

Development and initial validation of the Hyperacusis in Children Questionnaire (HiCQ).

Iskra Potgieter

Supervisors: Kathryn Fackrell, Derek Hoare

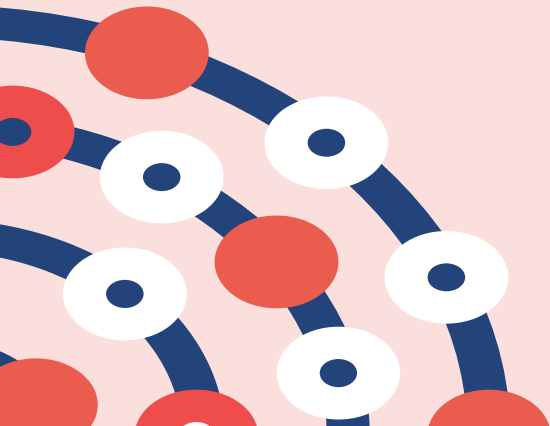
University of Nottingham



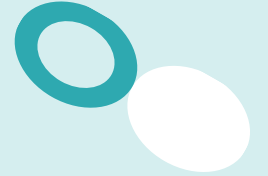
Hyperacusis in children



- Everyday sounds cause severe long-lasting distress and pain
- Avoidance/ear protection
- Isolation
- Disturbed daily activities & interpersonal development



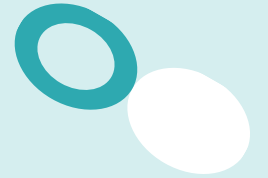
Research rationale



- No formal clinical guidance in paediatric hyperacusis
- No validated child-specific assessment tool grounded in the children's experiences of hyperacusis
- Key clinical indicators of hyperacusis
- Monitor treatment-related change
- Promote RCTs and prevalence studies



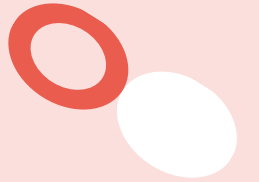
Stages of questionnaire development



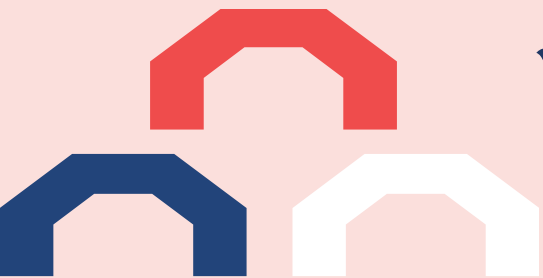
1. Conceptualisation – via scoping review and investigation of online discussion forums
2. Item elicitation – via semi-structured interviews
3. Questionnaire design – via focus group and cognitive interviews
4. Psychometric validation – via online survey



Scoping review

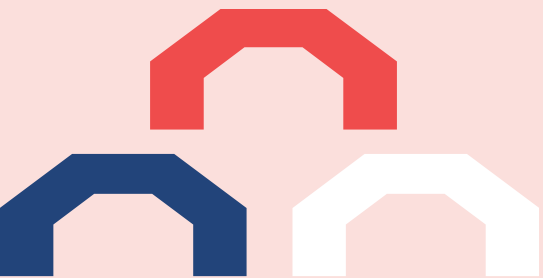


- 21 primary reports of hyperacusis: case studies & retrospective cohort studies
- Key findings: modal age 5 yrs; frequently alongside ASD, ADHD, tinnitus
- ✓ Children under 8 years with developmental disorders: parent-completed (proxy) questionnaire
- ✓ Source of candidate items (26 codes)

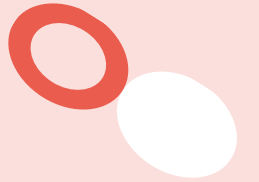


Qualitative investigation of online discussion forums

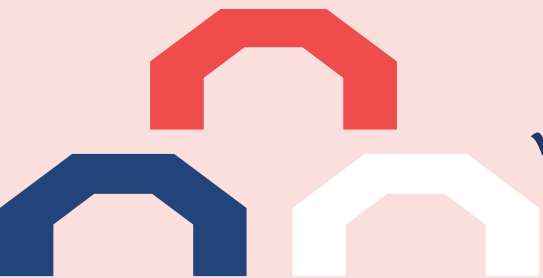
- 1832 posts, >1000 individual users
- Lived experiences of hyperacusis in children
- ✓ Hyperacusis impact at home, school, socially & recreationally
- ✓ Source of candidate items (39 codes)



Semi-structured interviews with parents and clinicians



- 6 clinicians: Audio Vestibular Physicians, Clinical Scientists & Clinical Psychologist
- 6 parents of children aged 2-11 years diagnosed with hyperacusis
- Qualitative content analysis (Elo & Kyngäs, 2008)
- ✓ Hyperacusis-related problems & experiences in children (138 codes)
- ✓ Primary source of candidate items (138 codes)

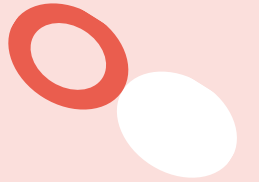


Demographics of the children

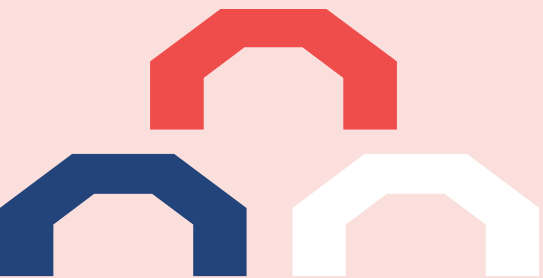
Child's age (years) and gender	Co-existing conditions
4, male	ASD
4, female	ASD and SPD/SID
6, male	Tinnitus
6, female	Tinnitus
9, male	Tinnitus
11, female	Tinnitus, SPD

Autism Spectrum Disorder (ASD); SPD (Sensory Processing Disorder)
SID (Sensory Integration Disorder)

Data synthesis



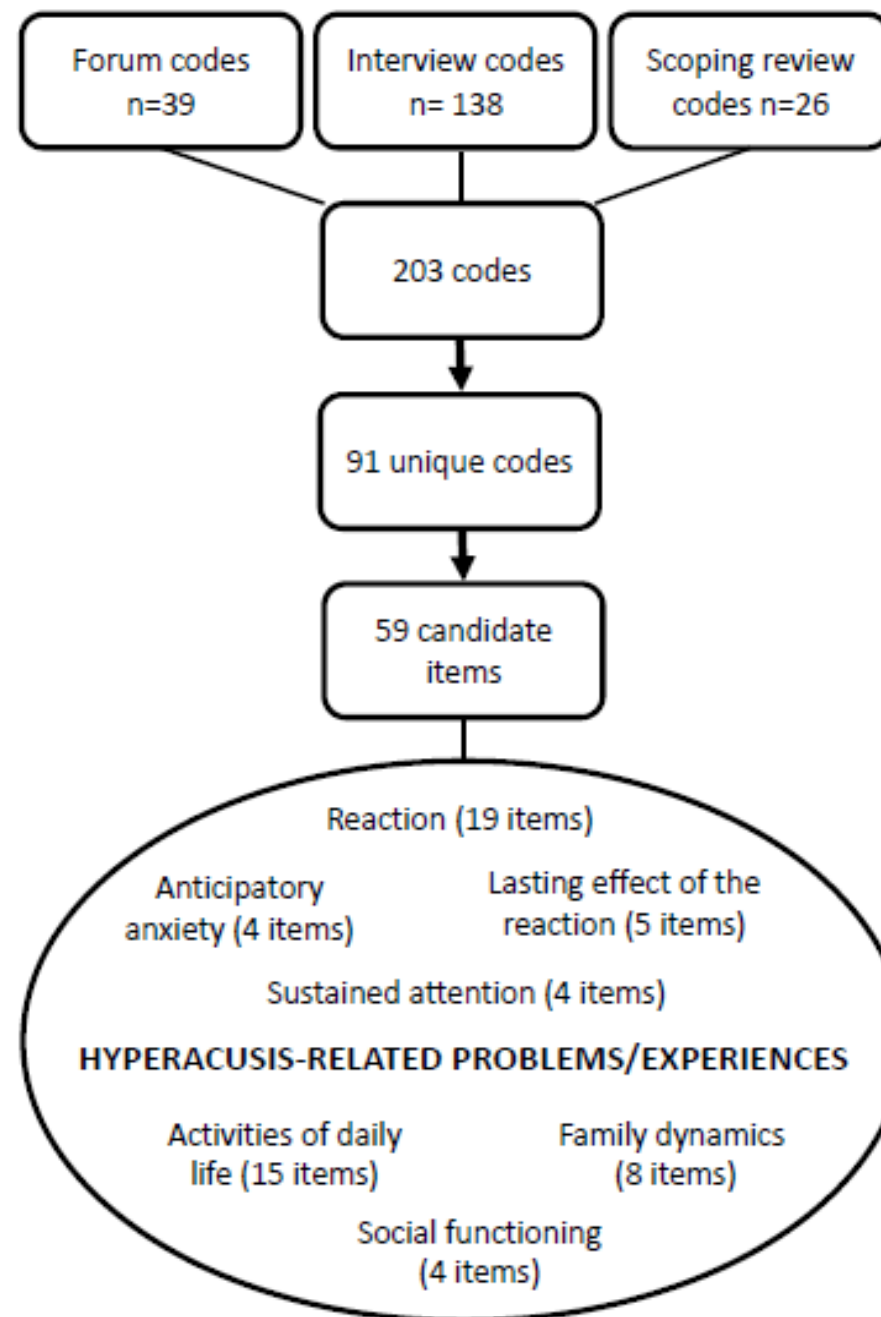
- Data from all three sources (203 unique codes) was synthesised semantically into candidate items (n=59) for the HiCQ



Example of item synthesis

Parent Interviews	Clinician Interviews	Forums Study	Scoping Review	Unique code (concept)	Candidate item
he will panic	panic	he panics	panic attack	panic	Some sounds cause my child to panic.

Diagram of data synthesis

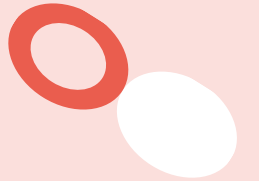


Expert focus group

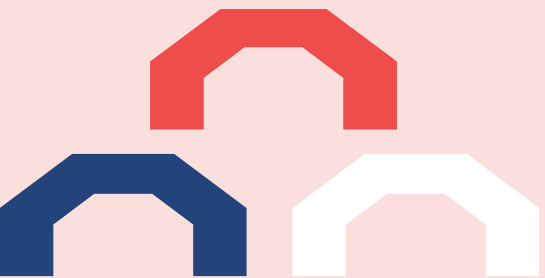
- n=6 (4 clinicians in paediatric hyperacusis & 2 questionnaire development)
- Item reduction & wording, domains
- Recall period, response options, usability
- **HiCQ pilot version 1**
(19 items)



Cognitive interviews

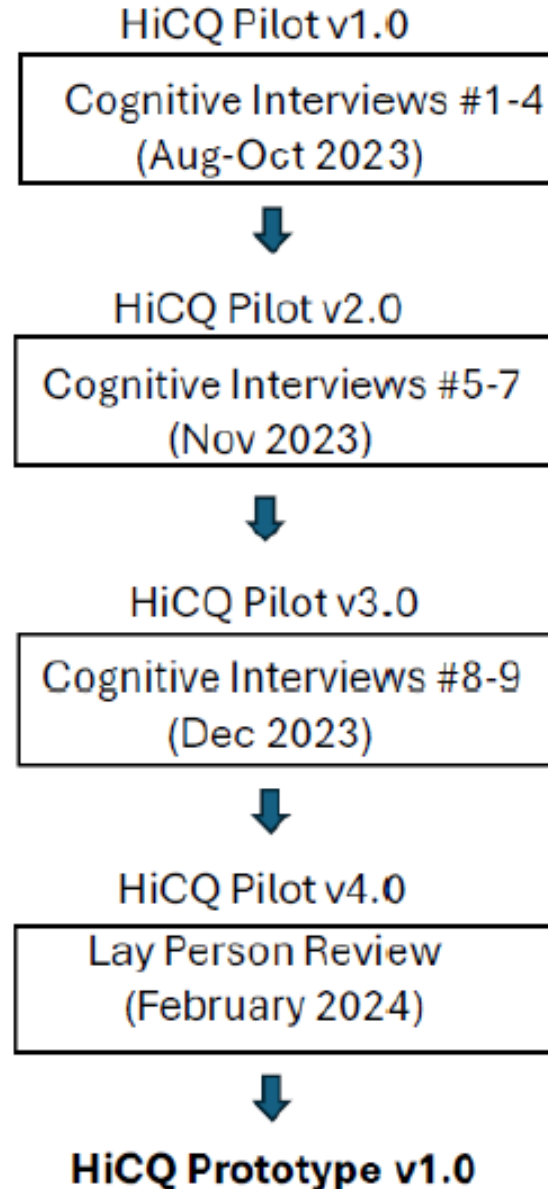


- n=9 parents of children with sound-sensitivity aged 2-11 years
- Tested the HiCQ online via Teams call
- To assess and improve HiCQ's clarity & comprehensiveness
- ✓ Optimized content validity & acceptability



HiCQ revisions at each round

- Removal of 1 item
- Reducing the recall period to 1 week
- Switched response scales
- Refined wording



HiCQ prototype v1.0

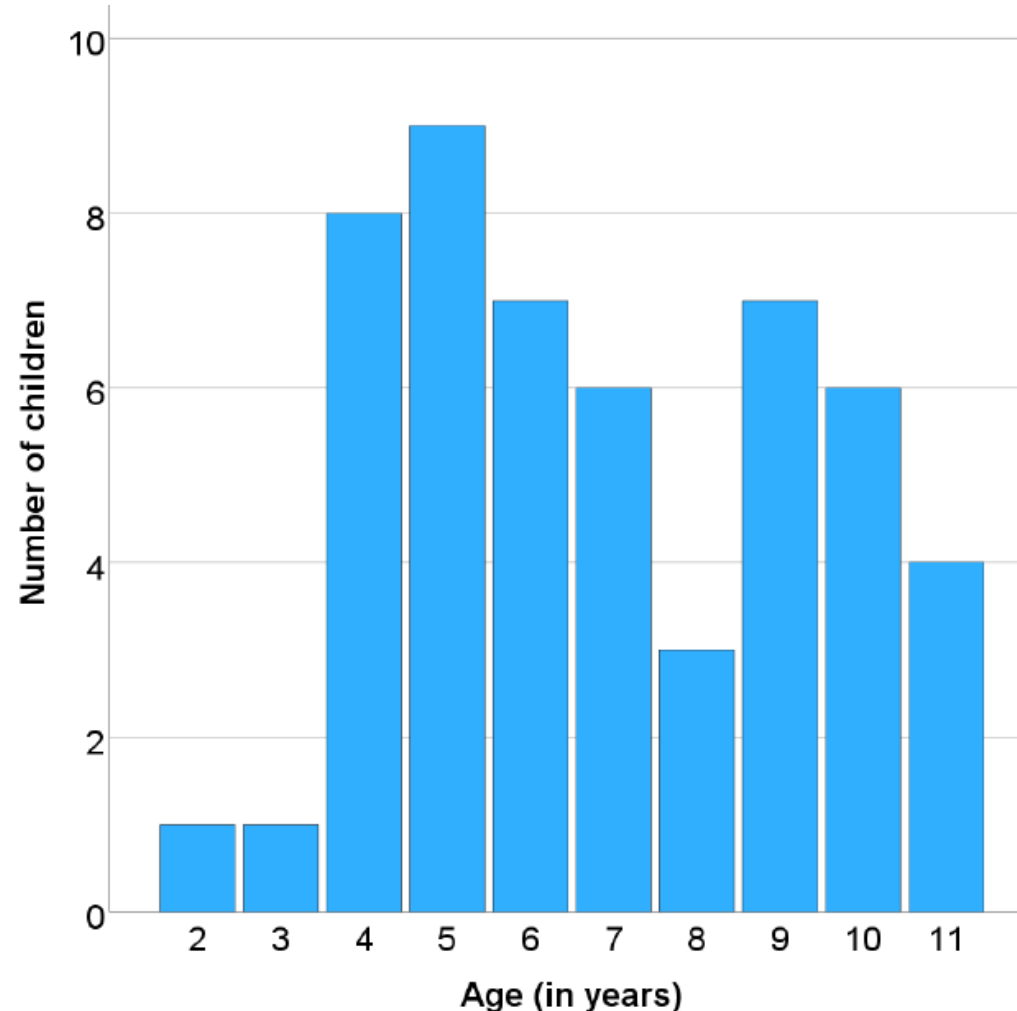
Domain	Sample items
Reaction (11 items)	In the last week, certain sounds caused my child to panic.
	In the last week, it took time for my child to calm after reacting to certain sounds.
	In the last week, my child became anxious about going to places where certain sounds might be present.
Activities of daily life (4 items)	In the last week certain sounds made it difficult for my child to take part in school/nursery activities.
	In the last week, certain sounds made it difficult for my child to engage in parties, play dates or busy play areas.
	In the last week, certain sounds made it difficult for my child to take part in leisure activities.
Family dynamics (3 items)	In the last week, family members in the home had to be careful not to make certain sounds that distress my child.

Initial psychometric validation

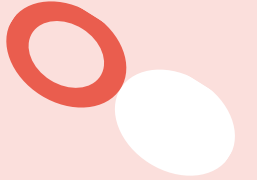
- Online survey via RedCap (Feb'24-Jan'25)
- n=52
- ASD, ADHD, tinnitus, SPID, glue ear, phonophobia, misophonia

		n (n=52)	%
Sex	Male	33	(57.7)
	Female	22	(42.3)
Ethnicity	White (British)	37	(71.2)
	Mixed	6	(11.5)
	Any other white background	3	(5.8)
	Asian	3	(5.8)
	Black	2	(3.8)
	Hispanic	1	(1.9)
Country of residence	UK	50	(96.2)
	US	2	(3.8)
Hyperacusis Diagnosis	Yes	14	(26.9)
	No	38	(73.1)
Diagnoses	Hyperacusis alone	5	(9.6)
	Hyperacusis with other conditions	9	(17.3)
	Non-hyperacusis diagnoses	22	(42.3)
	No diagnoses	15	(28.8)

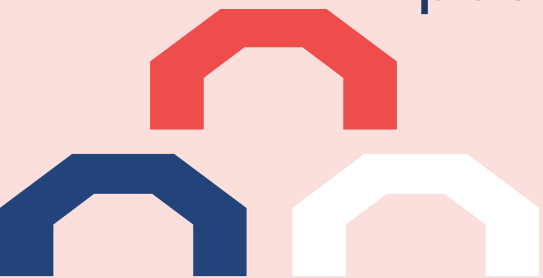
Age distribution of the children (n=52)



Results



- ✓ Good internal consistency
- ✓ Good convergent validity (P-HQ) and discriminant validity (EQ-5D-Y)
- Floor and ceiling effects – possible redundancy of some items
 - Future powered research ($n > 100$) to verify & address possible item redundancy





Thank you for listening...Questions?

Iskra.Potgieter@nottingham.ac.uk

