding. Parents also described how gaps in collective understanding have impacted CYP with Long Covid. One mother described Long Covid in CYP as "Russian roulette" in reference to the unpredictability of who becomes afflicted [43]. Parents reported feelings of invisibility for CYP with Long Covid, in part due to lack of recognition or proof of the disease.

# Knowledge produced about parents

**Mother presented as having Long Covid.** Mothers (but never parents) were sometimes presented as also having Long Covid. In many of these instances, mothers also described siblings who had Long Covid.

Table 2 displays themes for parents with supporting data.

#### **HCPs**

Knowledge produced by HCPs. Rarity discourse. HCPs were often included in the articles discussing the prevalence of Long Covid in CYP. Of all instances identified in the corpus, 30% of the time HCPs quantified prevalence neutrally and 70% of the time HCPs subjectively appraised the rarity of Long Covid. CYP suffer fewer chronic conditions as adults [50], so the often-used comparison of prevalence across these groups is unlikely to provide a complete account of "rarity" relative to CYP. When attaching a value judgement, 19% of the time HCPs viewed Long Covid in CYP as not rare, and 81% of the time HCPs described Long Covid in CYP as rare. When calling the condition rare, HCPs frequently stated that this should be reassuring for concerned parents. Usually, the CYP with Long Covid were not addressed in this context, but sometimes it was recognised that rarity is not a consolation for those currently affected. One HCP stated "Long Covid seems to be rare in children, but it doesn't matter. If it's your child there needs to be a service for even one child with Long Covid [51]." This deviant example provides a subjective judgement on rarity while still recognising the impact of Long Covid on affected families.

Perceptions of disease validity. HCPs also offered their perceptions on the validity of Long Covid in CYP. In most occurrences that explicitly addressed disease validity, the HCP emphasised that the condition is important to take seriously. However, in some instances the manner

Table 2. Themes for parents.

Theme/subtheme	Supporting data
Theme: Parents providing information Sub-theme: Parents recounting CYP's symptoms or experience in the context of contributing to research	He [research professor] added: "Current studies lack a clear case definition and age-related data, have variable follow-up times, and rely on self- or parent-reported symptoms without lab confirmation." (PA Media, 16 <sup>th</sup> September 2021) [44]     The Office for National Statistics said only one in 100 primary-aged pupils actually have the condition, despite half of parents reporting at least one of its symptoms. (Mail Online, 1 <sup>st</sup> March 2022) [45]
Theme: Parents highlighting a lack of support Subtheme: Minimisation	<ul> <li>Despite the severity of her symptoms, [redacted CYP name] and her mother [redacted parent name] feel the illness hasn't been taken seriously. (Mail Online, 30<sup>th</sup> June 2021) [40]</li> <li>Parents say they are being dismissed or regarded with suspicion by medical professionals over their child's unexplained symptoms. (The Guardian London, 3<sup>rd</sup> May 2021) [46]</li> <li>Christmas Eve [redacted CYP name], from Osbournby, Lincolnshire, had such intense nerve pain she vomited when touched. In A&amp;E she was told she was "one of the lucky ones" for having antibodies and should "get on with it", her mother, [redacted parent name], said. (The Times, 13<sup>th</sup> March 2021) [47]</li> </ul>
Theme: Parents highlighting a lack of support Subtheme: Barriers to care and lack of services	Her mum [redacted parent name] said: "We were told she could access the specialist clinic in Glasgow. But they said no, it would "open the floodgates" for people with long Covid. It's ludicrous." (Scotsman, 5 <sup>th</sup> June 2022) [48] Children left battling long Covid symptoms months after first contracting the virus have received little support from the NHS or Government, parents have said. (PA Media 26 <sup>th</sup> January 2021) [49] Parents tell the group they face a lack of support at every turn, from healthcare to support or children falling behind with school work. (Scotsman, 5 <sup>th</sup> June 2022) [48]
Theme: Parents report experiencing personal attacks Subtheme: Parents reporting experiencing personal attacks	• "doctors have been dismissive to the point of telling me I'm an anxious mother and needed to calm down because children of my daughter's age are not affected by Covid or long Covid." (The Guardian London, 3 <sup>rd</sup> May 2021) [46] • "They opened a multi-agency referral form against me saying I was an unfit mother because of how I broke down." (PA Media, 26 <sup>th</sup> January 2021) [49] • "Many parents on our site have experienced poor care for their children, including diagnoses of anxiety in the child and even, in some cases, some form of Munchausen by proxy in the parents," said [redacted parent name]. (The Guardian London, 3 <sup>rd</sup> May 2021) [46]
Theme: Parents describing gaps in collective understanding Subtheme: Unseen and unverified	• [Redacted CYP name]'s mum [redacted parent name], 51, said: "I think because [redacted CYP name] looks fine, people think she is OK but she's really not" (The Daily Record, 12 <sup>th</sup> September 2021) [42] • The government insistence that children did not need to be tested means there is a "whole wave of children who were never diagnosed but now have long Covid, who are just a bit invisible in the system", said one parent. (The Times, 13 <sup>th</sup> March 2021) [47]
<b>Theme:</b> Knowledge produced about parents <b>Subtheme:</b> Mother presented as having Long Covid	• "I look at all my children and none of them are the same children," she said. [Redacted parent name], a mother-of-two who has also been experiencing symptoms for seven months, added: "We have no answers to this." (PA Media, 26 <sup>th</sup> January 2021) [49]

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in which validation was delivered could be interpreted as backhanded. In one remark, Long Covid is seen as a "side effect [52]" as opposed to a distinct and legitimate condition.

In addition, HCPs engaged in pathologisation avoidance [22], where they hesitated to characterise the experiences of CYP as abnormal or requiring a diagnosis. Pathologisation avoidance was also located in the CYP lines, where one professor quoted in *The Daily Telegraph* noted

"...just how common symptoms such as tiredness or headaches are in children and teenagers, regardless of whether they had Covid or not [53]."

Pathologisation avoidance in the case of Long Covid in CYP may be a form of wrongful depathologisation as the diagnosis is important for receiving care.

Wrongful depathologisation could be observed in a PA Media article,

"Dr [redacted HCP name] of the MCRI and University of Fribourg said symptoms of long Covid were difficult to distinguish from those attributable to the indirect effects of the pandemic, such as school closures, not seeing friends or being unable to do sports and hobbies [44]."

The implication that indirect effects of the pandemic could be erroneously conflated as Long Covid suggests that symptoms of Long Covid are normal aspects of life for CYP impacted by the pandemic.

In other instances, HCPs engaged in overpsychologisation (where they over-attributed Long Covid to mental illness) of Long Covid or they gave an alternate mental health diagnosis based the psychological symptoms of Long Covid. The media articles featured a mix of HCPs perpetuating versus challenging the overpsychologisation of Long Covid.

Difficulties with diagnosis. HCP's also referenced difficulties with diagnosing Long Covid, especially with no confirmation of an initial covid-19 infection. Many media articles were published before a definition was created. Even when the case definition was created, HCPs faced difficulties, with a *Scotsman* article noting

"Leading public health experts have warned it is underestimated, due to a lack of understanding of the post-viral condition among doctors. And there is no simple test [48]."

Knowledge produced about HCPs. HCPs as uninformed. Throughout the corpus, HCPs were characterised as uninformed. One paediatrician warned that "experts are still baffled by the long-term complications of the disease [40]." This lack of knowledge may come from both the novelty of the condition (a pragmatic, not inherently unjust barrier), and a societal lack of conceptual framework to understand Long Covid (an inherently unjust barrier) [9,21]. In other instances, HCPs were outwardly characterised as unjustly ignorant. A Wales Online article read, "Long COVID is a well-recognised condition in children but sadly, there's still poor awareness among some medical professionals [54]." For either reason, HCP's being uninformed appeared to contribute to negative experiences and created a formidable barrier to diagnosis.

Table 3. displays themes for HCPs with supporting data.

#### **CYP**

**Knowledge produced by CYP.** *Describing personal experience.* The most significant aspect of the knowledge generated by CYP was its noticeable absence. While the discourse of the

Table 3. Themes for HCPs.

Theme/Subtheme	Supporting data
Theme: Rarity discourse from HCPs Subtheme: Long Covid is rare	Dr [redacted HCP name], consultant paediatrician at the UK Health Security Agency and study chief investigator, said: 'It is reassuring that the vast majority of primary and secondary school aged children surveyed since March 2020 have not experienced long Covid symptoms. 'These new data should be reassuring for parents, clinicians and policy-makers. (Mail Online, 1st March, 2022) [45]     Dr [redacted HCP name], based at Mater, UCD and Rotunda hospitals, warned: "Long Covid seems to be rare in children, but it doesn't matter. If it's your child there needs to be a service for even one child with Long Covid. It's a failure once again." (The Sun, 15th August, 2022) [51]
Theme: HCP perceptions of disease validity Subtheme: Long Covid is validated	• [Redacted HCP name] warned: 'Kids get less Covid symptoms, they are less likely to die, they are less likely to end up hospital patients. But they do get side effects.' (The Scottish Daily Mail, 22 <sup>nd</sup> July 2021) [52] • GP and author Dr [redacted HCP name] said that while the virus was mild in young children, they were getting long Covid, which was a "real concern". (The Daily Mirror, 14 <sup>th</sup> March 2022) [55]
Theme: HCP perceptions of disease validity Subtheme: Pathologisation avoidance	<ul> <li>Dr [redacted HCP name] of the MCRI and University of Fribourg said symptoms of long Covid were difficult to distinguish from those attributable to the indirect effects of the pandemic, such as school closures, not seeing friends or being unable to do sports and hobbies. (PA Media, 16<sup>th</sup> September 2021) [44]</li> <li>Dr [redacted HCP name] said long Covid exhibits the same pattern as other post-viral illnesses, which children are as susceptible to, as adults. Most people will experience some level of post-viral fatigue at some point in their lives. (The Daily Mirror, 1<sup>st</sup> November 2020) [56]</li> <li>"I'm talking to paediatricians who are already getting referrals—the numbers aren't huge I don't think there's a huge cause for concern," she said, adding that what parents are most frustrated by is that nobody knows much about it because it's a new condition. "The good news is that the majority of young people who get chronic fatigue tend to get better with appropriate support." (The Guardian, 2<sup>nd</sup> March 2021) [57]</li> </ul>
Theme: HCP perceptions of disease validity Subtheme: Long Covid as an already established psychological disorder	Other doctors had determined that her condition was psychological. (The Guardian, 10 <sup>th</sup> August 2021) [58] The study, which has been running since March 2020, involved 134 schools and inputs from the parents of 4,870 pupils. Dr [redacted HCP name], of King's College London, said: "There was no significant difference in the numbers presenting with a 'probable mental disorder' between both groups, whether test positive or negative" (The Daily Telegraph, 1 <sup>st</sup> March 2022) [53] Kids with long Covid are treated terribly. The failings of doctors on this is huge. Most still put it down to anxiety. (The Scotsman, 5 <sup>th</sup> June 2022) [48]
Theme: Difficulties with diagnosis Subtheme: difficulties with diagnosis	• Dr [redacted HCP name], a GP and Glasgow Tory MSP, has raised concerns that long Covid in children is that it can be particularly difficult to diagnose. He said: 'The problem with kids is that, unless it's blindingly obvious, it's difficult getting information out of them.' (The Scottish Daily Mail, 22 <sup>nd</sup> July 2021) [52] • Dr [redacted HCP name], a champion for Long Covid Kids Scotland, told Scotland on Sunday: "Long Covid in kids seems to be hidden but the data shows it's a big problem. My concern is what happens if we don't get confirmation of infection. This is so important. It will have an impact and will increase inequalities. Those who can pay will access tests." (The Scotsman, 5 <sup>th</sup> June 2022) [48]

(Continued)

Table 3. (Continued)

Theme/Subtheme	Supporting data
Theme: HCPs uninformed	<ul> <li>"From the start we have been doing this blind. Doctors have no strategy for how to help [redacted CYP name]" (The Scotsman, 5<sup>th</sup> June 2022) [48]</li> <li>"Our children aren't being recognised as Long Covid sufferers because doctors aren't joining the dots between a wide range of symptoms." (The Sun, 7<sup>th</sup> February 2021) [43]</li> <li>Her mother, [redacted parent name], said clinicians have been supportive, but they have "openly admitted they don't know a lot about long Covid". (Independent Print, 16<sup>th</sup> June 2021) [59]</li> <li>"GPs deal in certainties but there are no certainties here, just a litany of new symptoms. We've been bounced endlessly between child and mental health services and the GP, but still no one has any idea how to help my son." (The Guardian, 3<sup>rd</sup> May 2021) [60]</li> </ul>

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corpus revolved around this actor, CYP were mainly spoken for or about. In the few instances CYP directly produced knowledge, it mainly consisted of CYPs describing the personal impact of Long Covid and grieving the parts of their lives that have changed. CYP sometimes highlighted uncertainty of their condition and the difficulty making sense of what has happened to them.

Knowledge produced about CYP. Overlap with other actor groups. Many of the lines identified for CYP were similar to the lines identified in the parents and HCPs actor groups. There were many lines highlighting a lack of support, mostly from the parent's perspective but sometimes from HCPs or the writer of the media article. In addition, the validity of Long Covid was frequently discussed in the CYP lines. Unlike the HCP actor group, the statements of validity often came from the writer of the media article. In both the validation and invalidation of Long Covid in CYP, explicit references to adults were frequently employed. In statements that validated the condition, the emphasis was on explaining that Long Covid does not only affect adults. In statements that invalidated the condition, the severity of the CYP's condition was regarded as not as serious as in adults.

Formerly very able. CYP were frequently described as formerly very able. The CYP was described by others, typically parents or the writer of the media article, as opposed to providing this information themselves.

**Table 4** displays themes for CYP with supporting data.

Our findings culminate in <u>Table 5</u>, where our main results are mapped onto a framework of epistemic injustice to demonstrate practical effects of the media discourse.

#### **Discussion**

The aim of the study was to determine how UK media articles characterise Long Covid in CYP. This was explored through identifying prominent actors via search terms. The thematic content and the discursive strategies employed in the articles were systematically identified and presented.

This research has demonstrated the ways in which media characterisations of Long Covid in CYP reflect and contribute to epistemic injustice. The media articles both report on instances of epistemic injustice and create them in the discursive strategies used by journalists. Some instances of epistemic injustice, such as when parents are wrongly accused of child abuse, are poignant. However, other examples of epistemic injustice, such as the use of a rarity discourse to reassure unaffected families, are nuanced. While each infliction of epistemic injustice may seem minor, the cumulative effect leads to pervasive marginalisation of affected individuals.

Table 4. Themes for CYP.

Theme/Subtheme	Supporting data	
Theme: Describing personal experience	The overwhelming sentiment among teens with long Covid is a sense of loss. "I have missed out on everything," says [redacted HCP name]. (The Guardian, 10 <sup>th</sup> August 2021) [58]  My teenager said 'we're in a half life, we didn't die and we haven't recovered'." (The Times, 13 <sup>th</sup> March 2021) [47]  What is happening to me? The teenagers trying to make sense of long Covid (The Guardian, 10 <sup>th</sup> August 2021) [58]	
<b>Theme:</b> CYP thematic overlap with other actors <b>Subtheme:</b> Validation of Long Covid	While long Covid is a condition that generally affects older people, teens and children can—and do—become ill. ( <i>The Guardian</i> , 10 <sup>th</sup> August 2021) [58] Children who have contracted Covid-19 are reportedly suffering the effects of the virus for months afterwards, debunking widespread opinion that children wouldn't be hit as hard as older patients. ( <i>The Mirror</i> , 1 <sup>st</sup> November 2020) [56] Now a new study from King's College London reveals that long Covid isn't just a condition of adults but can also affect children and young people. ( <i>The Daily Mirror</i> , 18 <sup>th</sup> October 2021) [61]	
Theme: CYP thematic overlap with other actors Subtheme: Invalidation of Long Covid	Researchers say the findings suggest long Covid is likely less of a concern among kids and adolescents than it is among adults (Mail Online, 1st October 2021) [62]  Long Covid symptoms rarely persist beyond 12 weeks in children and adolescents unlike adults, new research suggests.(PA Media, 16th September 2021) [44]	
Theme: Formerly very able	<ul> <li>The previously sporty teenager—who played football and rugby for local teams—could not take more than a few steps without being overwhelmed with exhaustion. (The Sun, 7<sup>th</sup> February 2021) [43]</li> <li>Aberdeenshire teen [redacted CYP name] used to be an avid skier, competing across the country and overseas but, since catching Covid, she struggles to walk far or carry out simple tasks.(The Daily Record, 12<sup>th</sup> September 2021) [42]</li> <li>Devastated parents have said their previously healthy kids are now confined to wheelchairs and too fatigued to attend school (The Mirror, 4<sup>th</sup> September 2021) [63]</li> </ul>	

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# Parents and testimonial injustice

Parents experienced testimonial injustice when they were featured as gendered, sick, and their accounts were reported as unverified opinions with questionable credibility. Mothers are often responsible for care-seeking, and their familial contributions are reported on more frequently than for fathers [64]. While it was unsurprising that mothers were disproportionately referenced, the absence of fathers on their own was striking. Featuring mothers and not fathers may reinforce gender stereotypes [65].

Table 5. Conceptual framework of findings.

How each actor may experience or enact testimonial injustice			
Parents	HCPs	СҮР	
Portrayed as gendered	Rarity discourse portrays CYP with Long Covid as outliers	Lack of their accounts	
<ul> <li>Mothers presented as also having Long Covid</li> </ul>	HCPs combats testimonial injustice when validating Long Covid	Portrayed as formerly very able in an	
Parental accounts reported as unverified	in CYP	attempt to bolster authority	
opinions	HCPs invalidates Long Covid through pathologisation	,	
Parents report experiencing personal attacks in	avoidance and overpsychologisation		
response to seeking care	Often seen as contributing to negative healthcare experiences		
-	How all actors experience hermeneutical injustice		

- Parents and CYP describe feelings of invisibility as Long Covid in CYP is often unrecognised and unverified
- HCPs seen as uniformed
- Issues with diagnosis
- Long Covid in CYP validated or invalidated in relation to adult Long Covid

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Mothers experienced testimonial injustice in the manner they were presented as also having Long Covid. Due to deeply-rooted societal prejudice against ill people [22], presenting mothers as having Long Covid may create stigma [18]. Ill people are especially vulnerable to testimonial injustice since they are often unfairly over attributed characteristics that pose credibility threats, such as being emotionally unstable [66], cognitively unreliable [66,67], irrational [66,67], psychologically fragile [68], and potentially incapacitated [68]. Additionally, illness is often stigmatised through being implicitly portrayed as a moral or conative failure [68]. This prejudice may be compounded by a historical scepticism of diseases defined as subjective that are more common in women, such as connective tissue disease, ME/CFS, and now Long Covid [22,69,70]. The negative consequences of this are exacerbated when the unique knowledge held by mothers with lived experience of Long Covid is unrecognised, as was seen in the corpus. Presenting mothers as also having Long Covid raised concerns of bias or CYP mimicking mothers. These concerns were explicitly expressed, with a Wales Online article stating, "Parents' perceptions of their own symptoms may have influenced their perception or reporting of their children's symptoms [71]." This speculation has direct negative effects. In PA Media, a mother was featured who "was told by a doctor that her daughter was only "mimicking" her symptoms [49]." This resulted in denial of care for the CYP with Long Covid.

There are many reasons why Long Covid may appear in family clusters. Researchers have identified potential genetic correlations with Long Covid [72–74]. Additionally, a family member's diagnosis can increase awareness and lead to other family members being correctly diagnosed with Long Covid. However, media articles emphasised research that "indicate[s] the critical role of family context on prolonged symptoms following SARS-CoV-2 infection" which "highlight the need for caution in interpreting the causes of prolonged symptoms in SARS-CoV-2 infected individuals, especially children" (*Wales Online*) [71]. Of note, the referenced study [73] acknowledges the potential genetic explanation, but this is misreported in the *Wales Online* media article [71] and mentioned as an aside.

Parents also may have experienced testimonial injustice when their accounts were subject to disproportionate incredulity. Some caution against attributing scepticism, credibility concerns, or alternate diagnoses as testimonial injustice in conditions that are not fully understood and difficult to diagnose [67]. Over-liberally labelling HCP behaviour as inflicting testimonial injustice risks failing to acknowledge the conceptual impoverishment and hermeneutical injustice of Long Covid in CYP [67]. However, conceptual deficits are no excuse for dismissal of parent's testimony on behalf of their CYP. In particular, portraying parental accounts of their CYP's symptoms as unverified opinions obscures the fact that symptoms, by their nature, are unverifiable [20]. Many cases where parental testimony was disbelieved in the corpus went beyond a reasonable clinical judgement to exercise caution in assuming parent testimony to be prima facie fully accurate and authoritative. The corpus revealed a pattern of diminished sensitivity, dismissal, and incredulity directed at parents from HCPs.

The articles also featured instances where parents were personally attacked when seeking care. While important to highlight these injustices, this may create anticipated stigma for other parents [18]. Anticipated stigma was discussed during the co-production stage of this research, where the public contributor recounted multiple cases where parents felt unsafe seeking care for their CYP due to potential allegations of abuse. Both the PPI input and the media articles referenced parents being accused of having Munchausen by proxy, which is both a mental illness and a form of child abuse. The corpus featured an account of a mother having a multi-agency referral form against her, which implied that custody of the child was at stake. When parents read media articles detailing personal attacks with such grave consequences, they understandably may decline to "come forward" to seek care for their CYP. This perpetuates the invisibility of CYP with Long Covid and decreases the likelihood of the CYP receiving appropriate care.

# Healthcare professionals and testimonial injustice

HCPs quoted in the corpus often played a role in perpetuating testimonial injustice through rarity discourse, invalidation of Long Covid as a physical illness, and as the actor contributing to negative healthcare experiences in the form of dismissal, personal attacks, pathologisation avoidance, and overpsychologisation. HCP's combatted testimonial injustice when validating Long Covid in CYP and highlighting the mistreatment of affected families.

While likely done to assuage fear, the rarity discourse from HCPs can perpetuate feelings of isolation for affected individuals. A value judgement of Long Covid as rare in CYP is unwarranted. Often the support given was that adults suffer higher rates of Long Covid, however this statement is of questionable value, as adults generally have higher prevalence of chronic diseases [50]. As of March 2023, a substantial 151,000 CYP in the UK were reported to have Long Covid [75]. During the co-production of this research, it was discussed how the portrayal of Long Covid in CYP as rare contributes to feelings of confusion and self-blame for parents. In addition, the alleged rarity of Long Covid does nothing to help those already afflicted and may silence them through characterising them as outliers. The rarity discourse may lead to the underestimation of prevalence and the under-allocation of resources to address Long Covid in CYP.

Given historical privileging of the authority of HCPs, particularly doctors [76], their validation and invalidation of Long Covid in the media holds great weight. Journalists significantly influence the direction of this discourse through the selection of HCPs to interview and quote. In the corpus, specific HCPs with repeated and unequivocally expressed scepticism of Long Covid in CYP were frequently quoted.

HCPs invalidated Long Covid in CYP through pathologisation avoidance. Pathologisation avoidance has been used to destigmatize groups such as the neurodivergent community [22]. However, pathologisation avoidance in the case of Long Covid in CYP may be a form of wrongful depathologisation as the diagnosis is important for receiving care. Wrongful depathologisation has been seen in both ME/CFS and obsessive compulsive disorder [22], and constitutes an epistemic injustice [22,25,77].

In addition, there was an implicit narrative that Long Covid is "just fatigue". One HCP stated that "most people will experience some level of post-viral fatigue at some point in their lives [56]," with another HCP noting "the good news is that the majority of young people who get chronic fatigue tend to get better with appropriate support [57]." By switching from the term Long Covid to describing fatigue, the articles framed Long Covid and fatigue as one in the same. As seen in the ME/CFS literature, fatigue from a chronic condition is often misconstrued as something everyone experiences and is subsequently trivialised [22].

HCPs also engaged in testimonial injustice where they overpsychologised Long Covid or they gave an alternate mental health diagnosis. Long Covid has psychological elements that should be recognised and addressed, but the whole attribution of the illness to mental health causes harm [78,79]. Long Covid is a predominantly a multi-system, multi-symptom disease [80]. Giving a psychological diagnosis as opposed to a Long Covid diagnosis can harm wellbeing, and may lead to neglecting the physical symptoms of Long Covid [16]. In addition, a wrong diagnosis is a form of hermeneutical injustice where patients are less able to make sense of their experience [25,68]. Misdiagnosing Long Covid as a mental illness hinders progress in understanding Long Covid and producing effective treatments [78,81].

People with Long Covid may experience testimonial smothering, where they underreport mental health symptoms because they reasonably believe their testimony will be misunderstood or taken as evidence that their affliction is entirely due to a psychological disorder. Testimonial smothering and its negative consequences have also been recorded in ME/CFS and in

domestic violence disclosures [22,82]. It can result in poor patient experience and may harm progress in understanding the psychological aspects of Long Covid [83]. In the corpus, HCPs both forwarded the overpsychologisation narrative and challenged it. In one example, an HCP challenged the narrative, stating that "Kids with long Covid are treated terribly. The failings of doctors on this is huge. Most still put it down to anxiety [48]." HCPs may be among the most effective voices in challenging the whole attribution of Long Covid to mental illness, given their professional expertise. However, the salience of individual HCP voices is greatly influenced by who the media chooses to approach and quote, and there may be a selective bias.

Lastly, HCPs perpetuate testimonial injustice through invalidating experiences of Long Covid. Trust in HCP's ability to address Long Covid in CYP may be eroded in those experiencing and reading about invalidating healthcare interactions. This loss of trust has profound public health implications [84]. Patient's trust is an important indicator of care quality, and is associated with better outcomes, treatment adherence, and timely seeking of care, which are important for recoveries and cost-efficiency [84].

# CYP with Long Covid and testimonial injustice

CYP may have experienced testimonial injustice in the lack of coverage of their voice and in the presentation of being formerly very able. Some reasons for the lack of CYP voices may relate to understandable concerns over privacy and ability to consent to public disclosure of medical information. While these are important considerations that protect CYP, they have the potential to contribute to lack of representation of CYP perspectives and the consequences that follow. Of note, it can be difficult to distinguish testimonial injustice in CYP from justified differential treatment based on an established understanding that CYP's capacity and legitimate epistemic ability develop with age [85]. However, being a CYP is often a heuristic for epistemic unreliability to a greater magnitude than appropriate [85]. Because of the difficulties in definitively identifying epistemic injustice in CYP, we cannot say with certainty where testimonial injustice has taken place. However, there are several instances we identified that may constitute or contribute to testimonial injustice.

CYP were largely excluded from producing knowledge in the corpus and were instead spoken for or about. While many are too young or too sick to contribute to articles, it is likely that there are CYP with Long Covid interested sharing their knowledge. As seen in how knowledge on Long Covid was created on Twitter, people with Long Covid have expertise that needs to be viewed alongside the traditional, medical knowledge base [3,4,6,39]. A potential alternate explanation is that media outlets did seek the opinions of CYP, but CYP declined to participate, potentially due to anticipated stigma (which the media contributed to) [18].

Journalists and parents likely attempted to proactively counter invalidation and minimisation of Long Covid through presenting CYP as formerly very able. This mirrors the way patients with ME/CFS have been described in the media [22]. Highlighting that the CYP was formerly healthy counteracts the tendency to blame the victim for poor health or to suggest that the CYP already had their symptoms before Long Covid due to other factors [22]. In addition, the formerly very able characterisation may draw more public interest, as it suggests that even the healthiest are at risk [22].

Characterising CYP as formerly very able highlights how significantly Long Covid affects lives but may have unintended consequences. Boer argued that this characterisation constitutes epistemic injustice [22]. The use of the formerly very able trope to bolster validity implies that Long Covid may be less valid in a CYP that was not formerly very able. This further stigmatises CYP with Long Covid that have a previous chronic illness or disability. Some chronic illnesses have been shown to be associated with an increased risk of Long Covid [86], and the

Long Covid experiences of individuals with comorbidities are equally important to take seriously. Additionally, this characterisation may undercut CYP's agency by focusing on their past abilities to highlight their current struggles. By focusing on a person's past abilities, the articles overshadow the current perspectives and experiences of the individual which still hold value. In viewing the CYP primarily through their loss of function, the emphasis on decline may also lead to a perceived decline in CYP's credibility. This may mean that a testimony is not evaluated based on its own merits.

# Hermeneutical injustice across actors

All actor groups are harmed by the hermeneutical injustice seen in Long Covid in CYP. One mother emphasised the difficulty of having her child's Long Covid unrecognised, saying "I think because [redacted CYP name] looks fine, people think she is OK but she's really not [42]." At the broader level, another parent noted that there is a "whole wave of children who were never diagnosed but now have long Covid, who are just a bit invisible in the system [47]." A diagnosis, while sometimes stigmatising, provides a hermeneutical device for CYP to understand their experience [22,25,87]. Without a clear way to make sense of their ongoing symptoms, one teenager explained that "we're in a half-life, we didn't die and we haven't recovered' [47]." This "middle ground" between recovery and death was one of the primary aspects of Long Covid identified on social media [3,6,88]. The idea that covid is "mild" if the individual is not hospitalised created a false dichotomy that ignores the reality of Long Covid [3,6,88].

Long Covid can only be diagnosed when there is a probable acute covid-19 infection. This presents a hurdle to a diagnosis and available care. One parent interviewed in *The Times* described how lack of testing hindered a Long Covid diagnosis, "we have heard so many times from doctors that it isn't related to Covid. They wouldn't do an antibody test, I felt that they wouldn't even give it a try. You hear about all these long Covid clinics, but no kids can get in them [47]."

One HCP outlined the broader public health implications of this, stating "My concern is what happens if we don't get confirmation of infection. This is so important. It will have an impact and will increase inequalities [48]." If confirmation of infection is essentially required to access services, many CYP will be unfairly denied care.

A few HCPs in the corpus mentioned an additional barrier to diagnosis, with one HCP in the *Scottish Daily Mail* stating 'The problem with kids is that, unless it's blindingly obvious, it's difficult getting information out of them [52]." While this may be overstated for older CYP, this is a legitimate concern for younger CYP. Some symptoms of Long Covid, such as anxiety, may be difficult for a CYP to fully comprehend, let alone explain [89].

CYP are inherently at a hermeneutical disadvantage within the adult-created healthcare system, as their unique understanding and experience of illness is projected onto an adult interpretive framework [25]. Within the covid-19 pandemic, there was a systematic deprioritization of children's interests [90]. The media initially portrayed children as vectors of covid-19 instead of individuals at risk [90]. With mounting evidence that children contract covid-19, the narrative morphed to how covid-19 in children is mild [90]. This narrative has been countered with evidence that children (with and without underlying conditions) can suffer severe acute covid-19. Now, the narrative that children do not get Long Covid is causing harm. Policy decisions related to the pandemic in general have failed to fully consider potential harms for CYP and the risks associated with infection (including the risk of Long Covid), and this has been described as a form of childism [91]. This builds off a historic context where medical research and discourse focuses on adults who are seen as those primarily at risk of chronic conditions [50].

Validating Long Covid through saying it is similar in CYP and adults fails to recognize the unique challenges of Long Covid in CYP. Invalidating Long Covid through claiming that Long Covid does not affect CYP as often or as severely as adults also constitutes hermeneutical injustice. Long Covid is not necessarily less severe in CYP than it is in adults. Regardless, the "hierarchy of suffering" is a problematic concept [92] that downplays the unique challenges faced by CYP.

#### Recommendations

There are several actions journalists can potentially take in the future which may reduce the epistemic injustice experienced by actors in the media characterisations of Long Covid in CYP. Journalists played a key part in perpetuating epistemic injustice but were not directly involved in many of the experiences of epistemic injustice they reported on. However, given their large platform and demonstrated importance in the knowledge construction in chronic diseases [22], they may be uniquely positioned to combat epistemic injustice.

Fig 2 outlines five recommendations for journalists for future reporting of Long Covid in CYP. Verifying information to avoid unsubstantiated opinions can bolster reports by parents and CYP through corroborating accounts. At the same time, this strategy can provide context for subjective perspectives that may be otherwise unscrutinised due to the perceived authority of the actor (e.g., a HCP reporting that Long Covid is "rare" in CYP). Providing a balanced perspective on CYP in Long Covid would challenge stigmatising narratives and prevent an oversimplification of Long Covid in CYP. Recognizing the often unique challenges and experiences of CYP with Long Covid will deepen societal understanding and combat hermeneutical injustice, and seeking direct insight from CYP will also combat testimonial injustice. Journalists should exercise caution when using sensationalism to attract readers given the existing stigma and barriers to care for CYP with Long Covid. Finally, journalists should be mindful of how subtle word choice can frame CYP with Long Covid and their parents in disempowering ways.

These recommendations would be strengthened with the input of CYP with lived experience of Long Covid and other relevant actors such as parents of CYP with Long Covid. Future research could evaluate the potential impact of these recommendations in the reporting of Long Covid in CYP, and potentially explore whether these recommendations would improve practices in reporting of Long Covid generally or on reporting on other diseases in CYP.

#### Strengths and limitations

The corpus-based method of this study was both a strength and limitation. The use of concordance lines enabled the researcher to review all articles located in a comprehensive, systematic search of UK media articles. The findings are therefore likely representative of UK media focused on Long Covid in CYP. A limitation is that the researcher did not read each line in the context of the entire article. This may have resulted in contextual misunderstandings. The researcher sought to compensate for this through an extensive data familiarisation phase. As is standard in corpus research [35], when the context of an element in the sentence was unclear, a larger section of the file was read and included. This resulted in a variable amount of context surrounding each search term, which may have resulted in the overcoding of certain themes based on inclusion of additional sentences. Another limitation of the study is that the data was initially single coded, and the study's validity would have been improved with a second coder's input throughout the analysis process. This limitation was partially compensated for with the (unblinded) review and input of a second coder after all data was initially coded.

# **RECOMMENDATIONS FOR JOURNALISTS Verify information to avoid** unsubstantiated opinions • Seek to corroborate the experiences of children and young people with Long Covid, and their parents Provide context for subjective perspectives on how "rare" or "serious" Long Covid is Provide a balanced perspective and challenge stigmatising narratives • Be aware and mindful of stigmatising narratives • Ensure that healthcare professionals validating Long Covid are adequately represented • Actively seek insight from those with lived experience, and recognize their expertise Recognise the challenges and experiences of children with Long Covid • This deepens societal understanding and helps combat hermeneutical injustice Prioritise care over sensationalism · Emphasise the need for proper diagnosis and care for children and young people with Long Covid, rather than focusing solely on dramatic elements of individual cases Be mindful of language How actors are introduced and described affects how credible they How Long Covid is described shapes views on its causes and legitimacy Consider how affected people might feel when reading the article

Fig 2. Recommendations for journalists to counter epistemic injustice in reporting Long Covid and similar conditions. Graphic created using Canva software.

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Additionally, a limitation of the search term method to identify actors is that actors were not located when they were referred to by personal pronouns or proper nouns. It is possible that the themes identified via search terms were systematically different from the themes around personal pronouns or proper nouns of the actors.

A notable strength of this research was the research being co-produced with people with lived experience of Long Covid and advocating for its recognition in children. This enabled the research questions to focus on what is impacting families of CYP with Long Covid. In addition, the use of the conceptual framework of epistemic injustice focused the research and facilitates comparison with related examples of epistemic injustice in healthcare.

# Conclusion

This study highlighted discursive practices employed by journalists that contribute to epistemic injustice. The study's findings also indicate a pattern of HCPs dismissing and stigmatising families impacted by Long Covid in CYP. Future research should seek to understand how families with Long Covid feel about media characterisations, and how this impacts efforts to seek and receive care. While this study focuses on the experience of CYP with Long Covid in the UK, findings may be generalisable. Readership for UK media articles is often global, and articles may impact perception of Long Covid in CYP beyond the UK. The UK is a leading much of the work on Long Covid [93], especially regarding research and investing in services for CYP. Despite the UK potentially offering better care for Long Covid in CYP compared to many other countries, families report facing significant barriers to care. These reported barriers likely mirror those in other countries, which may face even greater challenges due to a lack of comparable investment in CYP services. Additionally, evidence of epistemic injustice has also been demonstrated in media reporting of ME/CFS [22], and there may be other conditions portrayed in a similar manner. Based on this study's findings, the researchers have identified recommendations for future reporting of Long Covid in CYP.

# **Supporting information**

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S1 Fig. Political leaning of media articles.
(TIF)
S2 Fig. Style of media articles.
(TIF)
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S3 Fig. Year media articles were published. (TIF)

**S4** Fig. Map of themes for parents. (TIF)

S5 Fig. Map of themes for HCP.

S6 Fig. Map of themes for CYP with Long Covid.

S1 Table. LexisNexis search strategy.

S2 Table. List of included and excluded publishers from Lexis Nexis.  $(\mbox{\scriptsize DOCX})$ 

S3 Table. Characterisation of each publisher.

(DOCX)

S4 Table. Search terms used for each actor.

(DOCX)

S5 Table. Analyses process for study.

(DOCX)

S6 Table. Codebook for actors.

(DOCX)

S7 Table. Trustworthiness of findings.

(DOCX)

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