

# Capturing information on childhood hearing loss diagnosed after 6 months in England for congenital CMV research: use of the Newborn Hearing Screening Programme (NHSP) national IT system (S4H)

Vishnuga Raveendran<sup>1</sup>, Hannah Garnett<sup>2</sup>, Catherine Magee<sup>2</sup>, Simone Walter<sup>3</sup>, Heather Bailey<sup>1</sup>

Affiliations: 1. Institute for Global Health, University College London, London, UK, 2. NHS England, London, UK, 3. St George's University Hospitals NHS Foundation



## BACKGROUND

**Sensorineural hearing loss** is the most common sequelae of congenital cytomegalovirus (cCMV)<sup>[1]</sup> and can be present at birth or develop later. This audit aimed to describe how audiology departments use the **Newborn Hearing Screening Programme (NHSP) national IT system (SMaRT4Hearing, S4H)** to report data on **children diagnosed with permanent childhood hearing loss (PCHI) between 6 months and 5 years of age**, to inform future research on hearing outcomes of children with cCMV and quality improvement. The audit also aimed to help NHS England identify inequalities in the management of babies who were referred from the newborn hearing screen and support quality improvements of paediatric audiology services.

## METHODS

A **web-based survey** was disseminated to:

- **Audiology departments** via NHSP local managers with a request for one response per department
- Members of British Association of Audiovestibular Physicians (BAAP) and British Association of Paediatricians in Audiology (BAPA) in England with a request for one response per **clinician investigating the aetiology of childhood hearing loss**.

The survey included questions on the use of S4H and questions on congenital CMV early detection pathways.

Responses were collected between **25<sup>th</sup> November 2022 to 6<sup>th</sup> January 2023** and shared with the UCL team thereafter. Data was subsequently cleaned, and descriptive analyses were undertaken in STATA.

## RESULTS:

### Audit Response Overview:

A total of **86 responses** were collected from England

- Of these, a total of **55 responses** were from **audiology departments** (representing an estimated 42% of the total in England)
- Of these, **31 responses** were from **clinicians investigating the aetiology of childhood hearing loss**

Of respondents, 86% were possibly interested in participating in a future study.

### Number of moderate, severe or profound PCHI cases (unilateral or bilateral) diagnosed per year at the department, among babies either referred via or not eligible for NHSP:

#### <10 cases per year:

- 56% by Audiology department & 17 responses from clinicians

#### 10-19 cases per year:

- 36% by Audiology department & 12 responses from clinicians

#### 30+ cases per year:

- Reported by one audiology department

#### Don't know:

- Reported by one clinician

### Availability of data on PCHI cases diagnosed between 6 months and 5 years of age

(Responses from audiology departments only)

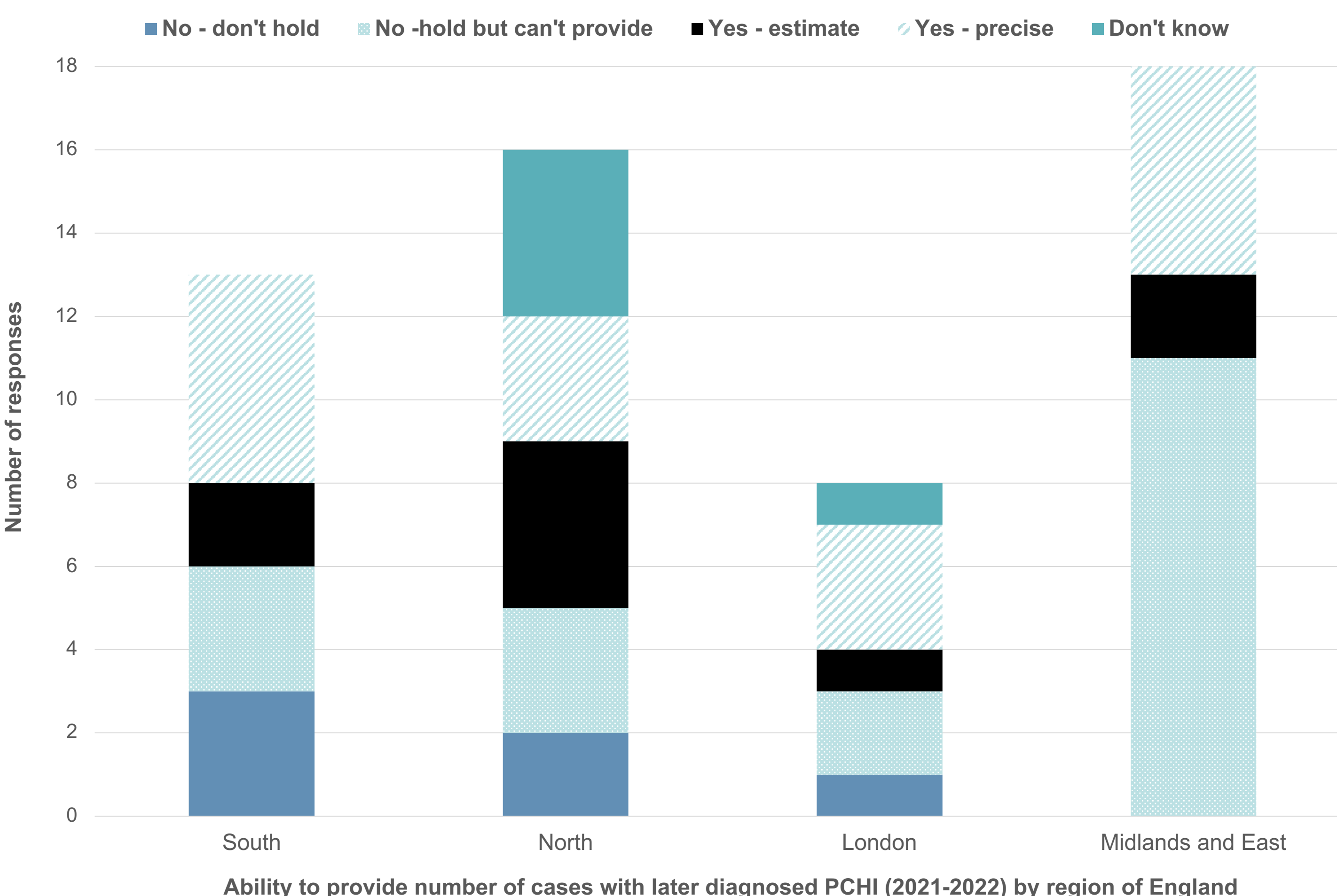


Figure 1: Whether audiology departments were able to provide a number (estimate or precise) on how many children not diagnosed in the first 6 months were later diagnosed with moderate, severe or profound PCHI up to the age of 5 years between April 2021 and March 2022, by region of England

## RESULTS (continued)

Approximately, **80% of audiology departments** reported **holding data** on the number of **PCHI cases** diagnosed between 6 months and 5 years by year (2019-2022) and 45% (25/55) were able to provide a precise or estimated number of cases of later diagnosed PCHI for this audit (Figure 1; similar for the years 2019-2020 and 2020-2021). **Most departments (52%-62%, differing by year) reported either no or one later-diagnosed PCHI case** per year, based on available numbers.

### Use of S4H and local information sources:

#### 1. Updating S4H with audiology information on later diagnosed PCHI cases (Audiology responses only)

- Data on later-diagnosed PCHI cases is **consistently, sometimes, or never** entered into S4H by **56% (31/55), 36% (20/55) and 8% (4/55)** of audiology departments, respectively.
- **Inadequate capacity (58%)** and being **unaware** that this is a requirement (33%) were the most common **reasons for not entering** data on later-diagnosed cases.

#### 2. Audiology departments updating S4H: Audiology departments reported that 21/55 (38%) experience barriers to updating S4H annually with **audiology test data** and 15/55 (27%) reported experiencing barriers to **updating key dates/amplification information**.

##### Reasons for not updating S4H include:

1. Time limitations
2. Forgetting to update the system
3. Having technological issues

#### 3. Information sources:

Of all respondents, **76/86 (88%)** hold a **local list** with data on PCHI cases seen at their departments/clinics; of which 51 respondents (67%) reported that this list contains data on all PCHI cases, including mild cases.

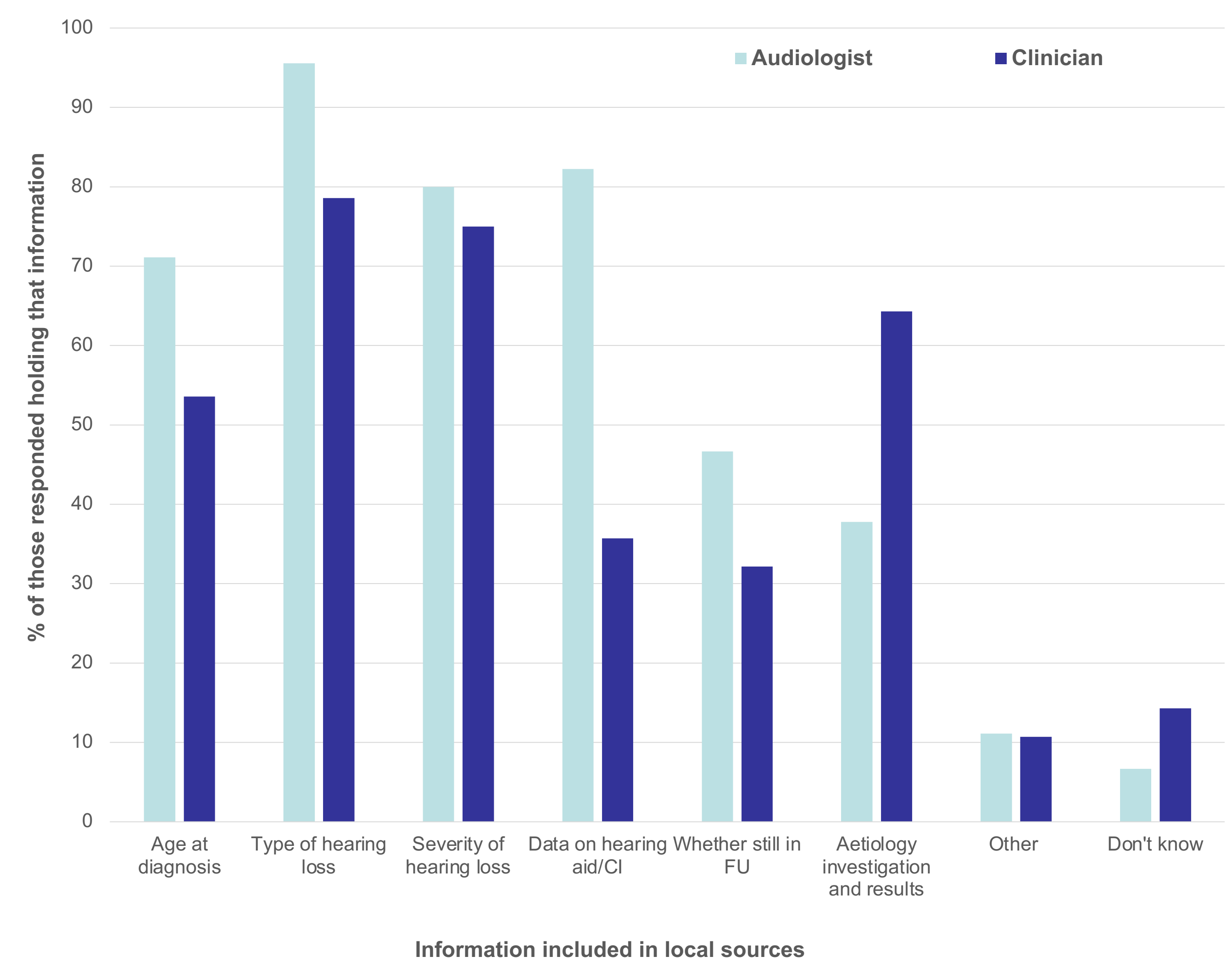


Figure 2: Type of data held in local lists on PCHI cases, by audiologists and clinicians

## CONCLUSION

- Data on later-diagnosed childhood PCHI cases is entered into S4H by most departments at least some of the time but with some inconsistencies.
- Whilst bearing in mind the limitation of the response rate (42% of audiology departments), responses indicate that capacity and time limitations impact data entry into S4H, especially for hearing loss diagnosed after 6 months.
- Most departments hold local records of PCHI data.

These findings have contributed to NHSP data quality improvement work and are feeding into future training plans and guidance updates.

Results will inform the use of S4H and other approaches for future research on hearing outcomes of children with cCMV and could also be used to inform research into other causes of PCHI.

**Reference:**  
1. Dreher AM, Arora N, Fowler KB, et al. Spectrum of disease and outcome in children with symptomatic congenital cytomegalovirus infection. *J Pediatr* 2014; 164: 855-859. DOI: 10.1016/j.jpeds.2013.12.007

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**Correspondence:** Vishnuga Raveendran, Email: vishnuga.Raveendran.19@ucl.ac.uk