

Expert Consensus on a Definition for Children with Medical Complexity in England: A Modified Delphi Panel

EPH102

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Objective

To establish expert consensus on criteria for identification of Children with Medical Complexity (CMC) in England, using a modified Delphi panel approach.

Background

- CMC are an emerging population of children with substantial and complex clinical care needs.^{1,2}
- Currently, the recognition and definition of CMC in England varies according to local practice, and there is no unique clinical code for CMC.
- This in turn limits the availability of accurate data on this patient population, which is needed to inform co-ordination and access to care, plan for national workforce needs and support research initiatives.

Methods

- The scope of the Delphi panel was informed by an initial targeted literature review, and a clinically-experienced steering committee provided input on the content and interpretation of each round.
- Clinicians, nurses and allied health professionals (AHPs) with experience of managing or treating ≥ 20 CMC and ≥ 5 years of clinical experience in primary, secondary or tertiary care were recruited, aiming for a diverse representation of roles and geographies across England.
- Three online survey rounds were administered between December 2024 and June 2025, with questions including free-text, categorical and five-point Likert scale formats. Consensus was set at a predefined threshold of $\geq 70\%$.
 - Round 1** comprised open-ended questions on local, formal and informal guidance for defining CMC, as well as the participants' professional opinion. Responses were analysed qualitatively to extract unique constituent criteria.
 - Round 2** asked participants for their level of agreement with each individual criterion that emerged in Round 1, with criteria reaching the consensus threshold retained for inclusion.
 - Round 3** gathered consensus on the proposed case definition for CMC and flexibility conditions (mandatory criteria and minimum number of criteria/domains required).

Results

- Fifty-five healthcare professionals (HCPs) across England completed the Round 1 survey (Figure 1); retention was high with 53 participants completing all three rounds.
- Thirteen individual criteria grouped across four domains (clinical conditions, healthcare resource use, functional limitations and wider needs) were extracted from the Round 1 responses.
- In Round 2, nine of the thirteen criteria reached the pre-specified consensus threshold and were retained to form a proposed case definition (Figure 2).
- The case definition was presented in Round 3 and obtained near total consensus (96.2% [51/53] of participants agreed or strongly agreed).
- Participants endorsed setting a minimum number of criteria and domains; the median values suggested were ≥ 4 out of 9 criteria across ≥ 3 out of 4 domains. Two criteria additionally reached consensus for inclusion as mandatory requirements in the definition (Figure 2).

Conclusion

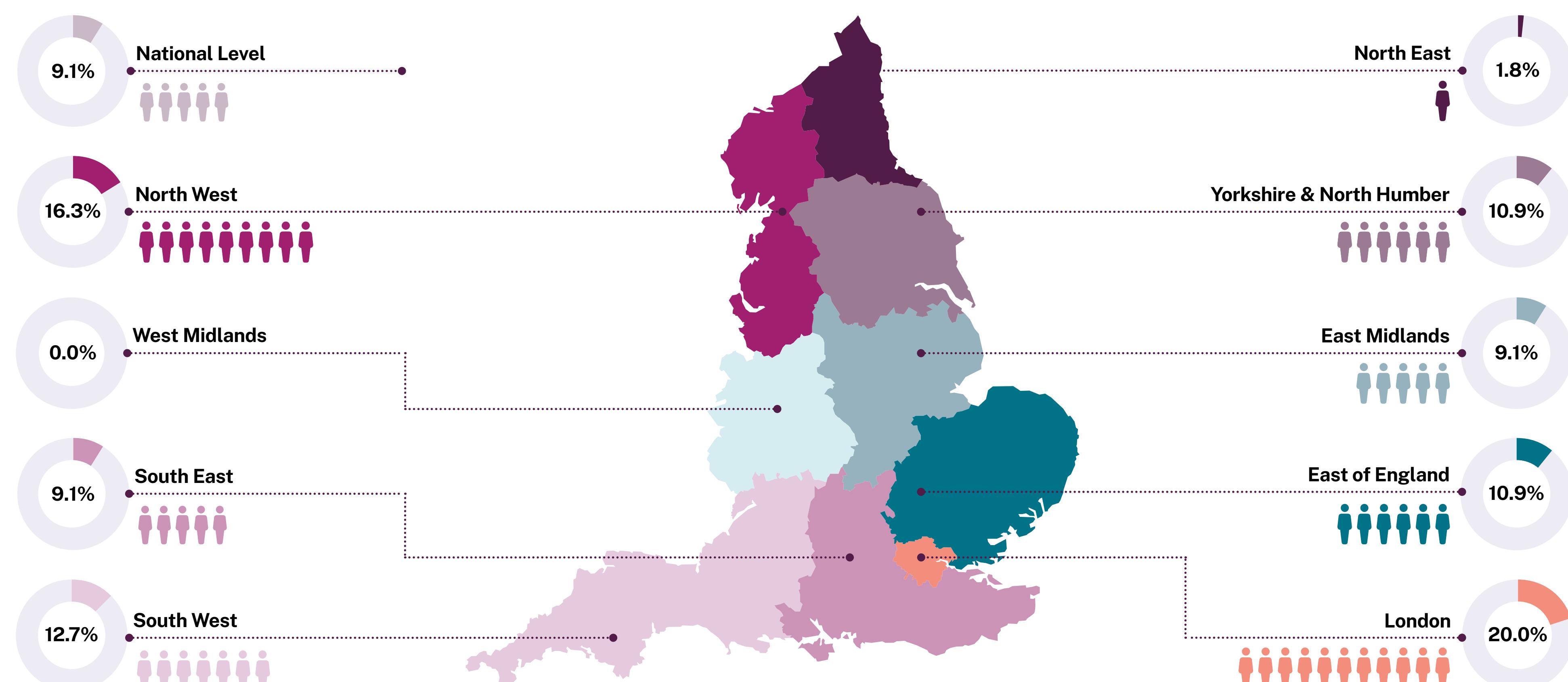
Near total consensus was obtained for a comprehensive case definition for CMC in England.

The results from this modified Delphi panel offer unified, yet flexible criteria to assist in the systematic classification of CMC in England. This research presents a framework for the development of a clinical code, which would enable accurate monitoring of the CMC population, facilitate resource planning and support dedicated research aimed at improving care for these patients.

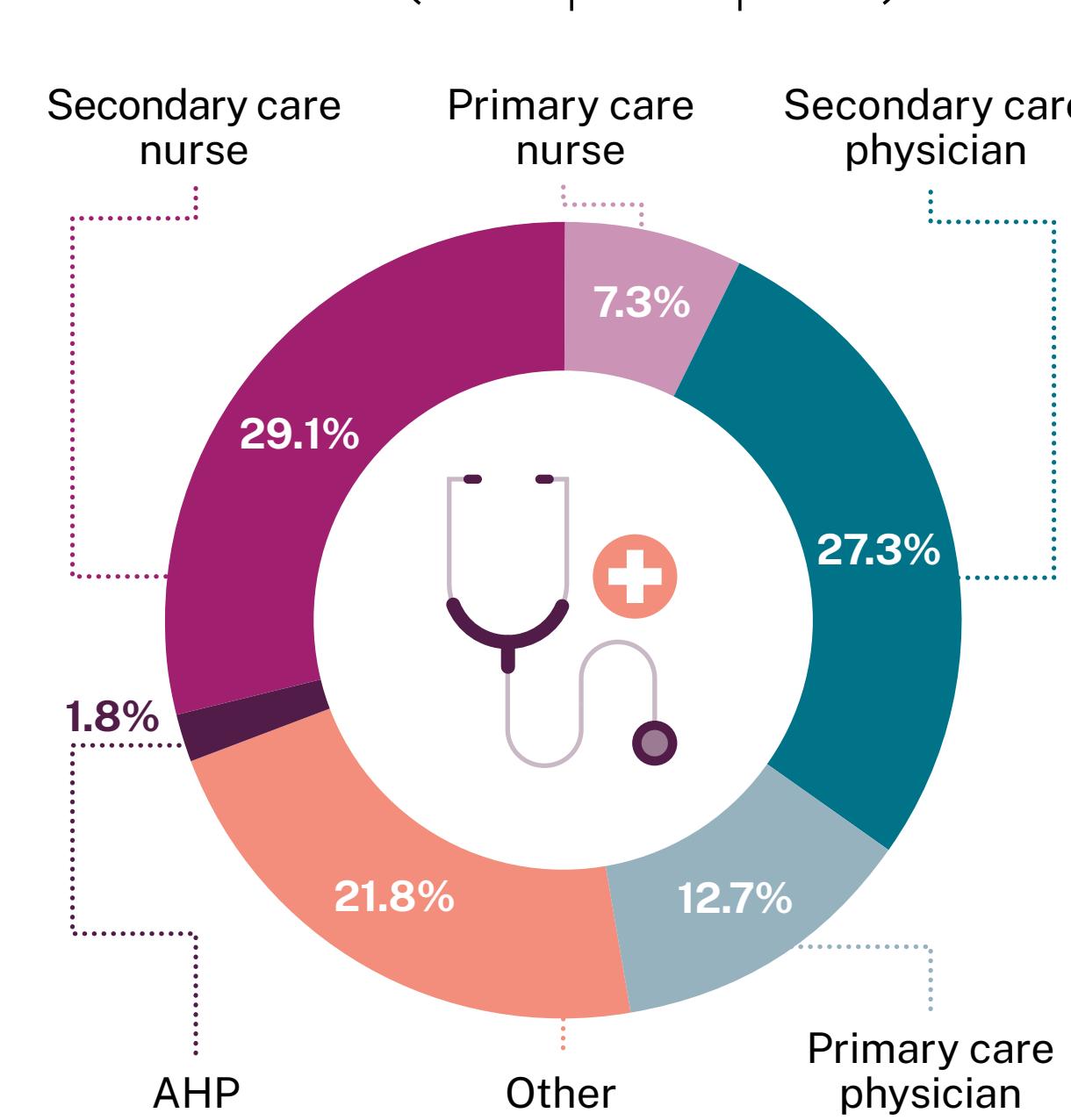
FIGURE 1

Characteristics of the Delphi panel participants

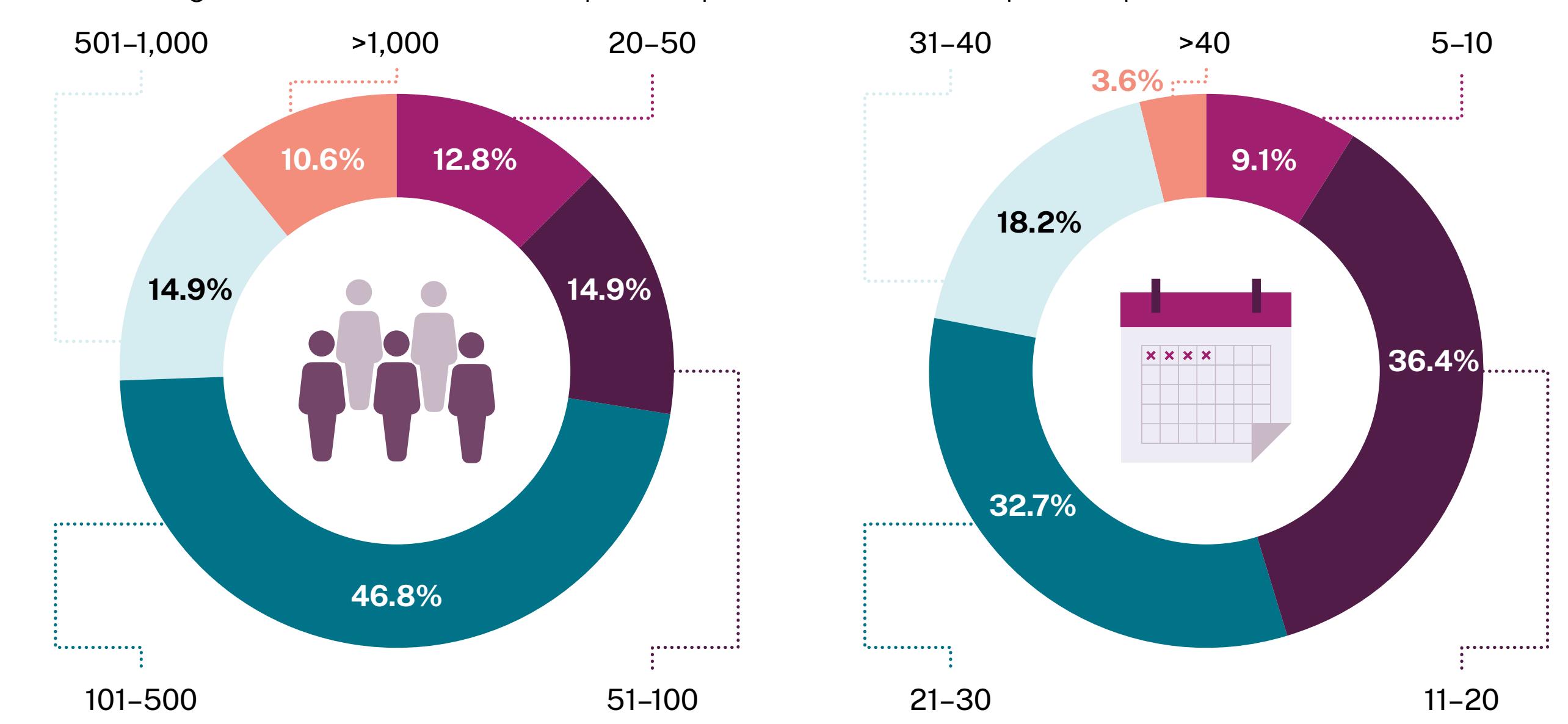
A. Regional distribution (% of participants)



B. Profession (% of participants)



C. Estimated number of CMC managed or treated (% of participants)



Round 1 survey participants: N=55, from a total of 67 individuals invited to participate in the Delphi panel. Figure 1B: "Primary care" includes primary and community care; "secondary care" includes secondary and tertiary care.

FIGURE 2

Output from the Delphi panel: A definition for CMC in England

At least 4 criteria from 3 domains (mandatory criteria bolded):



Level of agreement for each criterion reflects the proportion of participants responding "Agree/Strongly Agree" in the Round 2 survey (N=54). The following criteria did not reach the pre-specified consensus threshold in Round 2: Presence of a palliative (life-limiting/life threatening/end of life) diagnosis (48.1% agreement); Multiple and/or prolonged admissions to hospital (63.0% agreement); Significant needs/frequent financial and emotional burden on the family due to caring responsibilities (59.3% agreement); Requirement of additional support for educational needs (48.1% agreement).

Abbreviations: AHP: allied health professional; CMC: Children with Medical Complexity; HCP: healthcare professional.

References: ¹Cohen E et al. Pediatrics 2011;127:529-38; ²Oliveira PV, Enes CC, Nucci LB. World J Pediatr 2023;19:928-938. Acknowledgements: The authors thank all members of the expert panel for their participation in the Delphi panel rounds. The authors thank Becky Chesworth, Costello Medical, for graphic design assistance, and Alex Porteous, Costello Medical, for their review and editorial assistance in the preparation of this poster.

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