



Paediatric CARE Measure (PCM)

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Research team: Dr Joan Murphy - Principle Investigator
Dr Stewart Mercer – Co-Investigator
Morag Place – Research Assistant
Talking Mats Centre www.talkingmats.com

Project Lead: Jane Reid
AHP National Lead for Children and Young People

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1. Background

For professionals working in healthcare, it is important to get feedback from patients following consultation or treatment. The Consultation and Relational Empathy (CARE) measure¹ was developed to gain the views of people consulting their GP. The CARE measure is a consultation process measure that is based on a broad definition of empathy, in the context of a therapeutic relationship, within the clinical encounter¹. Empathy is the basis for all therapeutic relationships² and it is important that it can be measured as it has been revealed to have an influence on patient enablement³ and patient and professional satisfaction during the clinical consultation⁴⁻⁵. Patients' definitions of quality of care are influenced by how empathetic the professional is during the consultation⁶ and the relationship between patient and professional has been shown to be enhanced by empathy³.

In 2010 the Scottish Government set out the quality strategy⁷ for the NHS which was designed in consultation with the people of Scotland. The strategy was based around six priorities, three of which relate directly to the CARE measure:

- Caring and compassionate staff and services;
- Clear communication and explanation about conditions and treatment;
- Effective collaboration between clinicians, patients and others.

These priorities were set by people who use NHS services. It is important that the NHS can measure how well they fulfil these goals. The CARE measure can allow health boards to do this.

User consultation is now common within adult healthcare services in the UK⁸⁻⁹. It has become best practice for patients to be consulted at every stage of their healthcare journey as well as having an input into service design and evaluation⁷. Children however are less commonly consulted due to the more complex nature of obtaining their views. The United Nations Convention on the Rights of the Child¹⁰ made it a legal obligation for governments to ensure that:

“the child who is capable of forming his or her own views [has] the right to express those views freely in all matters affecting the child, the views of the child being given due weight in accordance with the age and maturity of the child” Article 12.1.

This was taken into account when the Scottish Government introduced ‘Getting it right for every child’¹¹, which promotes :

“a child-centred, children’s rights approach to the planning and delivery of children’s services across agencies. The values and principles and the core components emphasise the rights of children to be heard and heeded as well as the right to privacy and confidentiality, health, education and safety”^{12 (p1)}.

Despite this legal and political context, the government recognises that whilst good practice exists, there is still a lot of work to do with respect to this goal.

Researchers who have worked with children as respondents recognise that children can offer a valuable and insightful perspective on their own situation or healthcare specifically and that this view may well differ from a parent's or other proxy respondent's view¹³. Although gaining reliable and useful information from children and young people can be challenging¹⁴, with careful design and testing, questionnaires can be developed which enable children to give their views on a range of issues including their own healthcare¹³⁻²⁰.

Following its development and implementation in General Practice, the CARE measure has since been validated for use with patients attending adult AHP clinics²¹. During these validation processes it was clear that the original CARE measure would not be appropriate for use by adults with communication, cognitive and/or literacy difficulties and therefore the Visual CARE Measure was developed for use by this patient group. The development of the Visual CARE Measure involved working with people with communication support needs and Speech and Language Therapists to adapt the measure to make it more accessible which has resulted in a version of the CARE measure which is supported by symbols and has less complex language²².

There is currently no tool that can be utilised by paediatric AHPs to gain the views of children or parents attending their services with regard to their relational empathy. The current project during phase 1²³ wished to determine whether the Paediatric CARE Measure (PCM) (based closely on the Visual CARE Measure) would be appropriate for use in paediatric AHP services. Following results of phase 1, although the PCM was felt to be appropriate, a number of adaptations were required which resulted in 3 versions of the PCM being assessed in phase 2. These were the

- 5Q which was a reduced version of the PCM (for children aged 7-11 or those children with a cognitive or language difficulty)
- 10Q (for young people 11-18) which remained very similar to the original PCM trialled in phase 1
- 10Q Parent (for parents of children aged 0-6 or children and young people who met the exclusion criteria) which again was similar to the original PCM with wording adjustments taking into account that parents were completing the measure on behalf of their child.

If the PCM was appropriate for these patient groups it would enable services to be evaluated and compared against each other. It would also allow the identification of any learning or development needs within services. With the publication of the AHP National Delivery Plan 2012-2015²⁴, the Scottish Government are clear in action point 5.6 that:

"AHP leaders across health and social care will lead innovation and improvement in the quality of their services, underpinned by data gathered from people who use services, their families and carers, to improve outcomes and demonstrate service impact", pp30.

It is important to have tools to gather that important feedback and the proposed PCM is one such potential tool for gathering feedback from children, young people and their parents who access a range of AHP services.

Figure 1: Example of the 5Q PCM

PCM 5Q TalkingMats® NHS Scotland

Please tick, circle or mark the scale.

How was the therapist at...

1... making you feel happy and relaxed?
(being friendly and caring and making you feel calm)

not very good ok good very good excellent does not apply

2... asking questions and letting you talk?
(being interested in you and giving you time to speak)

not very good ok good very good excellent does not apply

3... listening and understanding?
(paying attention and knowing the things you find difficult)

not very good ok good very good excellent does not apply

4... explaining things?
(answering questions, giving you clear information and instructions)

not very good ok good very good excellent does not apply

5... making a plan?
(encouraging you, talking about what to do next, involving you as much as you want)

not very good ok good very good excellent does not apply

If you would like to explain any of your answers, please use the space overleaf.

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Adapted in 2012 by Dr Joan Murphy & Morag Place, Talking Mats Centre, www.talkingmats.com & Jane Reid, NHS Scotland. Images © Adam Murphy

2. Aim

To evaluate a measure to assess empathy and patient-centredness of AHP interventions in paediatric AHP services.

3. Objectives

1. To assess the feasibility, reliability and validity of the 'PCM: 10Q' with secondary-aged children accessing AHP services
2. To assess the feasibility, reliability and validity of the 'PCM: 10Q Parent' with parents of young children (0-6) or parents of children with profound cognitive or language impairment accessing AHP services
3. To assess the feasibility, reliability and validity of the 'PCM: 5Q' with primary-aged children or children of any age attending special school accessing AHP services
4. To assess the feasibility and validity of the PCM when used in AHP services from the perspective of AHPs

4. Methods

4.1 Procedure

4.1.1 Recruitment of AHPs

Prior to recruitment in phase 2, liaison with key individuals (e.g. AHP National Lead for Children and Young People, AHP managers for Forth Valley, Tayside and Lothian) allowed the researchers to explain the project methodology and plan recruitment. These individuals then identified key staff members to coordinate recruitment within their teams. These key individuals (normally team managers) were contacted and invited to meet with the researcher along with their staff team. Prior to the meeting, project information sheets (detailing the background to the project and what it

would involve) and a copy of the PCM and evaluation form were sent by email. The research assistant then met with each staff team to explain the project in depth and to explore how their involvement would fit with their existing caseload. This allowed any problems or questions to be resolved prior to the study beginning. At the meeting with the researcher, AHPs were asked to identify how many new patient assessments or review appointments they had in their diaries over the coming two months. This was because the PCM questions follow the process involved in these types of appointments. AHPs then took the number of packs corresponding to the number of patients they expected to see. Meeting with staff teams as part of their standard team meeting time reduced the time required of therapists and streamlined the process for the researchers. As the project progressed the research assistant liaised with AHPs by email and telephone where necessary. AHPs could ask the researchers questions at any point throughout the course of the study.

4.1.2 Recruitment of participants

Each AHP was asked to collect PCM data from children or parents who they would be seeing as part of their normal caseload for an initial assessment or review appointment. This requirement resulted from feedback from phase 1 which found that the PCM questions reflected the process participants would have gone through during this type of appointment. Participants were recruited consecutively. These individuals could be:

- Children in mainstream primary or secondary education
- Children in special needs primary or secondary education
- Parents of young children (0-6) or parents of children of any age who met the exclusion criteria

Participants were excluded from the study if:

- they had a profound cognitive or language impairment;
- they had a severe visual impairment;
- they were acutely unwell.

Based on these criteria, AHPs used their clinical judgement to decide whether or not a patient was suitable for inclusion, but they were explicitly instructed not to exclude based on a 'bad' consultation.

In a clinic or school setting, the child, or parent, was asked by the therapist if they would be willing to complete the PCM pack. If the participant agreed, they were given the pack immediately following the consultation. The participant was asked to spend a few minutes completing the forms. The participant then placed all completed forms into the addressed envelope and sealed it. The envelope was then handed in at a designated point. The AHP was not present during completion of the measure. If the child required support completing the forms, a supporter, independent from the AHP, provided support. At the end of the clinic or school visit the AHP collected all sealed envelopes and returned them in batches to the research team. In the home setting, the AHP asked if the participant would be willing to complete the forms following their appointment. The participant then completed the forms at home once the AHP had left and posted the envelope directly to the research team in the SAE provided.

4.1.3 Data

Quantitative data was then recorded in SPSS based on responses from the PCM and evaluation form. Qualitative data was recorded and was organised based on common themes. This allowed the team to make judgements about whether further recommendations for use of the PCM or additional changes to the PCM were required.

4.1.4 AHP feedback

On completion of their participation in the project, AHPs were asked to complete an online feedback questionnaire about their experiences of using the PCM and their thoughts on the measure itself.

4.2 Participants

4.2.1 Allied Health Professionals

One hundred and fifty four Allied Health Professionals (AHPs) from 6 professional groups (Speech and Language Therapy, Physiotherapy, Occupational Therapy, Podiatry, Orthoptics and Dietetics) were involved. Sixty two worked within NHS Forth Valley, 50 within NHS Lothian, and 42 within NHS Tayside. AHPs worked across a variety of settings including clinic, hospital, school and home visits. Each participating AHP was assigned a unique identifying code, to allow the researcher to match their patient's PCM to them and keep track on return numbers. 153 AHPs were female and 1 was male.

4.2.1.1 Response rate - AHPs

The completion rate was 60% (i.e. 154 signed up, 93 completed). The main reasons given for not completing were that they kept forgetting (5), didn't have any new referrals (4) or hadn't heard about the project (3) (possibly if colleagues had signed them up). Other reasons given were that they didn't have time (2), didn't want to bother people (1), didn't think it was a good tool (2), didn't have any appropriate patients (2) (i.e. caseload was patients who met the exclusion criteria), were running joint clinics and other members of staff participated (1) and that it was just another bit of paperwork (1).

Table A: Breakdown of professions involved and number who participated

AHP Profession	No. of AHPs signed up	No. of AHPs who participated	No. of completed measures returned	Mean No. of measures returned per AHP	No of completed AHP online surveys returned
SLT	52	38 (73%)	161	4.24	42 (81%)
OT	45	29 (64%)	107	3.69	28 (62%)
Physio	40	19 (48%)	70	3.68	21 (53%)
Dietetics	9	1 (11%)	2	2	1 (11%)
Orthoptics	6	4 (67%)	10	3.56	4 (67%)
Podiatry	2	2 (100%)	15	7.5	2 (100%)
Totals	154	93 (60%)	365 (+ 4 missing = 369)	3.97	98(+1 preferred not to state profession)

4.2.2 Children and Parents

The original target of 300 completed measures was exceeded and a total of 369 PCMs were returned. Of these, 149 (40%) were from children and 220 (60%) were from parents. 161 (44%) were attending Speech and Language Therapy, 107 (29%) Occupational Therapy, 70 (19%) Physiotherapy, 15 (4%) Podiatry, 10 (3%) Orthoptics and 2 (1%) Dietetics. Four (1%) measures were missing an ID number and had no indication of AHP profession. One hundred and sixty PCMs (43%) were returned from patients within NHS Forth Valley, 128 (35%) from within NHS Lothian, and 81 (22%) from within NHS Tayside. Two hundred and four (70%) PCMs were returned from respondents seen in a clinic setting, 42 (14%) seen at home, 40 (14%) seen in school and 5 (2%) seen as inpatients in hospital. Seventy eight respondents failed to give information on the context of their appointment.

Table B: Summary table of children's information

Age category	Gender	Education	Language / Cognitive Impairment	Language used at home
7+8: 29 (27%)	Male: 71 (65%)	Mainstream primary: 87 (58%)	None: 81 (70%)	English:116 (97%)
9+10: 29 (27%)			Mild: 21 (18%)	Urdu: 1 (1%)
11+12: 28 (26%)	Female: 38 (35%)	Mainstream secondary: 52 (35%)	Moderate: 12 (10%)	Bilingual- English / Turkish: 1 (1%)
13+14: 14 (13%)		Special school primary: 2 (1%)	Severe: 1 (1%)	Bilingual – English / Urdu: 1 (1%)
15-18: 7 (7%)		Special school secondary: 8 (5%)		
Mean age: 10.43				
Range: 7-18				
107/149 provided age details	109/149 provided gender details	149/149 provided education details	115/149 provided details of language / cognitive level	119/149 provided language details

Table C: Summary table of parent's information

Age category of child	Gender of parent	Language / Cognitive Impairment of parent	Language used at home
0,1+2: 58 (30%)	Male: 75 (41%)	None: 180 (91%)	English: 174 (93%)
3+4: 85 (44%)	Female: 109 (59%)	Mild: 13 (7%)	Arabic: 1 (0.5%)
5+6: 50 (26%)		Moderate: 4 (2%)	Bangla: 1 (0.5%)
Mean age: 3.37		Severe: 0	Polish: 4 (2%)
Range: 0-6			Turkish: 1 (0.5%)
			Chinese: 1 (0.5%)
			Bilingual – English / French: 1 (0.5%):
			Bilingual – English / Urdu: 1 (0.5%)
			Bilingual – English / German: 2 (1%)
			Bilingual – English / Czech: 1 (0.5%)
193/220 provided age details	184/220 provided gender details	197/220 provided details of language / cognitive level	187/220 provided language details

All data was anonymous, so no participant could be identified from their individual PCM or evaluation form.

Table D: Length of appointment

Length of appointment	Number of participants for each appointment length
<10 mins	1 (<1%)
10-29 mins	37 (12%)
30-59 mins	153 (51%)
1hr or more	109 (36%)
Total	300/369 provided details

Most appointments (87%) lasted more than 30 minutes.

4.2.2.1 Response rate – children and parents

In the AHP online survey AHPs answered the question – ‘Did anyone refuse to participate by not completing the forms?’. Only 3/73 AHPs reported that patients had refused to participate (4%) and this accounted for 11 patients. AHPs recorded any refusal reasons that patients gave for not wanting to complete the PCM. These reasons were not having time, children demanding attention or being overloaded with forms to complete. Although some patients did not refuse at the time, some AHPs gave the PCM away to complete at home rather than completing before they left. In our experience this has resulted in much lower return rates as many other priorities take over when participants leave the clinic and understandably they don’t end up completing and returning the measure. Although we did recommend that participants completed the measure immediately following their appointment, some AHPs reported feeling it was too much to ask families (especially with several young children) who had just attended a lengthy assessment appointment. The AHPs who used this method had very few completed measures returned.

4.3 Materials

4.3.1 AHP information sheet

AHP information sheets were sent out prior to meeting with AHPs. These detailed the background to the project, the project procedure, exclusion criteria and what was expected of AHPs.

4.3.2 Project packs

On meeting with the AHPs, PCM packs were distributed. There were three separate packs:

1. PCM 5Q: for children aged 7-11 at mainstream primary school or any child attending special school.
2. PCM 10Q: for young people aged 11-18 at mainstream secondary school.
3. PCM 10Q Parent: for parents of children aged 0-6 or parents of children who met the exclusion criteria and could not complete the measure themselves.

The PCM 10Q Parent pack included a participant information sheet for parents, a PCM (10Q - parent) and an evaluation form. The PCM 5Q pack included a participant information sheet for children and anyone supporting the child to complete the forms, a copy of the PCM (5Q), and a PCM (5Q) evaluation form. The PCM 10Q pack included a participant information sheet for young people, a PCM (10Q), and an evaluation form. All packs included an A5 addressed envelope.

4.3.3 PCM - from phase 1 to phase 2

In phase 1, two versions of the PCM were used; The PCM and PCM (parent). All children and young people completed the same version of the PCM. This had 10 questions and has now been labelled PCM (10Q). In phase 2, based on analysis of the findings from phase 1, three versions of the PCM were used. A reduced version of the PCM was produced (PCM (5Q)). From the findings in phase 1, this reduced version was recommended for children aged 7-11 attending mainstream primary or children of any age attending special school.

This reduced version of the PCM has 5 questions and asks the individual to rate their response based on a 5-point scale. Each question is still supported by a symbol to represent each concept however some of the symbols were modified from the PCM (10Q) to reflect the change in questions and feedback from participants in phase 1. The question wording differs from the PCM (10Q) to reflect the need for less complex vocabulary and the combining of concepts to reduce the measure by half. The scale was also symbolised and again the wording was altered based on feedback received in phase 1 (see report for phase 1²³ for a detailed explanation of how the PCM 5Q was developed).

The PCM (10Q) and PCM (10Q – parent) remained virtually unchanged from phase 1 other than to make it clearer in the instructions how to mark the form as it came through strongly in the phase 1 feedback that participants wanted clearer guidance.

4.3.4 Evaluation forms - from phase 1 to phase 2

In phase 1 the research assistant (RA) was present when the PCM was completed. The RA completed an evaluation form recording a judgement on how much support the participant required and whether they could have completed the measure alone. Details were also noted on the usability of the scale (vocabulary and number of points), any problems which came up including difficulty understanding questions or errors made on the PCM. In phase 2 these details were added to the participant evaluation forms in order to get as much feedback as possible on the feasibility of the PCM. This information was particularly important for the PCM (5Q) which had not been tested for usability and acceptability since its development following results of phase 1.

The phase 2 participant evaluation form consisted of questions asking individuals to rate, on a 4-point likert scale, how easy or difficult they found the PCM to complete and understand and how important the questions were to them. In addition it requested information on the age and gender of the child / parent, any cognitive or language difficulties present, language used at home, length and purpose of appointment and the context (home, school, clinic, hospital, other) the child was seen. At the bottom of the form was an opportunity for the child or their supporter to record any comments they wished regarding the scale or questions.

4.3.5 Prepaid envelopes

Prepaid envelopes were provided for AHPs to return batches of completed forms to the research team, or arrangements were made to collect them. Any AHPs seeing patients at home were provided with stamps so that participants could send back their completed forms independently.

4.3.6 AHP online survey

At the end of the study, an online survey was issued via email to all participating AHPs. This asked their views on:

- how easy the PCM was to use in their day to day work
- how useful the PCM was
- how relevant the PCM items were
- positive and negative feedback on the PCM
- whether they would use it in the future

Ninety nine AHPs returned surveys out of a possible 154 AHPs who originally signed up for the project (64% return rate). Three quarters (75.5%) of surveys returned were from AHPs who had handed out the PCM and a quarter (24.5%) were from AHPs who for various reasons had not handed out the PCM. For a breakdown of which professions returned the survey see Table A.

4.4 Analysis

All quantitative data was analysed using SPSS version 18.

Firstly, **feasibility** of the measure was analysed. This was done in order to establish whether the measure was appropriate for use within paediatric services and was done in several ways. Descriptive analysis was done for the likert ratings given by participants regarding ease of understanding and completion of the measures as well as how much support was required to complete the measures. Counts of frequency of responses and median values were calculated. Any differences between the three measures were calculated using chi-square with a significance level set at $p=0.05$. Counts were calculated for any incomplete forms returned by participants when completing the measure as a further indication of feasibility. Descriptive analysis of the AHP likert ratings of ease of use of the PCM was also carried out providing again counts of frequency of responses. Qualitative data in the form of any written comments were analysed thematically.

Secondly, analysis focused on assessing the **reliability** of the PCM for use by children as well as for parents. Reliability was determined by analysing the internal consistency of the measures using Chronbach's alpha. In addition, analysis of the percentage of participants scoring the maximum possible score as well as analysis of the level of skew and kurtosis of the three measures was provided.

Thirdly **face and content validity** were assessed using counts of 'not applicable' responses. This allowed us to judge whether the measure was asking the right questions and was relevant to participants. Qualitative data in the form of written comments from parents on the validity of the measure were also analysed. Finally, AHPs ratings regarding the relevance and usefulness of the measure were analysed. Ratings of whether they would use the measure again were also analysed. Descriptive analysis of ratings produced a measure of validity for the AHPs. AHPs also gave written feedback on the measures (see section 5.3.2) and this was analysed thematically.

4.4.1 Exclusions

Twelve of the 369 completed measures were excluded from analysis (3%). Measures were excluded for two reasons.

1. If the participant completing the measure was younger than the recommended age for that measure (e.g. a 10 year old completing the 10Q measure or a 6 year old completing the 5Q).
2. If the supporter felt that the child's responses were unreliable and not a reflection of their views (e.g. if the child completed the measure by making a pattern of their responses or if the child did not understand the questions)

During the analysis of the qualitative data all the supporter's feedback relating to completion of the measure was included.

In 16 out of 369 completed measures (4%) the participant had missed the back page of the 10Q measure and therefore only completed the first five questions. This meant that their data could only be included in the analysis of individual questions but was excluded from any analysis involving the measure as a whole.

4.5 Ethics

Permission was granted to undertake this project on the understanding that it was service development and therefore did not require specific ethical approvals. We were advised by the NHS Research Ethics Service that we did not "require an NHS ethical review for this project". Equally we were advised by the NHS Caldicott Guardian that "you do not need formal approval from the Caldicott Guardian". The research was however conducted ethically and consent was discussed with participants and was understood to have been granted if participants completed the forms.

5. Results

5.1 Feasibility

5.1.1 Quantitative - Ease of understanding and completion rated by children and parents

Children and parents rated how easy or difficult they found the measures to understand and to complete and the results are presented below for each of the three measures.

Table E: How easy were the questions to understand for children and parents completing the 10Q and 10Q parent measure

Measure	Very difficult	Quite difficult	Quite easy	Very easy	Total	Median rating for ease of understanding
10Q	0	0	15 (31%)	34 (69%)	49 (+3 missing)	4 (very easy)
10Q Parent	0	1 (1%)	52 (24.5%)	158 (74.5%)	211 (+6 missing)	4 (Very easy)

All of the 11-18 year olds completing the 10Q measure and 99% of parents completing the 10Q parent measure, found the measure easy to understand with a median rating for both of 4 'very easy'.

Table F: How easy were the questions to understand for children completing the 5Q measure and how did supporters rate the child's ease of understanding

Measure	Very difficult	Quite difficult	Quite easy	Very easy	Total	Median rating for ease of understanding
5Q (child rating)	1 (1%)	6 (7%)	26 (30%)	53 (62%)	86 (+1 missing)	4 (very easy)
5Q (Supporters rating)	0	3 (4%)	29 (38%)	44 (58%)	76 (+11 missing)	4 (very easy)

The majority of children completing the 5Q measure (92%) rated it as being easy to understand. This was confirmed by the majority of supporters (96%) who also felt the children found it easy to understand. Both ratings had a median score of 4, 'very easy'.

Table G: How easy was the measure to complete for children and parents completing the 10Q and 10Q parent measure

Measure	Very difficult	Quite difficult	Quite easy	Very easy	Total	Median rating for ease of completion
10Q	0	1 (2%)	10 (20%)	38 (78%)	49 (+3 missing)	4 (very easy)
10Q Parent	0	2 (1%)	52 (25%)	156 (74%)	210 (+7 missing)	4 (Very easy)

Ratings of ease of completion were similar to those of ease of understanding with 98% of older children and 99% of parents rating the measure as easy to complete. Again the median rating was 4, 'very easy'.

Table H: How easy was the measure to complete for children completing the 5Q measure and how did supporters rate the child's ease of completion

Measure	Very difficult	Quite difficult	Quite easy	Very easy	Total	Median rating for ease of completion
5Q (child rating)	0	3 (3%)	27 (32%)	55 (65%)	85 (+2 missing)	4 (very easy)
5Q (Supporters rating)	1 (1%)	3 (4%)	34 (45%)	37 (49%)	75 (+12 missing)	3 (quite easy)

As with the ratings of ease of understanding, most children (97%) rated the 5Q measure as easy to complete. The median rating for the children was 4, 'very easy'. The majority of supporters (94%) also felt that the children found it easy to complete. The median rating for the supporters was 3, 'quite easy'.

5.1.2 Quantitative - How much support was required rated by children and parents

Children and parents rated how much support they or their child required to complete each of the three measures and results are presented below.

Table I: Ratings of how much support was required to complete the measure

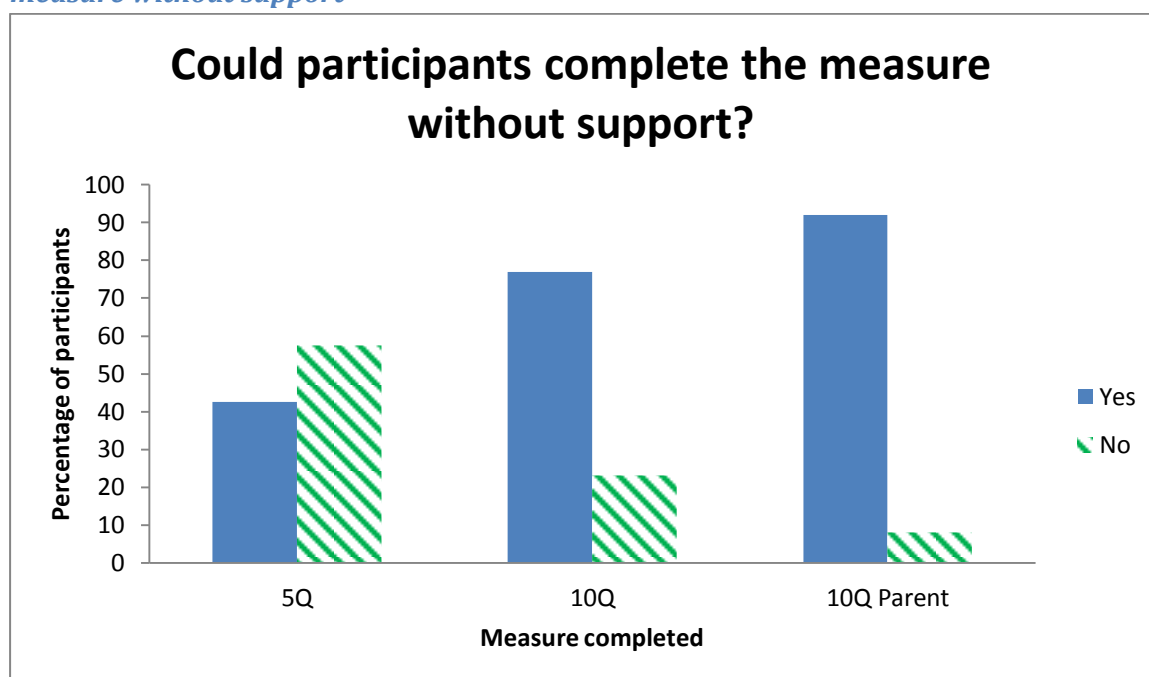
Measure	No support required	Support with up to two questions	Support with most questions	Support with all questions	Total	Median rating for support required
5Q	20 (29%)	24 (34%)	16 (23%)	10 (14%)	70 (+17 missing)	2 (support with up to two questions)
10Q	30 (68%)	8 (18%)	5 (11%)	1 (2%)	43 (+9 missing)	1 (no support required)
10Q Parent	160 (89%)	12 (7%)	5 (3%)	2 (1%)	179 (+38 missing)	1 (no support required)

As expected, the majority (71%) of children completing the 5Q measure required some level of support to fill in the measure. This balance changed with the older children as most (68%) did **not** require any support to complete the measure. Finally, the majority of parents (89%) needed no assistance to complete the measure.

Table J: Rating of whether person could have completed the measure alone (i.e. without support)

Measure	Yes	No	Total	Median rating
5Q	31 (42.5%)	42 (57.5%)	73 (+14 missing)	No
10Q	34 (77%)	10 (23%)	44 (+9 missing)	Yes
10Q Parent	159 (92%)	14 (8%)	173 (+44 missing)	Yes

Chart A: Comparing whether participants completing each measure could complete the measure without support



As can be seen from table J and chart A above, it was felt by participants that children completing the 5Q measure **could not** complete it without support in the majority of cases (57.5%) whereas most older children (77%) completing the 10Q and parents (92%) completing the 10Q parent, **could** complete these without support. This difference was statistically significant using chi square analysis ($\chi^2 = 71.388$, $df = 2$, $p < 0.001$).

5.1.3 Quantitative - Factors impacting on level of support: analysis of impact of age

A more detailed analysis of whether the age or cognitive / language ability of the children completing the measure had any impact on how much support they required is explored in the tables below. In addition the impact of first language was explored for parents completing the 10Q parent measure.

Table K: Support required analysed by age of children (excluding those with any cognitive or language difficulties) completing the 5Q measure

Age category	No support required	Support with up to 2 questions	Support with most questions	Support with all questions	Total
7-8	4 (31%)	5 (38%)	3 (23%)	1 (8%)	13
9-10	5 (45.5%)	5 (45.5%)	0	1 (9%)	11
11	4 (100%)	0	0	0	4

Analysis was done looking at those children who completed the 5Q measure, who did not have any cognitive or language difficulties. Numbers are lower than those that completed the measure as not everyone provided age and language / cognitive level details. Although values are too small to do chisquare analysis, it can be seen by the table that as expected, most (69%) of the younger children (7-8) required some support and even the 9-10 year olds often needed support with at least 2 questions. When supporters were asked whether the child could have completed the 5Q without support most (54%) of the supporters of children 7-8 said no, whereas most of the supporters of children 9-11 (80%) said yes they could have completed without support.

Table L: Support required analysed by age of children (excluding those with any cognitive or language difficulties) completing the 10Q measure

Age category	No support required	Support with up to 2 questions	Support with most questions	Support with all questions	Total
11-12	10 (67%)	3 (20%)	2 (13%)	0	15
13-14	7 (70%)	3 (30%)	0	0	10
15-18	5 (100%)	0	0	0	5

Younger people (11-12) completing the 10Q measure were more likely to need support, compared with the older children, however, as previously shown, the majority (67%) could complete independently.

5.1.4 Quantitative - Factors impacting on level of support: analysis of impact of cognitive / language ability

Table M: Analysis of whether children could complete the 5Q measure without support comparing those with and without any cognitive or language impairment

Any cognitive or language impairment?	Complete without support – Yes	Complete without support - No	Total
No	22 (67%)	11 (33%)	33
Yes	5 (22%)	18 (78%)	23

Overall most children (78%) with some level of cognitive or language impairment would need support to complete the 5Q measure. This difference is statistically significant ($\chi^2 = 10.957$, $df=1$, $p=0.001$).

Table N: Analysis of whether children could complete the 10Q measure without support comparing those with and without any cognitive or language impairment

Any cognitive or language impairment?	Complete without support – Yes	Complete without support - No	Total
No	31 (84%)	16(16%)	37
Yes	1 (20%)	4 (80%)	5

A similar pattern is observed with the 10Q measure (bearing in mind that those completing the 10Q did not have any significant impairment or attend special school) whereby those with some cognitive

or language impairment were more likely to require support. Values were too low to analyse using chi square analysis.

Table O: Analysis of how much support was required by parents to complete the 10Q parent measure comparing those parents with and without any cognitive or language impairment

Any cognitive or language impairment?	No support required	Support with up to 2 questions	Support with most questions	Support with all questions	Total
No	138 (90%)	9 (6%)	5 (3%)	2 (1%)	154
Yes	13 (93%)	1 (7%)	0	0	14

No effect of cognitive level was observed when looking at whether parents required support to complete the 10Q Parent measure.

5.1.5 Quantitative - Factors impacting on level of support: analysis of impact of first language

Table P: Analysis of how much support parents required to complete the 10Q Parent measure comparing those parents with and without English as their first language

First Language	No support required	Support with up to 2 questions	Support with most questions	Support with all questions	Total
English	135 (92%)	7 (5%)	3 (2%)	2 (1%)	147
Other	7 (58%)	3 (25%)	2 (17%)	0	12

It can be seen from the table above that parents whose first language was not English were more likely to require support to complete the measure. Values are too low to analyse using chi square.

5.1.6 Qualitative – Children and Parents

As well as the quantitative data gathered from parents and children, some of the participants provided qualitative feedback in the form of written comments regarding any aspect of understanding / using the scale and understanding the questions.

Of 220 **parents** who completed the measure, two parents felt that they would like a tick box as well as the faces to circle. Two parents commented that they were unsure how many adults needed to use the faces / visual representations rather than just words.

Several commented that the scale was clear, easy to complete, simple, and did not create any problems. In terms of the questions, again parents commented that they were very clear, straightforward, easy to understand and that the symbols were useful and appropriate.

Most of the **young people** (11-18) completing the 10Q measure said they found the scale clear, easy and had no difficulties using it. One of the 52 young people completing the measure would have preferred a tick box.

Feedback from some of the young people suggested that they required some support to complete the measure and understand the questions (these were all 11-12 year olds). One of the young

people said that question 10 'making a plan of action' was a bit confusing and one 12 year old said question 5&6 were difficult ('fully understanding your concerns' and showing care and compassion').

Feedback from people supporting the 149 **children** (7-11) and **young people with cognitive or language difficulties** to complete the PCM 5Q was that many of them coped well with the measure and required little support to complete the PCM 5Q. Supporters commented that the children understood well, that the images were a good way to illustrate the questions, and that good, clear English was used. There were some children, however, who required support to understand and read the scale and questions. Two supporters mentioned that the longer 'memory' questions were more difficult. One supporter mentioned having to 'chat around the questions' with a 7yr old. Two supporters commented that question 5 'making a plan' was difficult for their child with one of them explaining that their child's 'future concept isn't very strong yet'.

5.1.6.1 Children with additional support needs

Some of the supporters also commented specifically on difficulties encountered by children and young people with moderate cognitive or language difficulties.

Some parents commented on the visual support the PCM offers. One parent of a 9yr old with moderate learning disability said:

"As my son has significant learning difficulties, pictures / faces / print together really help"

Another parent of a child with moderate difficulties (also 9yrs old) said they responded positively to the faces scale. On the other hand, one child with moderate Autistic Spectrum Disorder (ASD) was so attracted to the visual scale that s/he could only focus on the scale, not the questions. S/he circled one of each type of face because that was 'fair'. This child's supporter was clear that the measure was not appropriate for them. Another supporter of a child with moderate ASD remarked that the child was choosing answers based on different variables, not the questions. They said the child:

"did understand the question and could comment verbally on their enjoyment of the session / therapy input, but couldn't transfer this information to the scale"

One supporter of a 14yr old with moderate ASD suggested that the level of verbal and physical support s/he required may have biased answers slightly.

One supporter used demonstration as the way to help three children with moderate difficulties understand the questions.

One child of 12yrs with moderate LD could answer the questions but was not keen to do so as he did not understand the purpose of the PCM. He questioned why he was being asked and wasn't satisfied with the answer that the people who pay for the therapists want to check that they are good quality. Another child aged 14 with moderate ASD commented that he shouldn't have to do this and that it is a bit rude to ask him to say if therapy is good.

Finally two children with some cognitive and language impairment were generally less keen to participate as form-filling was a challenge and one child was very reluctant to use pen and paper, whilst another found handwriting difficult.

5.1.7 Quantitative - AHPs

As well as the views of children and parents, feedback on the measure was also gathered from AHPs via online survey. The table below reports the results of 74 AHP views on how easy the PCM was to use in their day to day work.

Table Q: Ease of use of the PCM for AHPs

Ease of use	Very difficult	Quite difficult	Quite easy	Very easy
Number of AHPs	0	12 (16%)	54 (73%)	8 (11%)

Most AHPs (84%) found the measure easy to use in their day to day work.

5.1.8 Qualitative - AHPs

As well as qualitative feedback from parents and children, comments from **AHPs** were analysed into themes.

5.1.8.1 Handing out the measure

A large proportion of the AHPs reported that it was very easy to hand out and explain.

“Easy to use in clinic setting and easy to explain to clients” (AHP 86, SLT)

There were however also a number of AHPs who felt that having just attended a long and busy appointment, families were reluctant to spend any extra time completing the measure.

“By the end of an assessment most parents just want to get away with restless small children” (AHP 13, SLT)

These AHPs tended to give the families the measure to complete at home. In hindsight some AHPs commented that they would plan in future to introduce the measure at the start of a session and factor in time to complete the measure at the end.

“I would do this in future and pre-warn it is going to be done from start” (AHP 26, SLT)

“I think if you don’t ask patients to complete the care measure there and then you are unlikely to get a return” (AHP 11, SLT)

A number of AHPs said that they kept forgetting to hand out the measure. One AHP mentioned that when doing joint clinics there needed to be agreement as to which AHP would give out the measure and to make it clear to the participant, which AHP they were rating. One AHP suggested that providing a space for families to complete the measure after the session was problematic in some clinical settings.

5.1.8.2 Participants’ responses

Many AHPs reported that both children and parents were very happy to give feedback and enjoyed expressing their views.

“Children all appeared to enjoy filling out the form ‘marking their therapist’” (AHP 89, OT)

“Children appeared to be pleased that they were being given the opportunity to have their say” (AHP 85, OT)

“Parents appreciated the opportunity to feedback on their experience” (AHP 48, Physio)

“Most patients/carers seemed very happy to help by completing the relevant forms in [the] waiting room” (AHP 45, Orthoptist)

5.1.8.3 Language level and appearance

Many AHPs felt that children and parents found the PCM quick and easy to understand and complete.

“Parents and children reported that it was easy to use” (AHP 75, OT)

“Thought the forms were parent/child friendly and quick/easy to complete” (AHP 52, OT)

There was some mixed feedback regarding the language level. Many AHPs felt the measure was aimed at just the right level with not too much language used, whilst others felt that some of the concepts were still difficult to grasp and that less able families may find it hard to understand. One AHP felt the layout was quite busy and could benefit from being more spaced out. A couple of AHPs requested that the appropriate age range for use was displayed clearly on each measure. Many AHPs thought the visual supports were good however one AHP pointed out that the symbols used in the measure are different from those that her patients were used to. One AHP said that a parent had commented that the symbols were patronising but that they understood that they could help those with poorer literacy skills.

5.1.8.4 Participants with Additional Support Needs

A few AHPs reflected that the measure will not be suitable for some of the patients they work with, for example some of the children attending special school with profound difficulties or children with visual impairment.

“I was unable to use the PCM as the questionnaire had not been modified for the client group that I work with of Visual Impairment” (AHP 87, OT)

“I don’t think it would be appropriate for the majority of our school case load which is children with complex needs” (AHP 17, Physio)

Other AHPs commented that they found that some of the children required help reading the questions and that they needed to provide a member of support staff to aid bilingual parents and children to complete the measure.

“Bilingual co-workers helped the parents who did not have sufficient English to fill in the questionnaires” (AHP 7, SLT)

5.2 Reliability

5.2.1 Single administration reliability estimate

The internal consistency of the 5Q measure was judged using Chronbach’s alpha. Chronbach’s alpha was .746 and removal of any of the individual questions on the measure would weaken the internal reliability. The value is acceptable and was expected to be lower than for the other measures due to having half the number of test items compared with the 10Q measure.

The internal consistency of the 10Q Parent measure was judged using Chronbach's alpha and was .963. Internal reliability would be weakened by the removal of any individual item.

Again when the internal consistency was judged using Chronbach's alpha for the 10Q measure, the value was .926 with removal of any of the questions weakening the internal reliability.

Table R: Max possible score, skew, kurtosis and Chronbach's alpha for each of the measures

	5Q	10Q	10Q Parent
Number of measures completed	87 (83 + 4 N/A or Missing)	53 (43 + 10 N/A or Missing)	217 (185 + 32 N/A or Missing)
Mean (SD)	22.2 (2.84)	45.7 (5.1)	46.3 (5.6)
Min – Max	13-25 (max score 25)	28-50 (max score 50)	25-50 (max score 50)
% of respondents with max score	28%	35%	54%
Skew	-1.158	-1.456	-1.595
Kurtosis	0.902	2.277	1.829
Chronbach's alpha	0.746	0.926	0.963
% not applicable	N= 3, 3%	N=6, 11%	N=19, 9%
% >2 not applicable	N=0, 0%	N=1, 2%	N=2, <1%
% missing values	N= 1, 1%	N= 4, 5%	N= 12, 6%

5.2.2 Maximum possible score

Twenty eight per cent (28%) of participants completing the 5Q measure scored the maximum score of 25. On the 10Q measure, 35% of participants scored the maximum score of 50 and on the 10Q parent, 54% scored the maximum score of 50.

5.3 Validity

5.3.1 Content validity – Children and Parents

One way of judging how relevant the questions were, for children and parents completing the PCM, was to use a method adopted by Mercer et al²⁵ when evaluating the original CARE measure. They analysed the number of 'not applicable' responses given by patients in order to examine how relevant patients found the questions to their consultation. As shown in Table R, the number of participants using the 'not applicable' response option was reasonably low (5Q – 3%, 10Q – 11%, 10Q Parent – 9%). The vast majority of participants responded with 'not applicable' once or twice with very few (5Q – 0%), 10Q – 2%, 10Q Parent <1%) using it three or four times.

All the missing values on the two 10Q measures were from participants not filling in the back page of the measure.

5.3.2 Content validity – AHPs

Content validity was also assessed using responses by AHPs to the online survey regarding their opinions on the PCM and how relevant the questions are to their consultations and how useful the measure is for their profession.

Most (95%) of the 82 AHPs who responded to the question – 'How relevant do you feel the PCM questions are, specifically to your profession?' – felt that the measure was relevant to their

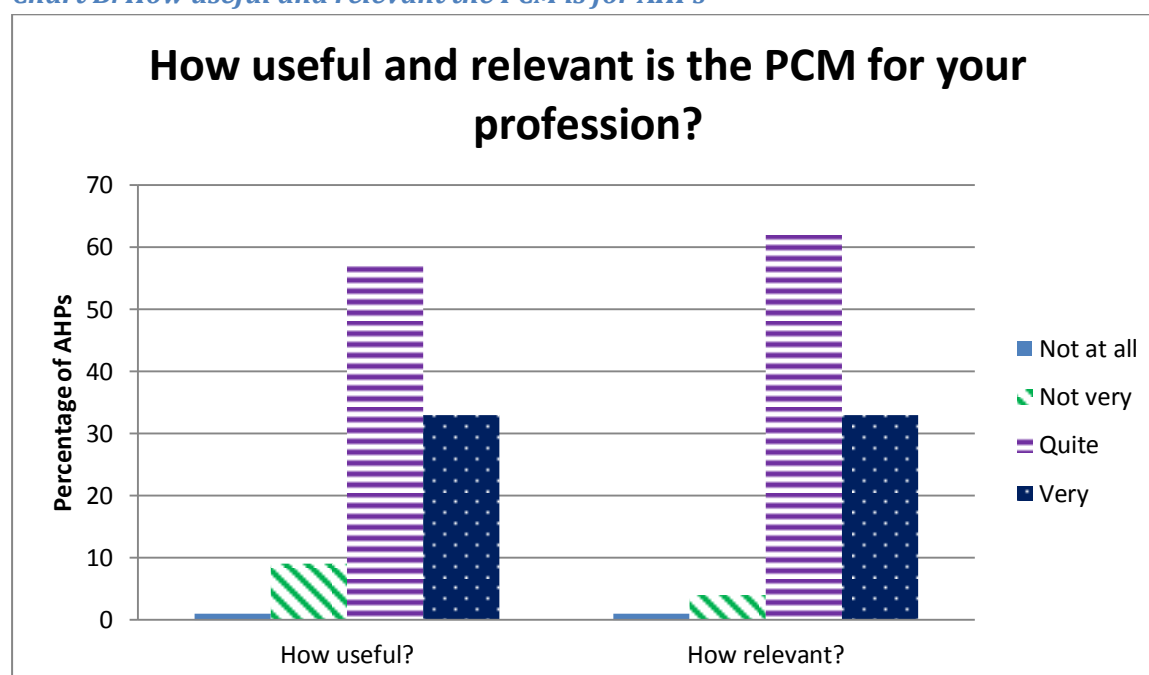
profession, with 62% feeling questions were quite relevant and 33% feeling they were very relevant. 1 AHP (1%) felt the questions were not at all relevant and 3 AHPs (4%) felt they were not very relevant. See below for a breakdown of responses per profession.

Table S: Profession specific responses to how relevant the PCM is to their profession

Profession	Not at all relevant	Not very relevant	Quite relevant	Very relevant	Total
Dietetics	0	0	0	1 (100%)	1
Occupational Therapy	0	1 (4%)	13 (57%)	9 (39%)	23
Orthoptics	0	1 (25%)	3 (75%)	0	4
Physiotherapy	1 (6%)	0	11 (65%)	5 (29%)	17
Podiatry	0	0	1 (50%)	1 (50%)	2
Speech and Language Therapy	0	1 (3%)	23 (66%)	11 (31%)	35

Ninety per cent (90%, 74/82) of AHPs felt the PCM was useful for their profession, with 57% (N=47) saying it was quite useful and 33% (N=27) saying it was very useful. Seven (9%) AHPs felt it was not very useful and 1 (1%) AHP felt it was not at all useful.

Chart B: How useful and relevant the PCM is for AHPs



Finally AHPs were asked whether they plan to use the PCM to evaluate their practice in the future. Ninety-six per cent (96%) said they would use it again although the majority (48/81, 59%) said they would do so only if it was a requirement of their post, e.g. audit.

AHPs also provided qualitative feedback on the face validity of the measure which was analysed thematically and is presented below.

5.3.2.1 PCM usefulness

There was a strong feeling amongst the majority of AHPs that the measure was a much needed tool and they felt it could provide helpful information about the service they provide, a good measure of patient satisfaction and patient's views.

"I'm sure it would give us very helpful information about the service" (AHP 28, Orthoptist)

"A measure of this type for this setting is long overdue" (AHP 24, Podiatrist)

"I think it is very important to get feedback from patients and this is a good tool to do so" (AHP 11, SLT)

"I liked the transparency of the measure and the chance to say to families that we do really care what they think of the service" (AHP 94, SLT)

They valued the opportunity to get feedback from both parents and children and felt it was a good tool to do this. One AHP stated –

"I think it made me reflect on my interactions with the parents and children. We need to do this anyway of course, but it brought it to the front of my mind as I was meeting people for the first time, and made me try to see the encounter from their point of view" (AHP 29, SLT)

One AHP considered what to do with the information gathered in order that it can be used to support AHP learning and improve the service –

"We need to think more carefully about a clear plan if feedback received indicates we need to be changing a lot of our practice, e.g. we then need to build in time to plan and effect change" (AHP 93, SLT)

5.3.2.2 PCM content

One AHP confirmed that the measure works best following initial assessments or review appointments as question 2 for example 'letting you tell your story' would not necessarily apply to on-going therapy. Another AHP would like to see a space provided on the measure for comments –

"The measure also didn't give any space for reflecting on the factors that may impinge on a therapist's perceived competency, such as resource limitations, time and workload pressures. In my experience, families are acutely aware of these issues and wish for a forum to express their concerns about these as a much higher priority than any concerns about a therapist's competency" (AHP 55, OT)

6. Discussion

6.1 Feasibility

Despite the acknowledged problems in obtaining the views of children (and especially young children and children with additional support needs) this study has shown that it is feasible to get the views of many, although not all, children. By adapting wording and adding visual images it is possible to assist understanding and provide easier ways for children to respond.

Additionally, by reducing the number of items the measure was made more accessible for young children and for some children with ASN. However even these adaptations did not make it possible for children with profound difficulties to be able to respond.

6.1.1 Ease of understanding and completion

The majority of children, parents and supporters rated the measures as easy to understand and complete. This also came through in the feedback received from parents, young people, supporters of the children and young people completing the 5Q and the AHPs. There were however some issues raised by the supporters regarding the suitability of the measure for some of the children with additional support needs (ASN). Some supporters felt that the level of 'guidance' required to complete the 5Q in some cases may have resulted in responses being influenced by the supporter. In other cases it was felt that the child did not understand the questions and therefore their responses were unreliable. Finally one of the supporters reported a child using a 'satisficing' strategy¹⁴ whereby he used an alternative strategy for responding rather than considering the questions and answering using the rating scale. In all these examples, it is clear that these children's completed measures should be (and were) excluded from any analysis. Having said that, it is still recommended that children with ASN are asked their views because many were able to successfully (with support) complete the measure and it would be important not to exclude these children based on a few whose responses were not reliable. Of the 115/149 children who completed the 5Q measure and provided details of cognitive / language level, 34 (29%) had some level of difficulties and therefore this is a large group who should continue to be asked their views.

6.1.2 Support

The majority of the children completing the 5Q measure required support to do so although 29% could manage without support.

As might be expected, for both the 5Q and 10Q measures, younger participants and those with some cognitive or language difficulties were more likely to require support to complete the measures. For parents, those with English as a second language were more likely to require support to complete the 10Q parent measure.

6.1.3 Administration

Overall AHPs were positive about the PCM and most said they would use it again if their department chose to use it as a tool for feedback. It came through quite strongly however, that some AHPs felt it was a lot to ask parents to complete another form after having attended a potentially long assessment or review appointment. Most appointments (262, 87%) were at least 30 minutes. Some AHPs therefore gave the measure to families to complete at home. Those families were much less likely to return the measure than those who completed it before they left the appointment location. Some of the AHPs suggested that a solution to this difficulty would be to introduce the PCM at the start of the appointment and let families know that they would be asked for their feedback at the end. Introducing the idea early then makes it easier to ask parents at the end. Some AHPs also suggested leaving 5 minutes spare at the end so that there was an allocated time for completing the measure.

It is important to note that, in clinical practice, parents or children would only be completing the PCM not the evaluation form which was part of the research project. This would cut the time required by at least half.

Finally, in 16 out of 369 completed measures (4%) the participant had missed the back page of the 10Q measure and therefore only completed the first five questions. A solution to this problem may be to either mark clearly on the instructions that participants should complete both sides of the form, or to make the form single pages.

6.1.4 Future use of the PCM in clinical practice

It was felt during phase 1 that the PCM was not suitable for a regular, recurring appointment where AHPs would not be going through the whole process outlined in the PCM. It was agreed that it should only be given to patients attending an initial assessment or review appointment. This does provide some problems for receiving the quantity of feedback (50 completed measures per professional) recommended by Mercer²⁵ in order to get a reliable picture of AHP performance. Many of the AHPs in this study had relatively low numbers of new patients or review patients and therefore use of the PCM may have to be over an extended period in order to capture the views of enough patients. This is not necessarily a bad thing however as it is likely to give a more representative view when done over a longer time period rather than a snapshot in time. This would be something for AHP team leads to consider when planning the implementation of the PCM. During the study, the teams who provided the greatest number of completed measures were those who had arranged an assessment 'block' whereby they had set aside a period of time (during school holidays) when all new referrals were assessed and prioritised. Not all teams are able to operate in this way but for any that are, this would be an obvious time to target the PCM. It is also easier for AHPs to remember to hand out as they are seeing each patient consecutively and therefore they can get into the routine of handing out the PCM after each appointment.

6.2 Reliability

From the results, all 3 measures (PCM -5Q, 10Q and 10Q parent) have been shown to be reliable with acceptable levels of internal consistency measured by Chronbach's alpha. This means that all the test questions are measuring the same concept (i.e. perceived relational empathy of the AHP).

6.3 Validity

6.3.1 Not applicable responses

Mercer et al.²⁵, in their paper examining the relevance of the original CARE measure for GP patients, concluded that low frequency of 'not applicable' responses suggested patients found the measure relevant to their consultation. When examining results for the PCM we also had low numbers of patients using the 'not applicable' response and therefore we can also conclude that the children and parents in our study found the PCM questions relevant on the whole to their consultation. In our study evaluating the PCM we also had very low numbers of patients using the 'not applicable' response more than twice (0-2%). Again Mercer et al.²⁵ discussed the issue of including or excluding patient's completed measures if they had used the 'not applicable' response and concluded that patient's completed measures could be included in any analysis of scores providing they had not used the response option more than twice.

6.3.2 Valuing Feedback

AHPs should view the measure as an opportunity to see the consultation from a patient's point of view and to get valuable feedback on how empathic the AHP is perceived to be during a therapeutic

consultation. The information received could be used to report on patient satisfaction and to improve service where necessary.

6.3.3 Validity across a range of professions

It was felt by most AHPs that the measure was relevant (95%), and useful (90%) specifically for their profession. This is a strong finding considering that six different Allied Health Professions were involved in the study with a range of different ways of working and a range of different focuses.

6.3.4 A much needed tool

Most AHPs (96%) said they would use the measure again and in the qualitative feedback many said it was a much needed tool. They emphasised the importance of gaining feedback from their patients and thought the measure could provide valuable information for their service. They were pleased to have a tool which showed patients that they care about what people think of their service.

6.3.5 A learning opportunity

One AHP highlighted the need to use the information provided by the PCM feedback to plan improvement of the service and to put in place opportunities for improving AHP performance and supporting learning for the benefit of the service and ultimately the patients they serve. There is a learning tool known as the 'CARE Approach' which is available free of charge and involves a web-based learning programme which can be used by a wide range of health care professionals. On their website²⁶ it states that it "has been specifically developed to help practitioners reflect on, practice, maintain and improve their communication skills and to use these skills effectively in helping empower and enable the patient".

6.3.6 Improvements to the measures

All versions of the PCM will be clearly marked to avoid any confusion when AHPs are handing out the measures. The 10Q measure will be recommended for 12-18 year olds. This recommendation is based on the findings from phase 2. It will also ensure there is no confusion over which measure to given to 11 year olds as that is the age when young people may be at primary or secondary school. The 10Q measures will be made single sided to avoid people missing the back page. A comments section will be added to allow patients completing the measure to qualify and explain any responses if they desire. In addition, the information sheets for participants will clearly explain the purpose of the measure so that children and parents understand why they are being asked to give their views.

7. Recommendations

7.1 Widespread PCM use for Paediatric AHPs

It is recommended that the PCM is used by all Paediatric Allied Health Professions as standard practice. This should be supported by AHP Child Health Leads and will inform the self-assessment component of recommendation 5.6 in the AHP National Delivery Plan²⁴ and will be integral in the development of the AHP Children's Services Plan (Recommendation 4.1). Evidence indicates that each AHP should collect feedback from 50 patients²⁵. The PCM, Patient information sheets and AHP guidance on the use of the PCM can all be accessed free of charge from the appendices which form part of this report or from the Children and Young People's Managed Knowledge Network website (<http://www.knowledge.scot.nhs.uk/child-services/communities-of-practice/ahp-cyp-network/paediatric-care-measure.aspx>) as well as the Talking Mats website (www.talkingmats.com).

7.2 Using the PCM

AHPs should let families know at the start of the appointment that they will be asked for their feedback at the end. Where possible extra time, and a suitable area should be set aside for families to complete the PCM before leaving.

7.3 Suitability of participants

It is recommended that all children who meet the inclusion criteria are offered the chance to complete the measure. It will be made clear on the supporters instructions that completed measures should be excluded if it is felt on completion that the child's responses were unreliable.

7.4 Support

Although young people (11-18) and parents completing the 10Q / 10Q parent measures may be able to complete without support, they should always be offered support especially when they are known to have literacy, language or cognitive difficulties or when English is not their first language. It is recommended that all children completing the 5Q measure must be provided with support to do so. This may be provided by a family member, carer, or other professional / support worker depending on the context of the appointment and who is available.

7.5 Using the feedback from the PCM

AHP child health leads or team leads analysing the data from the completed PCMs can find information on how to analyse the data on the Children and Young People's Managed Knowledge Network website (<http://www.knowledge.scot.nhs.uk/child-services/communities-of-practice/ahp-cyp-network/paediatric-care-measure.aspx>). Other tools which leads may find useful include:

- The CARE measure website developed at University of Stirling where data from AHPs working with adults has been entered and normative data is available. It is hoped that the PCM data will be added to this database in due course.
(<http://www.caremeasure.org/index.php>)
- The CARE Approach website developed at University of Glasgow. This is a free online learning tool which has six modules to work through with practical activities and written work. All activities are directly linked to improving a professional's relational empathy. It can be helpful for professionals at different stages of their career including trainees and can be used individually or as a team.
(<http://www.gla.ac.uk/researchinstitutes/healthwellbeing/research/generalpractice/careapproach/>)

8. Conclusion

Phase 2 of this project has resulted in three paediatric versions of the CARE measure which are appropriate for obtaining the views of children and their parents accessing paediatric services within the Allied Health Professions. It has found that the measure is feasible, reliable and valid across a range of AHPs and can be used to obtain the views of children and parents with a range of ages and abilities. It is an excellent way of gaining evidence as to how patients perceive the interpersonal aspects of the clinical encounter and how they rate an AHP's relational empathy.

9. Acknowledgements

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10. Summary report

The 4-page summary report for phase 2, **Place M, Murphy J, Reid J. *Paediatric CARE Measure (PCM): Phase 2 summary report*. Talking Mats Centre, Stirling, Scotland; 2012** can be accessed from the Talking Mats website <http://www.talkingmats.com/index.php/research-projects> or from the Children and young people's service Managed Knowledge Network <http://www.knowledge.scot.nhs.uk/child-services/communities-of-practice/ahp-cyp-network/paediatric-care-measure.aspx>

11. Contacts

For information about the Paediatric CARE Measure project or access to the PCM please contact:

Dr Joan Murphy and Morag Place
Talking Mats Centre
2 Beta Centre
Stirling University Innovation Park
Stirling
FK9 4NF
01786 479511
joan@talkingmats.com
morag@talkingmats.com
www.talkingmats.com
Twitter: @talkingmats.com

Jane Reid
AHP National Lead for Children and Young People
AHP Directorate
Kings Cross Hospital
Cleington Road
Dundee
DD3 8EA
01382 424177 or Internal 71177
07770537104
jane.reid@nhs.net
Twitter: @janerahpd

For more information about the original CARE Measure please contact:

Dr. Stewart Mercer
General Practice and Primary Care
Division of Community-based Sciences
University of Glasgow
1 Horselethill Road
Glasgow G12 9LX
Stewart.Mercer@glasgow.ac.uk

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