
Summary Report: Validation of a Patient Reported Experience Measure for Paediatric Allergy Care

Validation concerns the degree to which evidence and theory support the interpretations of test scores entailed by proposed uses (American Educational Research Association, American Psychological Association, National Council on Measurement in Education, & Joint Committee on Standards for Educational and Psychological Testing (U.S.), 1999).

Cognitive testing

Question comprehension, interpretation and response processes were assessed using cognitive testing to ensure that people understand the questions as intended and can respond accurately. Cognitive interviews were conducted with patients aged 8-17 and parents of patients aged 0-7 attending a paediatric allergy clinic at St Mary's Hospital London. Two rounds of interviews were conducted, with survey amendments made after each round. Round one included 12 participants and round two involved a further six people. Each interview lasted approximately 30 minutes, and participants were given a £15 gift voucher for their time.

Main changes to the questionnaires as a result of cognitive testing were:

- Amendments to question wording to facilitate understanding and ensure that questions were interpreted as intended;
- Changes to terminology – e.g. medical and healthcare terms to reflect the understanding of participants;
- Changes to response options to ascertain that all possibilities were covered and that the wording reflected respondents' experiences;
- Reducing the length of some survey sections;
- Removal of questions that were deemed irrelevant or difficult to answer;
- Addition of definitions for phrases that required added clarity (e.g. 'personal management plan');
- Changing the order of some questions to facilitate better flow and user experience.

Score validation

Items evaluating the quality of care were converted into ‘problem-scored’ items. Problem scores are allocated to reports of sub-optimal care, with ‘not applicable’ options excluded from the scoring.

I Parent questionnaire

Basic item data

The response frequencies to all selected-response items and to their problem-scored equivalents are shown in Appendix 1 (provided as a separate document). Item non-response is at a generally low level throughout the questionnaire, and was below five per cent for all except Q12 (*Do you and your child have a personal management plan?*). There was no tendency to drop out of the survey before completing all evaluative items.

Problem-scored items

The distributional statistics for the problem-scored items are shown in Table 1. Questions 11, 13 and 30 had low scores (indicating few problems), and these questions are therefore not very good at discriminating between poor and good experience. However, questions 11 and 30 provide measures of overall, rather than specific, experience.

Table 1: Item statistics

	N	Mean	Std. Error	Std. Deviation
Q3. How many times did you see a health professional about your child's first allergy symptoms before they were given a firm diagnosis?	244	.34	.030	.475
Q4. From when you first saw a health professional about your child's condition, how long did you wait for tests to be carried out (to confirm what causes their condition or makes it worse)?	244	.37	.031	.483
Q6. Did this healthcare professional talk to you in a way that you could understand?	245	.15	.023	.355
Q7. Were you given a chance to discuss your child's treatment (including any medication options and avoidance advice)?	236	.23	.028	.424
Q8. Did you feel that this healthcare professional knew enough about your child's allergic condition?	237	.27	.029	.445
Q9. Did this person answer your questions in a way you could understand?	223	.24	.029	.427
Q10. Did you have confidence and trust in this member of staff?	244	.20	.026	.404
Q11. Overall, how well do you think your child was looked after by this person?	247	.06	.015	.232
Q13. Does your child's school or nursery know about their personal management plan?	124	.09	.026	.285
Q14. Do you and your child follow their personal management plan?	150	.14	.028	.348

Q16. Do you have enough information about when your child should use their medication(s)?	216	.14	.024	.351
Q17. Do you know how to use the medication(s)?	216	.10	.021	.303
Q18. Have health professionals told you about the medication side effects (including complications of long-term use) to watch for?	206	.70	.032	.460
Q20. Did staff give you enough information about this emergency treatment?	83	.19	.044	.397
Q22. How do you feel about how often your child has an allergy review or check-up (e.g. An appointment with their GP or at an allergy clinic)?	246	.30	.029	.458
Q23. Do you know enough about what allergens and irritants your child should avoid (e.g. Food, dust, pets)?	244	.36	.031	.482
Q24. Do health professionals (e.g. Doctors and nurses) communicate with your child's school or nursery about their condition?	196	.75	.031	.434
Q25. Do health professionals communicate with each other about your child's condition?	228	.41	.033	.493
Q26. Are you involved in decisions about your child's allergy care and treatment?	230	.35	.031	.477
Q27. Do you have the phone number of a doctor or nurse who you can contact about your child's condition?	241	.41	.032	.492
Q28. Do you have information about support groups for your child's condition (such as Allergy UK, Asthma UK, Anaphylaxis Campaign, National Eczema Society)?	243	.52	.032	.501
Q29. Overall, do you have enough information about your child's allergic condition(s)?	242	.51	.032	.501
Q30. Overall, how well do you think your child's condition is looked after by healthcare staff?	242	.07	.017	.263

Relationship between summary and item scores

Correlations between Q30 (scored 1-4 with 1 as the most positive response) and the other evaluative items are shown in Table 2.

Table 2: Correlation with summary score

Polychoric correlations	
	Q30
Q29_Problem_Scored	.647
Q8_Problem_Scored	.625
Q9_Problem_Scored	.617
Q10_Problem_Scored	.602
Q11_Problem_Scored	.584
Q6_Problem_Scored	.580
Q16_Problem_Scored	.555
Q7_Problem_Scored	.491
Q23_Problem_Scored	.478
Q22_Problem_Scored	.433
Q26_Problem_Scored	.413
Q25_Problem_Scored	.341
Q28_Problem_Scored	.304
Q27_Problem_Scored	.260
Q13_Problem_Scored	.255
Q18_Problem_Scored	.239
Q17_Problem_Scored	.223
Q24_Problem_Scored	.121
Q3_Problem_Scored	.112
Q4_Problem_Scored	.093
Q14_Problem_Scored	.077
Q20_Problem_Scored	.062

These show relationships in the expected direction. The ordering of these correlations suggests that the relationship with the individual selected at Q5 (*Who was the most recent person your child saw about their allergy?*) is particularly important in determining overall satisfaction.

Variation

Variations in scores by various subgroups were examined for Q30 and reported in Appendix 1. Demographic items (gender, ethnicity and who completed the questionnaire) were not associated with differences in overall score. Scores did differ by the type of clinician last seen: the most positive scores were associated with specialist allergy staff and the least positive with dieticians.

II Child/Parent questionnaire

This survey was aimed at children aged 8 years and above. There was a smaller section at the end of the survey for their parent or carer to complete.

Basic item data

The response frequencies to all selected-response items and to their problem-scored equivalents are shown in Appendix 2 (provided separately). Item non-response is at a generally low level throughout the questionnaire, and was below five per cent for all except for Q14. For 13 responses (5 per cent), no parent section was completed. Other than this, there was no tendency to drop out of the survey before completing all evaluative items.

Problem-scored items

The distributional statistics for the problem-scored items are shown in Table 3. Questions 6 and 19 had very low scores indicating few problems, and these questions were therefore not very good at discriminating between poor and good experience. However, both of these questions provide a measure of overall, rather than specific, experience.

Table 3: Item statistics

	N	Mean	Std. Error	Std. Deviation
Q4. Did this person talk to you in a way that you could understand?	247	.22	.026	.414
Q5. Did this person answer your questions in a way you could understand?	168	.29	.035	.453
Q6. Overall, how well do you think you were looked after by this person?	249	.03	.011	.177
Q8. Do you have enough information about when you should use your medicines or creams?	240	.19	.025	.394
Q9. Do you know how to use your medicines or creams (for example how to put on your cream, take your tablets, or use your injector)?	240	.15	.023	.354
Q10. Have health professionals told you about the side effects of the medicines or creams to watch for?	222	.64	.032	.480
Q12. Did staff give you enough information about this emergency treatment?	119	.13	.031	.343

Q14. How do you feel about how often you have an allergy review or check-up (for example an appointment with your GP or at an allergy clinic)?	249	.27	.028	.446
Q15. Do you know enough about the things that make your allergy worse (such as food, dust, pets)?	247	.28	.029	.452
Q16. Do you have a say in how your condition is looked after?	198	.44	.035	.498
Q17. Do you have information about support groups for your condition (such as Allergy UK, Asthma UK, Anaphylaxis Campaign, National Eczema Society)?	244	.34	.030	.473
Q18. Overall, do you have enough information about your allergic condition(s)?	242	.32	.030	.468
Q19. Overall, how well do you think your condition is looked after by healthcare staff (doctors and nurses)?	245	.03	.011	.178
Q23. How many times did you see a health professional about your child's first allergy symptoms before they were given a firm diagnosis?	233	.33	.031	.470
Q24. From when you first saw a health professional about your child's condition, how long did you wait for tests to be carried out (to confirm what causes their condition or makes it worse)?	232	.38	.032	.486
Q26. Were you given a chance to discuss your child's treatment (including medication options and avoidance advice)?	227	.25	.029	.435
Q27. Did you feel that this healthcare professional knew enough about your child's allergic condition?	231	.26	.029	.439
Q28. Did you have confidence and trust in this member of staff?	231	.18	.025	.387
Q30. Does your child's school or nursery know about their personal management plan?	143	.13	.028	.341
Q31. Do you and your child follow their personal management plan?	144	.20	.034	.402
Q32. Do health professionals (e.g. Doctors and nurses) communicate with your child's school or nursery about their condition?	220	.73	.030	.446
Q33. Do health professionals communicate with each other about your child's condition?	214	.32	.032	.467
Q34. Do you have the phone number of a doctor or nurse who you can contact about your child's condition?	228	.39	.032	.490

Relationship between summary and item scores

Correlations between Q19 (scored 1-4 with 1 as the most positive response) and the other evaluative items are shown in Table 4.

Table 4: correlation with summary score

Polychoric correlations	
	Q19
Q18_Problem_Scored	.670
Q26_Problem_Scored	.636
Q5_Problem_Scored	.582
Q28_Problem_Scored	.581
Q10_Problem_Scored	.580
Q27_Problem_Scored	.558
Q15_Problem_Scored	.516
Q16_Problem_Scored	.482
Q6_Problem_Scored	.380
Q8_Problem_Scored	.372
Q17_Problem_Scored	.337
Q14_Problem_Scored	.304
Q12_Problem_Scored	.278
Q4_Problem_Scored	.263
Q9_Problem_Scored	.257
Q31_Problem_Scored	.211
Q33_Problem_Scored	.147
Q32_Problem_Scored	.124
Q24_Problem_Scored	-.022
Q34_Problem_Scored	-.049
Q23_Problem_Scored	-.138
Q30_Problem_Scored	-.292

There was no clear pattern to the ordering of these relationships, although the highest relationships were associated with items about the giving of information. A few items (all in the parent section) were negatively related to the child summary score.

Variation

Variations in scores by various subgroups were examined for Q19. Results are reported in Appendix 2 (provided as a separate document). Demographic items (gender, ethnicity and who completed the questionnaire) were not associated with differences in overall score. Scores did differ by the type of clinician last seen: the most positive scores were associated with specialist allergy staff and the least positive with the 'other' category.

Agreement between child and parent items

Two sets of child and parent items covered similar aspects of care, and their relationship was examined by cross-tabulation. For Q16 x Q26 the correlation (Kendall's tau-b) was 0.39. For Q6 x Q28, the correlation was 0.43.

In both cases there is a moderate correspondence between the two perspectives, showing that responses from parents and children were to some extent related.

III Conclusions

Item completion rates were good for both questionnaires, and there was no evidence of fatigue, at least for those questionnaires that were returned. There were a small number of children's questionnaires where the parent section was not completed.

Problem scores were generally capable of showing discrimination, but for reasons to do with ceiling effects, it would be preferable not to report the overall summary items (Q30 in the parent questionnaire and Q19 in the child questionnaire) in terms of problem scores, but to use the full range of response options.

In terms of overall ratings of care on both questionnaires, there were no significant differences associated with demographic variables, but there was differentiation between the most recent member/type of clinical staff that they saw about their/their child's allergy.

References

American Educational Research Association, American Psychological Association, National Council on Measurement in Education, & Joint Committee on Standards for Educational and Psychological Testing (U.S.). (1999). *Standards for educational and psychological testing*. Washington, DC: American Educational Research Association.