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Identifying priority areas for research in the post COVID-19 Community Care Context for Babies, Children, and Young People with Medical Complexity: An adapted James Lind Alliance approach

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Abstract

Background

Seven years on from the COVID-19 pandemic, professional nursing and family carers worldwide remain significantly impacted, including Long COVID. This research priority exercise, conducted in England, aimed to identify priority research areas in the post COVID-19 community care context of babies, children, and young people experiencing medical complexity.

Methods

Four phases: Phase 1 - rapid review, exploratory focus group (n = 63), one-to-one conversations/interviews (n = 6), secondary data analysis (n = 78); Phase 2 - electronic survey distributed to community professionals (n = 65) for rating on importance; Phase 3 – ranking exercise via an electronic survey consisting of top research ideas from Phase 2 distributed to six community experts; Phase 4 - final ranking through an online expert group with nine senior Community Children's Nurses/managers. Descriptive statistics were used to analyse quantitative variables, whilst qualitative data were analysed using content analysis.

Results

The review identified 384 articles. Following screening, five were identified for full-text review, but were later excluded, leaving no articles to inform the survey. Following synthesis of Phase 1 data, a list of 33 'research ideas' formed the Phase 2 survey. Based on mean scores, 17 research ideas were advanced into a ranking exercise in Phase 3 which resulted in two broad consensus themes of 1. DIRECT (impact as a direct result of Long COVID) and 2. INDIRECT (broader impact issues arising from COVID-19). In Phase 4, nine priority research areas with two themes (DIRECT/INDIRECT) were identified.

Conclusions

This study identified priority research areas in community care context of babies, children, and young people experiencing medical complexity post-COVID-19. In short, the COVID-19 pandemic is still impacting on services. Results are important to guide politicians, clinicians, researchers, and funders in addressing these priorities. Despite the global pandemic having passed, understanding the implications and ramifications on professional and family carers of Long COVID remains important.

Key Messages

- Four research priorities were identified that represent a roadmap for research to support this population and their professional and family carers in the continuing context of Long COVID.
- Research investigating transition, workforce planning, and remote working remains critical to undertake in the post pandemic context.
- Results are vital to guide all stakeholders, policymakers, and funding organisations in addressing the concerns of highest importance and impact in what is a landscape of increased demands and scarcity of resources.
- Research is needed to explore the potential ramifications on family and professional carers to this vulnerable and increasing population of babies, children, and young people and to identify who has been most impacted in the context of Long COVID.
- Uniquely this study examined views around research priority areas as voiced by professionals and family carers caring for babies, children, and young people with medical complexity in community settings, considering the impact of Long COVID and the post COVID-19 pandemic context.

Background

Seven years on from the COVID-19 pandemic, professional nursing and family carers worldwide remain significantly impacted, including Long COVID. This often-debilitating condition emerged as a post-viral reaction to COVID-19 infection (Faux-Nightingale et al., 2024). According to the National Institute for Health and Care Excellence (2024), a person is considered to experience Long COVID (Post COVID syndrome) when there is continuation or development of new symptoms three months after the initial SARS-CoV-2 infection, with these symptoms lasting for at least two months with no other explanation[1]. In the United Kingdom (UK) the prevalence and impact on people's health and functioning was significant with some guidance for services developed (National Health Service England [NHSE], 2023).

Babies, children, and young people with medical complexity are a rising population internationally (Breneol et al., 2019; Fraser et al., 2021; González et al., 2017; Yamada et al., 2020; Yu et al., 2021). Predominantly this group are cared for in the home (Coad et al., 2015; Schröder et al., 2024) by both family carers (such as parents, carers, siblings) and health and care professionals (such as medical doctors, nurses, physiotherapists, psychologists, social care, and support workers). This population and their families experience a confluence of risk factors identified internationally by Michelen et al. (2021) and nationally by NHSE (2023) and the Office for National Statistics (2023) that are associated with Long COVID. For example, parents or carers experience a higher incidence of mental health issues (Bayer et al., 2021; Fraser et al., 2021; Verma et al., 2020). Although there is no direct evidence studying this subset of parents or carers, Robinson et al. (2021) reports that during the pandemic mental health challenges were exacerbated in those who are vulnerable. Concurrently, for anyone in need, access to mental health services was reduced (Liberarti et al., 2022; Patel et al., 2021). Any illness in either care group impacts on the distribution of available care and consequently the health of this fragile population of babies, children and young people.

Internationally, healthcare settings that already faced multiple challenges and structural inequalities faced unprecedented pressures from COVID-19 (British Medical Association, 2024; Filip et al., 2022; Kahn, 2023; Liberarti et al., 2022). Subsequently significant and unprecedented change (British Medical Association, 2024; Dopher et al., 2020; Filip et al., 2022; Fong et al., 2025) and existing barriers to care were exacerbated (Asan et al., 2025; Beight et al., 2022; Curran et al., 2024). In England, Coad et al. (2023) reported inequity in service provision and delays in access to treatments, resources and appointments to babies, children, and young people experiencing medical complexity. Changes to care provision were reported in England by Adams et al. (2024), in Italy by Grigoletto et al. (2022), in Canada by Diskin et al. (2020), and in the United States of America by Tager et al. (2024). Further, families were reluctant to seek healthcare services (Adams, et al., 2024; Dopfer et al., 2020; Hu et al., 2022; Isba et al., 2020). Thus, the health and social care context babies, children, young people and their families changed.

The early reports that COVID-19 exposed the vulnerabilities of children with medical complexity and their families (Asan et al., 2025; Baumbusch et al., 2022; BBC Children in Need, 2020; Driansky et al., 2022; Mitchell et al., 2021; Robinson et al., 2021), is supported by emerging data by the Children's Commissioner (2026). This report documents significant delays in discharge and a lack of care coordination. While the UK government has invested £57 million into clinical Long COVID research (UK Government, 2025) research priorities have not been fully described in the context of how Long COVID is impacting on these families. Thus, signalling to relevant funders and researchers, remains at a very early stage. Emerging research on heathy babies, children, and young people and their families by Faux-Nightingale et al. (2024) reports a severe impact of Long COVID on their lives. Babies, children, and young people and their families living with medical complexity are at highest risk for poor medical outcomes (Yu et al., 2021) and experience existing fragility and high parental stress (Mitchell, 2021). Therefore, it follows that their lives may have been significantly impacted and seven years on this may remain (Barach et al., 2020; Diskin et al., 2022; Tager et al., 2024). An examination of how Long COVID disrupts care relationships is therefore vital, to mitigate the impact on services to this vulnerable population and their families. Indeed, the importance of research into Long COVID is recognised in a recent policy document by the UK Government (2025).

Aims

The purpose of the study reported here, was twofold.

1: To understand the current Long COVID landscape of evidence in terms of working with and caring for babies, children, and young people and families, in community settings.

2: To identify and to prioritize nursing research topics of importance as defined by Community Children's Nurses working with and caring for babies, children, and young people and families with medical complexity in the context of Long COVID.

Specifically, a Research Priority Exercise was used drawing on the principles of an adapted James Lind Alliance (JLA) approach (Apea et al., 2025; Cowan et al., 2021; Gray et al., 2017; JLA, 2025; O'Connor et al., 2023). This paper presents the results obtained from this four-phased study within this emerging field of evidence, examining an important area of practice that hitherto was lacking.

Methods

Design

A rapid appraisal design (Johnson & Vindrola-Padros, 2017) was undertaken using multiple different data collection methods to allow for the triangulation of findings. Adapted from the James Lind Alliance methodology (JLA, 2013, 2021, 2023) a modified four-phase process was conducted to identify priority areas for research between May 2023 and February 2024. The authors have reported in line with Tong et al. (2019) and Viergever et al. (2010).

Ethical approval was granted by the Research Ethics Committee, Faculty of Medical and Health Sciences at the University of Nottingham (reference number FMHS 290-0523). Informed consent was obtained electronically from survey participants at the time of completion. Written informed consent was obtained by a member of the research team prior to initiation of interviews and online focus groups.

Participants

Three purposive samples of stakeholders in Community Children's Nursing participated in phases 2 to 4. In survey one most participants (46/65; 68%) were aged between 36 and 55 and all those in the second survey were aged between 56 and 65. Overall, most participants were female (61/65; 94%) and White British (64/65; 98%). In the first survey, 58/65 (89%) respondents stated the areas they worked within in relation to medical complexity. Twelve specialisms were stated, the most being long term ventilation 25/58 (43%), transition services 22/58 (38%), with all others stated by less than 10 participants.

Procedure

Phase 1 Identifying Priority Areas for Research

Areas for research about the healthcare context that babies, children and young people with medical complexity are cared for in the post COVID-19 environment were obtained from a rapid review, an exploratory focus group, interviews and secondary data analysis of two free response questions within a previous mixed methods study (Coad et al., 2023) (Ethics FMHS 12–0422 n = 72 & 73) (JC, ST).

Methods in the rapid review were informed by the World Health Organisation's guide on rapid reviews (Tricco et al., 2017). The search strategy for peer reviewed literature was developed with input from a health information specialist and included the following electronic databases: Medline, Cumulative Index to Nursing and Allied Health Literature (CINAHL), PsycINFO and Scopus. Preliminary searches to identify relevant search terms were carried out July-September 2023. The final searches were carried out by SA on 27th November 2023. No articles met the inclusion criteria and so the review could not inform the survey. The full review protocol including the inclusion and exclusion criteria is available from the Open Science Framework (Aldiss et al., 2023). Two researchers (SA and ST) screened the articles in the title/abstract and full-text phases. No articles met the inclusion criteria and so the review could not inform the survey.

The focus group was thus vital in shaping the survey. It was held using Microsoft Teams (MS Teams) and was facilitated by JC. Focus group participants (n = 63) were community professionals including Community Children's Nurses who came from various regions of England and the interviewees included a parent and one young person with complex health needs. Broad areas included roles during and following COVID-19 and nursing research topics of importance when working with and caring for babies, children, and young people and families with medical complexity in the context of Long COVID. The questions posed to the focus group participants and interviewees are provided in Supplementary File 1.

Following content analysis of qualitative data (Graneheim & Lundman, 2004; Renz et al., 2018), an electronic questionnaire consisting of 33 broad research questions was developed in JISC online software (JC, ST).

Phase 2 and 3 Refining the Priority Areas for Research

Phase 2: Following synthesis of Phase 1 data sets, quantitative data were obtained by an electronic survey (Supplementary File 2) distributed by email to community professionals including Community Children's Nurses (120+). The survey had three sections divided into: section 1–33 research ideas, two free response questions for suggesting further ideas or providing comment; section 2 - nine demographic questions; section 3–16 COVID-19 related questions. Participants were asked to rate each research idea according to how much of a priority they considered it to be for research to answer it from '1 = not important at all' to '10 = very important'. Questions in section 2 and 3 comprised open ended questions, closed, and multiple-choice type questions. The number of questions varied between 55 and 60 depending on the answers previously provided.

Team members (ST, JC) defined a priori items with a score of less than 5.0 (on 0–10 Likert Scale) as not achieving consensus but adjusted this to less than 7.5 considering the high ranking of all topics (all research ideas mean score 7.53, mode 7.52). Seventeen research ideas had a mean score of over 7.5. The 16 research ideas with a mean below 7.5 were removed and the remaining 17 research ideas developed into a second survey for use in Phase 3.

Phase 3: To further refine these research ideas, six experts (Registered Nurses and families) were invited via email by a member of the research team to complete a second electronic survey to blind rank the 17 research ideas from 1–17 lowest to highest priority for research. However, consensus in ranking was not agreed as indicated by the standard deviations. Consequently, as permissible under JLA (2021) methodology an alternative working was applied. Namely the 17 research topics were revisited and discussed by three researchers (ST, FG, JC). Ensuring not to lose any content, topics containing overlapping concepts were combined, resulting in nine research topics. Fabbri et al. (2024) employed a similar technique at a workshop, and it is allowable and necessary to combine similar uncertainties, especially at the final priority setting to include as many topics as possible (JLA, 2013, 2021). The topics aligned to two priority themes and were subsequently agreed by the six community experts as defined by JLA (2013). These included A. DIRECT (Impact as a direct result of Long COVID) and B. INDIRECT (broader impact issues that arose due to COVID-19). This process is provided as Supplementary File 3. A final round (Phase 4) with nine senior Community Children's Nurses/managers was added to rank the research ideas.

Data from the JISC online surveys in Phases 2 and 3 were download into Microsoft Excel (Microsoft Corporation, Redmond, WA) and analysed using descriptive statistics. Descriptive statistics were calculated for all demographic variables. The sample size for sections two and three of the survey varied because of the nature of the survey (i.e. questions adapted to respondents' previous answers). There was no need to impute missing values.

Phase 4: Prioritisation of Areas for Research

Phase 4: To complete the process of identifying priority areas for research, an online consensus workshop led by JC with logistical support from ST was held with nine Registered Community Nurses working in England. Participants were asked to undertake two separate ranking exercises for each of the two themes identified through Phases 2 and 3 so that the top priority could be identified. Mentimeter Interactive Presentation Software was used with participants completing the ranking exercise on their own devices. No support was required. The responses from the Mentimeter Interactive Presentation Software exercise comprised the data for Phase 4.

The stages of data collection and steps that were carried out to reach consensus are outlined in Fig. 1.

INSERT FIGURE 1 **HERE**

Results

Phase 1

Rapid Review

Results were imported into Covidence which removed duplicates automatically on import.

The rapid review searches identified 443 articles, 59 were duplicates and removed. The list of duplicates removed was checked by SA for accuracy with no errors found. Three-hundred and eighty-four articles were screened based on title/abstract. Five articles were identified for full-text review. Following full-text review, all five were excluded as they did not fit the inclusion criteria. One of these articles was a review (Hossain et al., 2023), the reference list was checked for further articles, and none were eligible for inclusion highlighting the poor evidence base in this area. As no relevant articles were identified, (Aldiss et al., 2023) no analysis could be undertaken to provide input to the survey.

Content Analysis of Qualitative Data

A total of 63 statements yielded from the focus group and interviews were subject to content analysis (Graneheim & Lundman, 2004; Renz et al., 2018). Also, a secondary analysis was undertaken on the free text responses from two questions within a mixed methods study by Coad et al. (2023). This analysis identified three themes: 1) Issues facing babies, children, and young people, and their families, 2) National Issues, and 3) Workforce issues, and 11 subthemes (see Table 1). From these themes, a list of 33 research ideas for Phase 2 were generated.

Table 1 *Themes Identified from the Qualitative Data in Phase I*

Theme	**Sub theme**	**Frequency** **From Focus Groups and Interviews**	**Frequency from Coad et al. (2024)** **Q.44** **How do you feel COVID has impacted professionals working within palliative and end of life care services?**	**Frequency from Coad et al. (2024)** **Q.45** **45. How do you feel COVID 19 has impacted children and their families?**
Issues facing BCYP and their Families	Transition: One topic	3.0%	0	0 %
	Coping: Seven topics	21.21%	21.6%	22.32%
	Experiences of BCYP One topic	3.0%	0	1%
	Experiences of marginalised groups: One topic	3.0%	2.06%	10.71 %
National Issues	Management of service and care: Nine topics	27.27%	41.24	44.64%
	End of Life Palliative care: One topic	3.0%	0%	0
	Technology: Two topics	6.00%	7.22%	0
	Clinical: One topic	3.0%	1%	14.29
Workforce Issues	Training: Four topics	12.12%	5.15%	0
	Staffing, retention, and wellbeing: Five topics	15.15%	20.62%	7.14%
	Risk and safety: One topic	3.0%	1.03%	0

Phases 2 to 4 Identifying Priority Areas for Research

Phase 2 Survey One Results

Sixty-seven (an approximate response rate of 55%) responded to survey 1. Two respondents were excluded from analysis due to answering the same to each research idea; therefore, the final number of respondents included was 65. From ranking the mean and standard deviations obtained from the responses, a list of 17 research priorities were identified and the mean scores and standard deviations for these items are shown in Table 2. The representation within this list of 17 research ideas from each of the three domains identified in Phase 1 was National Issues – six topics, babies, children, young people Issues – four topics, and Workforce Issues – seven topics. The 17 represented all subthemes from the content analysis in Phase 1. Seventeen (26.5%) of respondents suggested a research topic.

Table 2

Top 17 Research Priorities from the Phase 2 Survey

Research Idea	Mean	S.D.
1.How can barriers faced by BCYP experiencing complex medical needs in the transition to adult services be overcome	9.15	1.23
2.Research to examine how we can develop a workforce and training plan to deliver equitable and essential services to BCYP experiencing complex medical needs and their families.	8.83	1.23
3.What are the best ways to develop an Advanced End of Life Plan for BCYP experiencing complex medical needs and for maintaining hospice care	8.58	1.57
4.What is the current image of children's nursing as a career: Where we are now and what future do we envisage	8.45	1.38
5.How can organisations support CCN's to maintain their health and support staff retention	8.42	1.31
6.To research how BCYP experiencing complex medical needs cope (practically and emotionally) in the face of crisis and uncertainty.	8.2	1.49
7.How do staff shortages impact on the work context and well-being of CCN's.	8.17	1.71
8.Reviewing the organisation's role in supporting BCYP experiencing complex medical needs and their families to maintain their health.	8.15	1.52
9.What would a workforce and training plan to deliver equitable and essential services to BCYP and their families look like	8.03	1.56
10.Research to understand risk to BCYP experiencing complex medical needs, families, and staff in the context of staff shortages and remote working.	7.97	1.49
11.Research to understand the impact of restricted face to face contact on staff, BCYP experiencing complex medical needs, and their families.	7.94	1.56
12.Research to develop a service delivery plan to BCYP experiencing complex medical needs and their families in the event of another pandemic or crisis.	7.77	1.61
13.Research to explore the use of digital technologies and non-face to face in the clinical assessment of BCYP experiencing complex medical needs and their families.	7.74	1.80
14.Research to understand how CCN's cope (practically and emotionally) in the face of crisis and contexts of uncertainty.	7.63	1.77
15.To research the role of external agencies such as of schools, charities, and allied professionals in supporting BCYP experiencing complex medical needs and their families.	7.58	1.71
16.Research to develop strategies to promote the wellness of staff, BCYP experiencing complex medical needs and their families during isolation.	7.52	1.61
17.In the context of a crisis such as the pandemic, what is the essential skill set for a CCN or for someone who may carry out the role	7.52	1.96

Phase 3 Survey Two Results

Analysis of means and standard deviations obtained from the ranking of the 17 research ideas in survey two showed consensus between stakeholders was not obtained. For example, in Table 3a difference in rank by five points or more for eight of the 17 research ideas can be seen.

Table 3
Comparison of Rank of Research Ideas from Phase 2 and 3

Survey one Phase 2 Rank by Mean	Survey two Phase 3 Rank by Mean	Domain	Research Idea
1	16	Babies, Children and Young People Issues	How can barriers faced by BCYP experiencing complex medical needs in the transition to adult services be overcome?
2	4	National	Research to examine how we can develop a workforce and training plan to deliver equitable and essential services to BCYP experiencing complex medical needs and their families.
3	11	National	What are the best ways to develop an Advanced End of Life Plan for BCYP experiencing complex medical needs and for maintaining hospice care?
4	17	Workforce	What is the current image of children's nursing as a career: Where we are now and what future do we envisage?
5	9	Workforce Issues	How can organisations support CCN's to maintain their health and support staff retention?
6	7	Babies, Children and Young People	To research how BCYP experiencing complex medical needs cope (practically and emotionally) in the face of crisis and uncertainty.
7	12	Workforce Issues	How do staff shortages impact on the work context and well-being of CCN's.
8	6	National	Reviewing the organisation's role in supporting BCYP experiencing complex medical needs and their families to maintain their health.
9	5	Workforce Issues	What would a workforce and training plan to deliver equitable and essential services to BCYP and their families look like?
10	2	Workforce Issues	Research to understand risk to BCYP experiencing complex medical needs, families, and staff in the context of staff shortages and remote working.
11	1	Babies, Children and Young People	Research to understand the impact of restricted face to face contact on staff, BCYP experiencing complex medical needs, and their families.
12	3	National	Research to develop a service delivery plan to BCYP experiencing complex medical needs and their families in the event of another pandemic or crisis.
13	10	National	Research to explore the use of digital technologies and non-face to face in the clinical assessment of BCYP experiencing complex medical needs and their families.
14	8	Workforce	Research to understand how CCN's cope (practically and emotionally) in the face of crisis and contexts of uncertainty.
15	15	National	To research the role of external agencies such as of schools, charities, and allied professionals in supporting BCYP experiencing complex medical needs and their families.
16	13	Babies, Children and Young People	Research to develop strategies to promote the wellness of staff, BCYP experiencing complex medical needs and their families during isolation.
17	14	Workforce	In the context of a crisis such as the pandemic, what is the essential skill set for a CCN or for someone who may carry out the role?

Note: The number one ranking of the first item was not accounted for by the 22 participants who worked in transition services

At this stage it was evident that participants were describing the impact of delivering services due to wider COVID-19 context, not all of which were specifically related to Long COVID. Therefore, as described in the method section, research ideas were allocated to one of two themes:

1. DIRECT (Impact as a direct result of Long COVID).
2. INDIRECT (Broader impact issues that arose due to the impact of COVID-19)

Phase 4 Ranking Exercise Prioritising Research Questions

Research ideas were then discussed by nine Community Children's Nurses at a consensus workshop in Phase 4 and subsequently ranked by eight (DIRECT) and nine (INDIRECT) participants (Table 4).

Table 4
Ranking Exercise

Rank Order of Long COVID Issues (n = 8)	**Rank Order of Indirect Broader Issues (n = 9)**
DIRECT	INDIRECT
Research Ideas	Research Ideas
1. What are the **priorities in terms of nurse training needs** to deliver essential care and support to babies, children and young people and their families living with the consequences of the COVID-19 pandemic namely Long COVID?	1. What are the key priorities for clinical assessment of babies, children and young people with complex medical complexity in the context of **community remote working** post COVID-19?
2. What is the **most effective role of external agencies** such as policy leaders, schools, charities, health and care professionals play in supporting babies, children and young people and families affected by Long COVID?	2. What format would an **equitable workforce plan** look like in another pandemic like COVID-19 to meet the essential services required by babies, children and young people and families?
3. What format would **a service delivery plan** look like to meet the needs of babies, children and young people, and their families affected by Long COVID?	3. Based on robust evidence what are the **key interventions that family carers use** with babies, children and young people with complex with medical complexity (both chronic and acute) to help them cope (practically and emotionally) in the face of crisis and uncertainty post COVID-19?
4. What is the **prevalence of babies, children and young people with medical complexity** (both chronic and acute) based on robust evidence who are directly affected by Long COVID?	4. Based on robust evidence what are the **key interventions Community Children's Nurses and other Professional carers** use to support babies, children and young people with complex medical needs, practically and emotionally, and their families, in the face of uncertainty post COVID-19?
	5. How can we understand and address the current processes for babies, children and young people with complex medical complexity when **transitioning to adult services** post COVID-19?

Discussion

Uniquely this study and approach examined views around research priorities as voiced by professional and family carers caring for babies, children and young people with medical complexity in community settings in the post COVID-19 care context. To our knowledge this is the first priority setting exercise to establish research priorities considering the impact of Long COVID on service provision in children's community nursing settings. These research ideas represent the areas of focus the community want researchers to prioritise. Further, this study highlights what research areas remain important seven years on from the pandemic within the specialism of paediatric medical complexity post COVID-19 in the context of changed healthcare.

Nine research priorities were identified and reported back to the funder, NHS England, in July 2024. Consistent with research by William et al. (2016) and von Scheven et al. (2020) the research priorities identified focus on a provider's ability to provide care and equitable, efficacious service delivery, and on healthcare systems. The importance of a focus on structural and macro level factors rather than nursing interventions is highlighted in a recent evaluation by Coad et al. (2023) where significant inequalities in access to care and services were documented. Additionally, the need for cost effective healthcare models for Long COVID highlighted in a recent report by the UK Government (2025). Such a research focus would respond to several of the United Nation's sustainable development goals SDG3 (good health and well-being), SDG10 (reduced inequalities), and SDG11 (sustainable cities and communities) (United Nations, 2015).

Four priority research areas were precipitated from the effects of the pandemic and Long COVID. They contribute to directing relevant research to focus on challenges that will be faced in the future by professional staff and babies, children and young people with medical complexity and their family carers. Despite the global pandemic having passed as described by NHSE (2023), the impact of Long COVID on people's health means understanding the implications and ramifications on professional and family carers of Long COVID remains important. Considering these results is timely and relevant to the reported impact of Long COVID (Faux-Nightingale et al., 2024; NHSE, 2023) and inequalities in provision of and access to services (Coad et al., 2023; Flasch, 2024; Liberarti et al., 2022, NHSE, 2023; Propper et al., 2020). In a climate of limited resources, the role of external agencies in providing support and an equitable service delivery plan are both critically important. Training needs are a theme consistently identified in the literature by Mörelius et al. (2020) and von Scheven et al. (2020) with findings by Coad et al. (2023) supporting the need for its analysis. The knowledge gap in terms of impact on working with and caring for babies, children, young people and families, in community settings is evidenced by the lack of literature available to support the rapid review. This highlights a need to answer the questions raised to inform service improvement and packages of care provision for this young population and their carer networks. Such research would be timely and supportive of current research developing a national service framework for Long COVID and ME/CFS (UK Government, 2025).

The five indirect broader research priorities parallel findings from empirical studies. Transition was identified as a priority area by Fletcher–Johnson et al. (2011) and remains poorly understood a decade on (Okumura et al., 2022). While recent literature identifies a range of variables acting as barriers and facilitators to the transition process (Benini et al.,

2024; Marani et al., 2020; Mooney et al., 2024) effective models of transition still require evaluation.

Further, the literature documents a significant unmet need for mental health and well-being support for parents and caregivers of babies, children and young people with chronic illness (Children's Commissioner, 2026; McClorie et al., 2023). This coupled with candidacy and the risk of suboptimal mental health in these parents and caregivers (Bayer et al, 2020; Verma et al., 2020) means interventions to support both them and the professional workforce are urgently

required. Moreover, with an abundance of literature showing that babies, children and young people and family / caregiver mental health are intrinsically linked (Durcan et al., 2021; Koob et al., 2024; McLachlan et al., 2024; Rodday et al., 2017) parental interventions require urgent investment.

A clear issue that emerged was the need to determine the makeup of an equitable workforce plan in another pandemic. As reported by Coad et al. (2023) and the Children's Commissioner for England. (2026) significant gaps exist in key service provision to these babies, children and young people. Integrated care systems need to consider how they will minimise these health inequalities to plan and deliver post COVID services (NHSE, 2023). The suggested strategies by Coad et al. regarding training, the forming of regional partnership, and single point of access provide a basis to work from to prevent this gap widening.

While McRoy et al. (2024) has provided guidelines and best practices for assessing young children remotely this work does not focus on those who experience medical complexity. Challenges in engaging with children and young people is stated by Mc Roy et al. and, owing to their vulnerability, is likely to be a greater issue in those who experience medical complexity. Therefore, work specific to this population is urgently required. Research directed towards this endeavour is morally, ethically, and legally required and aligns to several national and international policies. For example, the NHS 2023/4 priority list (NHS England, 2022), Department of Health and Social Care's (2023) equality, diversity and inclusion strategy, Healthy People 2030 (Office of Disease Prevention and Health Promotion, 2020), the NHS 10 year plan by the Department of Health and Social Care (2025) and articles within the United Nations Convention on the Rights of the Child (Convention on the Rights of the Child, 1989). Approaches such as James Lind Alliance priority setting exercises ensure that to achieve such endeavours, the voices of patients, families and professionals are prioritised.

Limitations/Scope

The short time frame impacted on time to unpick research areas and recruitment to the research, with the response rate and sample size compromising external validity. However, this was offset by the countrywide sample with the voices of a range of healthcare professionals gained through the secondary data analysis from Coad et al. (2023). Further, most participants were female and white British. Identification of research priorities based on Community Children's Nurses experiences rather than explicitly asking for research questions as recommended by the JLA (2021, 2023) is one strength of this research. Methodologically the study was rigorous with successive phases, intensive engagement and concordance between phases. Whilst the rapid review was conducted in a systematic way some published articles may have been missed, and we did not include grey literature. The overarching theme of the need to develop strategies to deliver equitable care was clear within in datasets and in the ranking and rating exercises.

Conclusion

The views of Community Children's Nurses surrounding research priorities relating to Long COVID and care post-pandemic in England have been explored and prioritised. All countries despite very different healthcare systems and levels of healthcare spending are grappling with the issue of how to reconcile growing demands and constrained resources (Kislov et al., 2023 so the findings here may also have international relevance. We believe the results of this research are important and should contribute to current research in the care, safety, and management of babies, children and young people experiencing medical complexity in community settings. This can only be achieved with determined research efforts, funding and ultimately changes to policy and practice. Enabling this population of babies, children and young people to thrive and reach their potential is beneficial to society overall. Their health must be protected and supported so that they may live longer healthier lives that are free from as many complications as possible.

Declarations

CONFLICT OF INTERESTS

The authors have no conflict of interest to declare.

DATA AVAILABILITY STATEMENT

The data that support the findings of this study are available from the corresponding author upon reasonable request.

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ETHICS APPROVAL STATEMENT

Ethical approval for this study was obtained from the Faculty of Medical and Health Sciences Research Ethics Committee at the University of Nottingham reference number FMHS 290-0523. All methods were carried out in accordance with relevant guidelines and regulations, including the Declaration of Helsinki. Informed consent was obtained from all participants prior to participation.

AUTHOR CONTRIBUTIONS

JC designed the study including ethical approval, reviewed the surveys, oversaw the data analysis and interpretation and the rapid review. FG designed the study, oversaw the rapid review, and reviewed the surveys. SA contributed to design of the study, reviewed the surveys, and conducted the rapid review. ST contributed to design of the study including ethical approval, developed the surveys, formulation of tables and figures; qualitative and quantitative data analysis and interpretation of the data. ST drafted the initial manuscript and with JC, FG and SA critically reviewed and edited it. JC is the corresponding senior author. All authors agreed intellectual content, approved the final manuscript as submitted and agree to be accountable for all aspects of the work.

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Footnotes

1. COVID-19 rapid guideline: managing the long-term effects of COVID-19 (nice.org.uk)

Figures

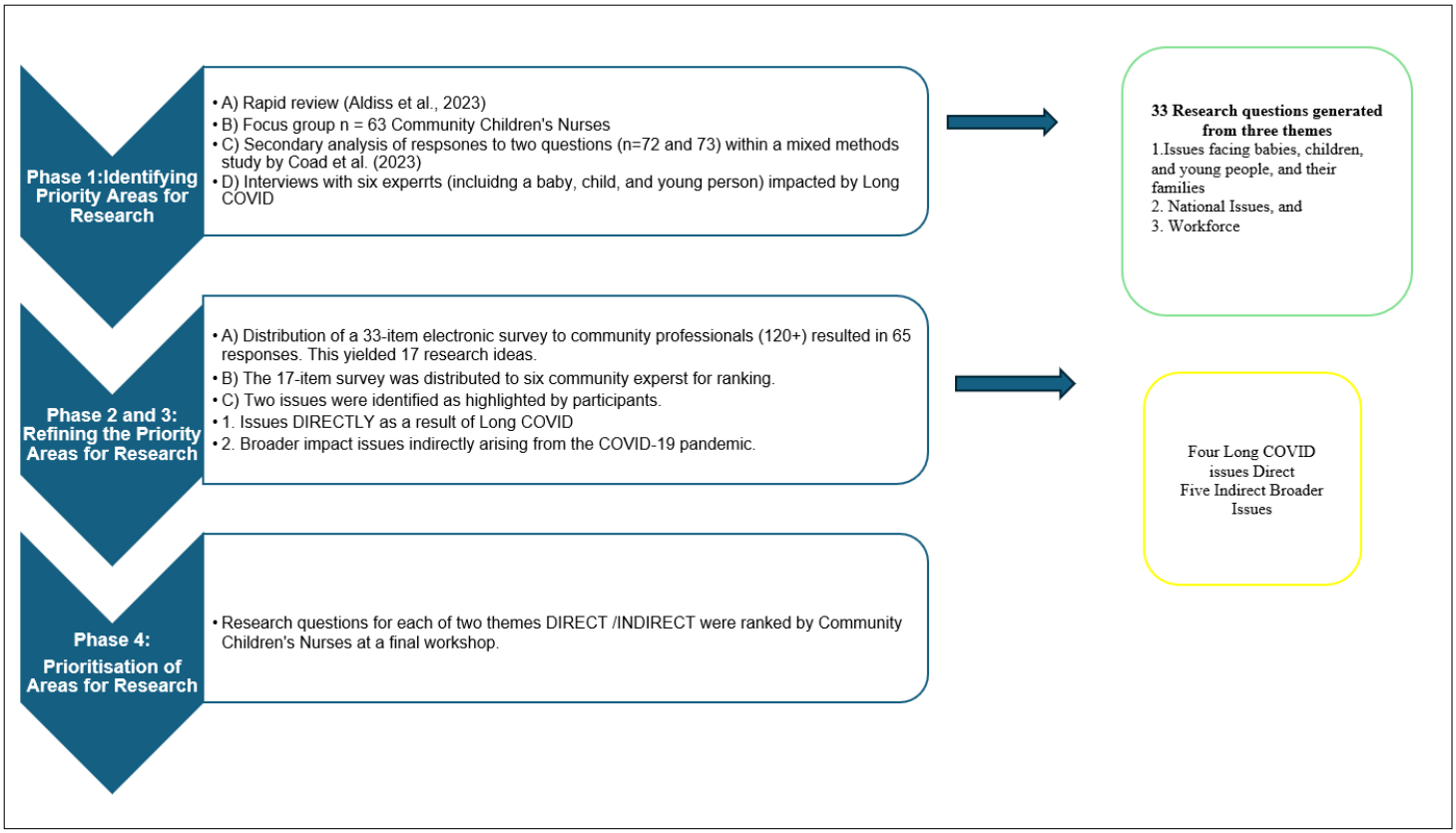


Figure 1

Phases of Data Collection and Steps Taken to Determine Areas for Research

Supplementary Files

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- SupplementaryFiles.docx