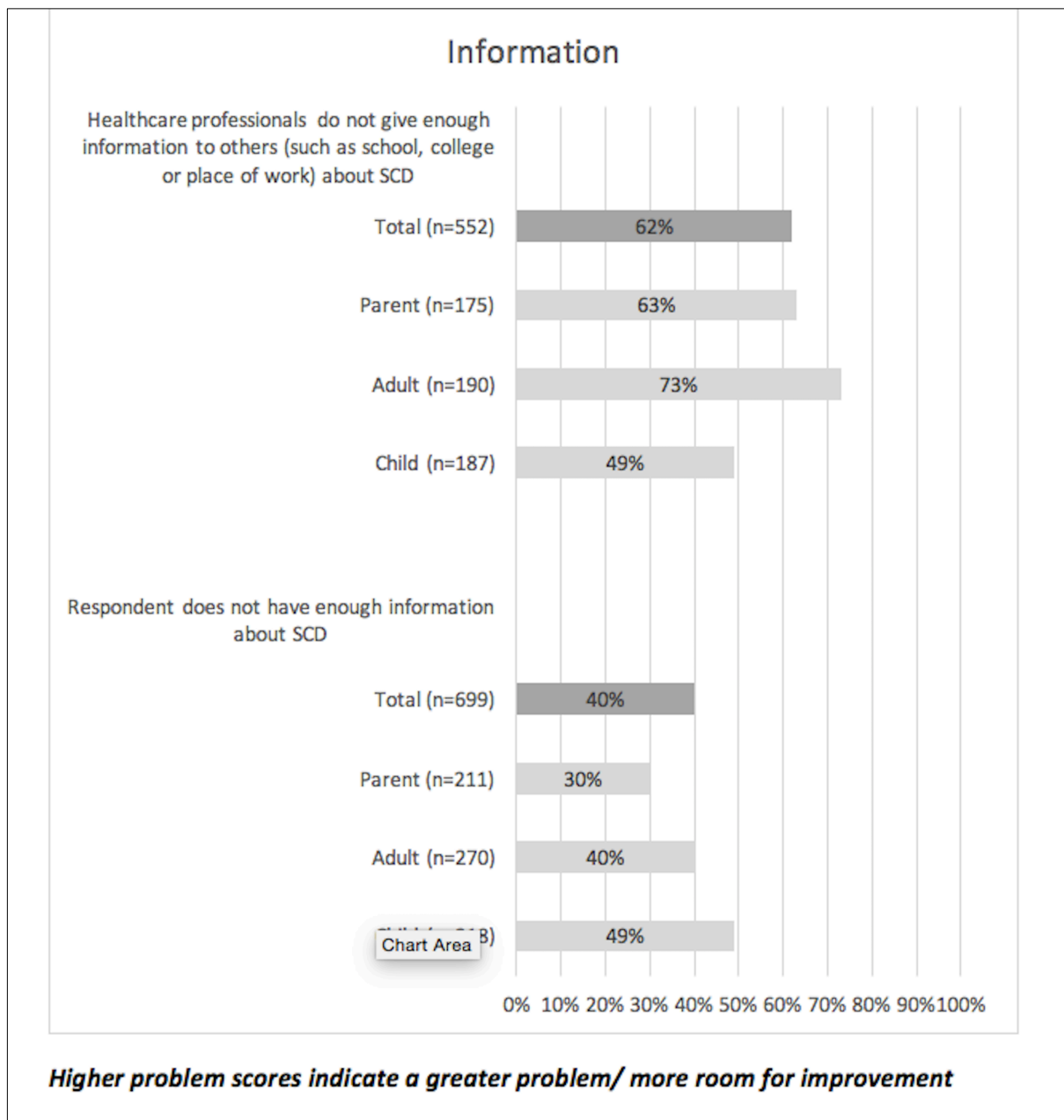
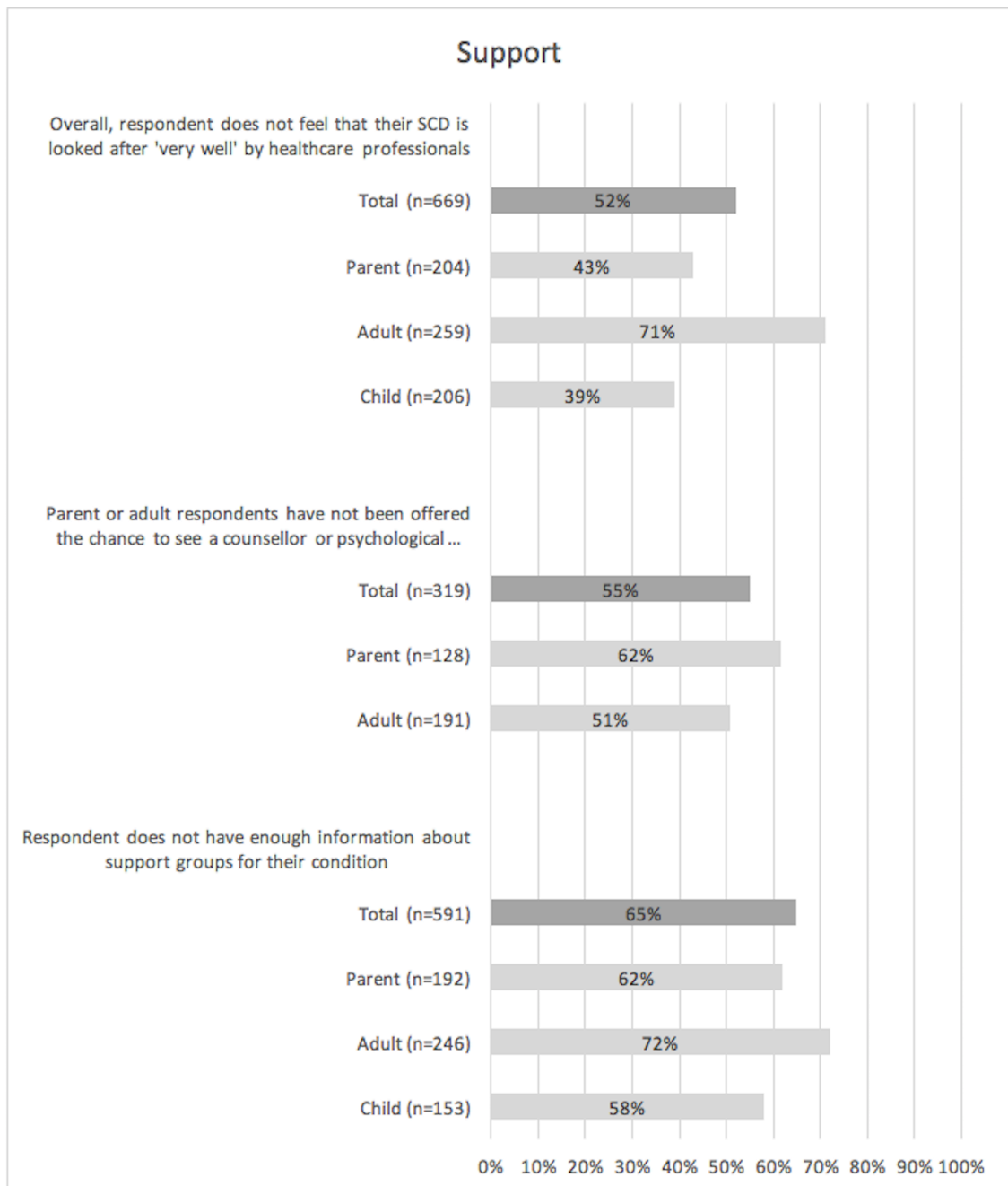




**Supplementary Figure 2: Problem Scores for 'Information about SCD' Survey Questions**

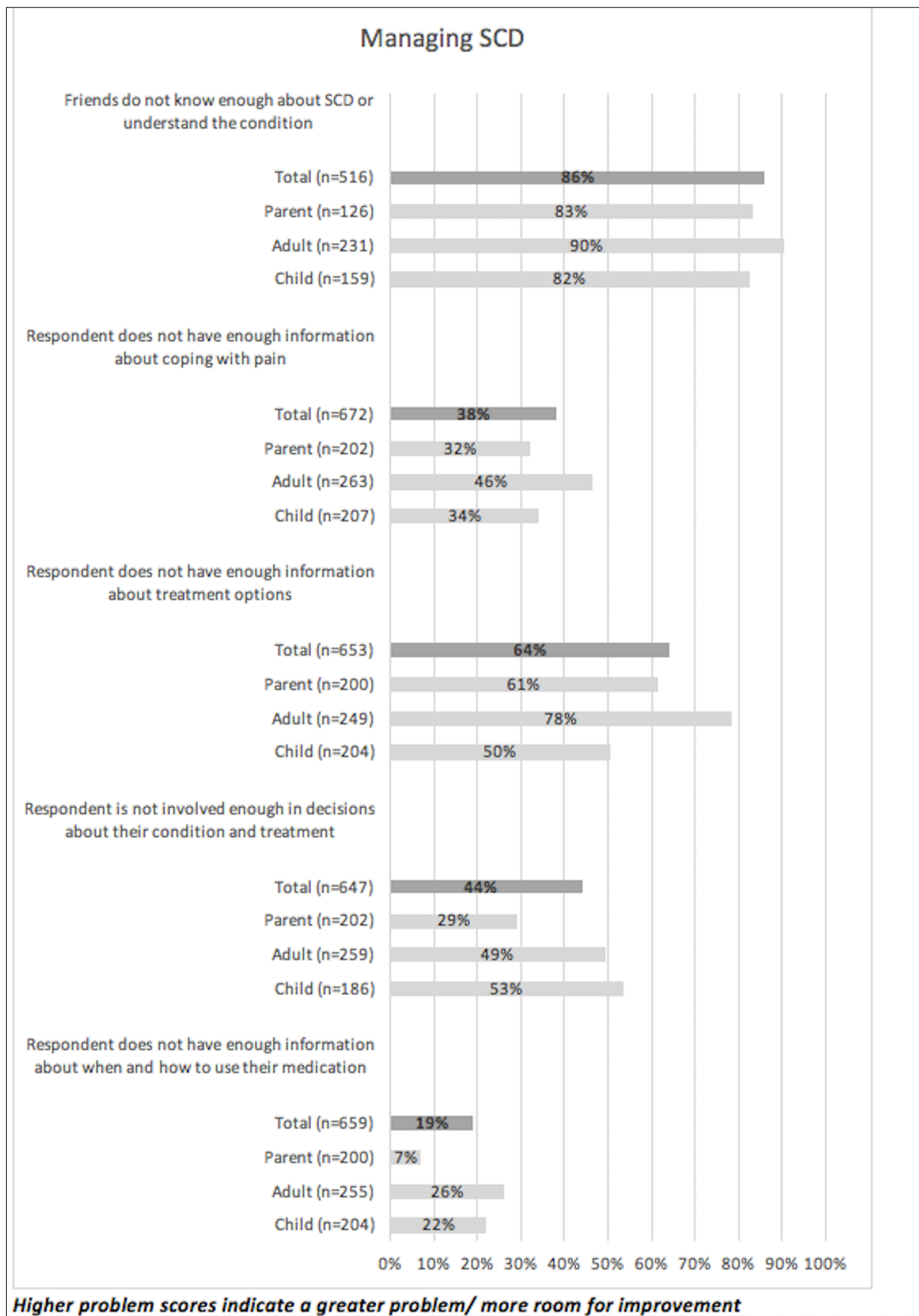


**Supplementary Figure 3: Problem Scores for 'Support for SCD' Survey Questions**

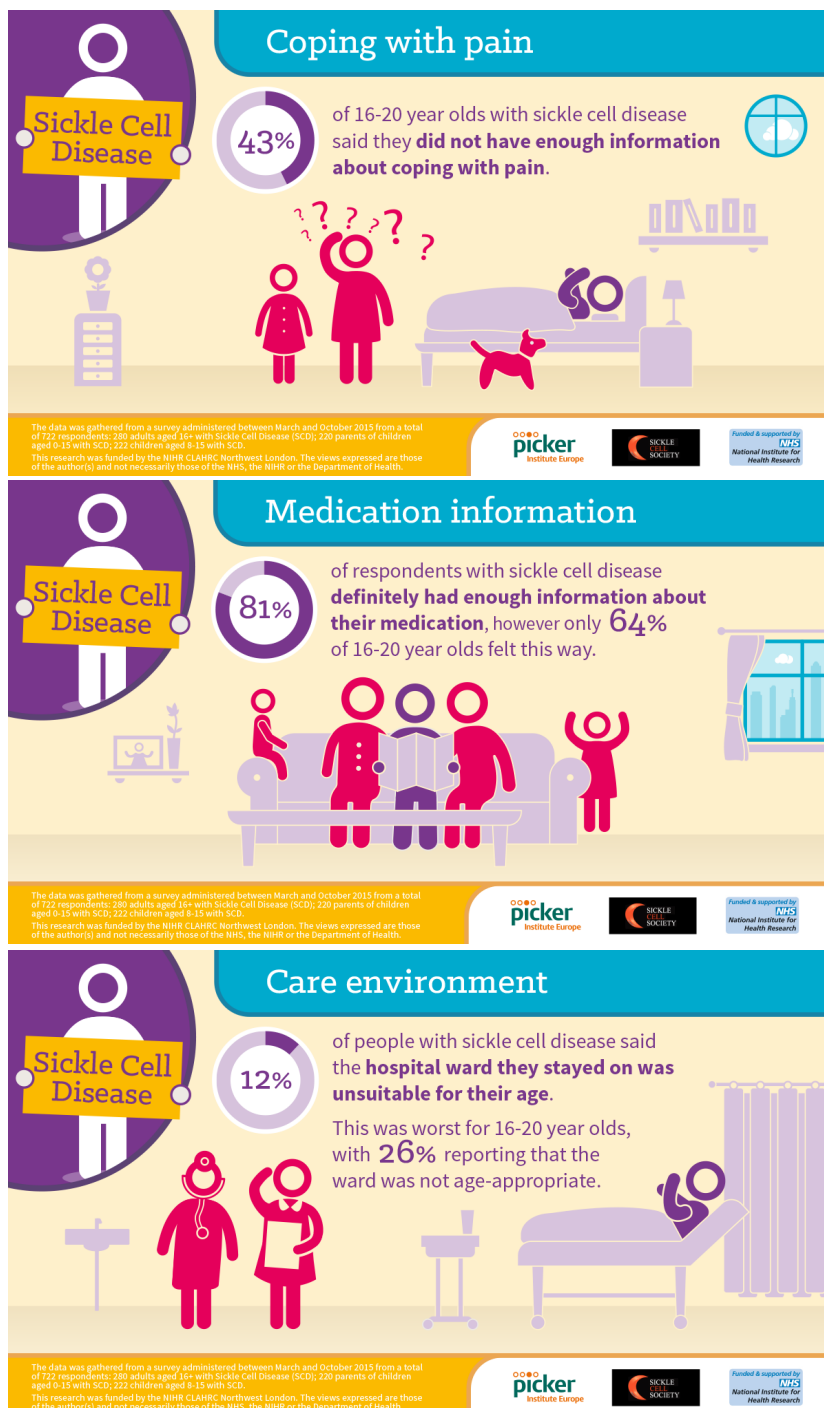


***Higher problem scores indicate a greater problem/ more room for improvement***

**Supplementary Figure 4** Problem Scores for 'Management of SCD' Survey Questions



Supplementary Figure 5 Twitter® card for dissemination of pilot survey findings



**Supplementary Table 1** Changes made to survey questionnaires following cognitive testing

Feedback received at cognitive testing	Action
<p>The following question was problematic for children in its current format:</p> <ul style="list-style-type: none"> <li>- After reading the question, some children answered with “<i>I asked my parents</i>”. This was not an available response option as the question intends to understand what service was accessed. When further prompted, they were able to answer this.</li> <li>- Some respondents found the number of response options confusing.</li> </ul> <p>10. When you last had emergency care for your sickle cell disorder, what did you <b>first</b> do for help?</p> <p><i>Please select ONE only. If you went to more than one then please select the one you went to <b>FIRST</b>.</i></p> <ol style="list-style-type: none"> <li>1 <input type="checkbox"/> Went to a hospital Accident &amp; Emergency Department</li> <li>2 <input type="checkbox"/> Went to a GP</li> <li>3 <input type="checkbox"/> Went to a sickle cell community centre</li> <li>4 <input type="checkbox"/> Went to an urgent walk-in centre</li> <li>5 <input type="checkbox"/> Called NHS 111/ NHS Direct</li> <li>6 <input type="checkbox"/> Called 999 for an ambulance</li> <li>7 <input type="checkbox"/> Called a specialist sickle cell nurse</li> <li>8 <input type="checkbox"/> Called the direct access number for the children’s ward</li> <li>9 <input type="checkbox"/> Other (please write in the box below):</li> </ol>	<p>Based on the feedback, the question was amended:</p> <ul style="list-style-type: none"> <li>- The question text was amended from ‘what did you do...’ to ‘what did you and your parent do’.</li> <li>- The number of response options was reduced.</li> </ul> <p><b>10</b> When you last had urgent treatment for your sickle cell, what did you and your parent <b>first</b> do for help?</p> <p><i>Please select ONE only. If you went to more than one then please select the one you went to <b>FIRST</b>.</i></p> <ol style="list-style-type: none"> <li>1 <input type="checkbox"/> Called a specialist sickle cell nurse</li> <li>2 <input type="checkbox"/> Treated at home without contacting anyone</li> <li>3 <input type="checkbox"/> Went to a GP</li> <li>4 <input type="checkbox"/> Went to A&amp;E</li> <li>5 <input type="checkbox"/> Called 999 for an ambulance</li> <li>6 <input type="checkbox"/> Other</li> </ol>
<p>A number of interviewees commented on the phrase ‘sickle cell disorder’ and explained that although the term ‘sickle cell’ is regularly used, the words ‘disease’ or ‘disorder’ are seldom used.</p>	<p>The terminology was altered across all surveys to reflect this. This is reflected in the question examples above.</p>
<p>Some sections of the survey ask about recent contact with specific parts of the healthcare system e.g. emergency care and inpatient stays – see example below. Several participants experienced difficulties recalling details about specific aspects of their care, particularly if it was over one year ago.</p>	<ul style="list-style-type: none"> <li>- Questions asking about recent healthcare were amended to a specific timeframe – within the last one year.</li> <li>- The example below shows that, at the request of participants, both the question text and the response options were amended to emphasise this timeframe. Those who received the named type of care over a year ago were routed past the subsequent</li> </ul>

**15.** Have you ever stayed in a hospital ward, either overnight (inpatient) or on a day unit (e.g. to receive treatment)?

*This does **NOT** include outpatient/clinic appointments*

- <sup>1</sup> Yes → Go to Question 16
- <sup>2</sup> No → Go to Question 19

questions asking about that particular care episode.

**13.** Within the last year, have you stayed on a hospital ward, either overnight or on a day unit (e.g. to receive treatment)?

*This does **NOT** include outpatient/clinic appointments*

- <sup>1</sup> Yes, within the last year  
→ Go to Question 14
- <sup>2</sup> No, not within the last year  
→ Go to Question 16

## Supplementary Table 2 Validation statistics

### 2a Inter-item polychoric correlations- Adults

Inter-item polychoric Correlations-ADULTS																				
	Q3 (T)	Q4 (T)	Q6+ (T)	Q15 (T)	Q16	Q18+ (T)	Q20+ (T)	Q21 (T)	Q22 (T)	Q24+ (T)	Q25+ (T)	Q26+ (T)	Q27+ (T)	Q28 (T)	Q29+ (T)	Q30+ (T)	Q31+ (T)	Q32+	Q34 (T)*	Q35 (T)
Q3 (T)	1.000	0.619	0.598	0.609	0.381	0.152	0.128	0.328	0.405	0.305	0.255	0.298	0.252	0.257	0.151	0.105	0.132	0.294	-0.324	0.446
Q4 (T)	0.619	1.000	0.658	0.538	0.415	0.178	0.211	0.372	0.504	0.079	0.399	0.497	0.379	0.340	0.498	0.230	0.308	0.125	-0.171	0.409
Q6+ (T)	0.598	0.658	1.000	0.462	0.282	0.285	0.243	0.409	0.452	0.152	0.299	0.466	0.174	0.237	0.328	0.125	0.173	0.065	-0.323	0.565
Q15 (T)	0.609	0.538	0.462	1.000	0.698	0.541	0.428	0.548	0.336	0.470	0.226	0.257	0.485	0.520	0.539	0.297	0.340	0.416	-0.519	0.453
Q16 (P&A)	0.381	0.415	0.282	0.698	1.000	0.627	0.165	0.269	0.326	0.473	0.297	0.367	0.436	0.318	0.287	0.320	0.042	0.384	-0.292	0.452
Q18+ (T)	0.152	0.178	0.285	0.541	0.627	1.000	0.315	0.201	0.161	0.228	0.169	0.423	0.378	0.188	0.238	0.304	0.211	0.073	-0.045	0.370
Q20+ (T)	0.128	0.211	0.243	0.428	0.165	0.315	1.000	0.420	0.202	0.211	0.002	0.071	0.114	0.242	0.295	0.196	0.365	0.242	-0.122	0.338
Q21 (T)	0.328	0.372	0.409	0.548	0.269	0.201	0.420	1.000	0.276	0.284	0.311	0.314	0.321	0.313	0.313	0.151	0.251	0.294	-0.570	0.499
Q22 (T)	0.405	0.504	0.452	0.336	0.326	0.161	0.202	0.276	1.000	0.446	0.556	0.584	0.543	0.488	0.354	0.368	0.271	0.477	-0.006	0.497
Q24+ (T)	0.305	0.079	0.152	0.470	0.473	0.228	0.211	0.284	0.446	1.000	0.435	0.406	0.393	0.477	0.432	0.121	0.156	0.325	-0.147	0.341
Q25+ (T)	0.255	0.399	0.299	0.226	0.297	0.169	0.002	0.311	0.556	0.435	1.000	0.525	0.489	0.378	0.425	0.203	0.215	0.244	-0.102	0.459
Q26+ (T)	0.298	0.497	0.466	0.257	0.367	0.423	0.071	0.314	0.584	0.406	0.525	1.000	0.564	0.345	0.370	0.244	0.185	0.191	-0.104	0.483
Q27+ (T)	0.252	0.379	0.174	0.485	0.436	0.378	0.114	0.321	0.543	0.393	0.489	0.564	1.000	0.555	0.296	0.163	0.178	0.212	-0.226	0.415
Q28 (T)	0.257	0.340	0.237	0.520	0.318	0.188	0.242	0.313	0.488	0.477	0.378	0.345	0.555	1.000	0.381	0.287	0.241	0.500	-0.191	0.389
Q29+ (T)	0.151	0.498	0.328	0.539	0.287	0.238	0.295	0.313	0.354	0.432	0.425	0.370	0.296	0.381	1.000	0.308	0.495	0.245	-0.077	0.372
Q30+ (T)	0.105	0.230	0.125	0.297	0.320	0.304	0.196	0.151	0.368	0.121	0.203	0.244	0.163	0.287	0.308	1.000	0.736	0.497	-0.125	0.334
Q31+ (T)	0.132	0.308	0.173	0.340	0.042	0.211	0.365	0.251	0.271	0.156	0.215	0.185	0.178	0.241	0.495	0.736	1.000	0.351	0.035	0.232
Q32+	0.294	0.125	-0.065	0.416	0.384	0.073	0.242	0.294	0.477	0.325	0.244	0.191	0.212	0.500	0.245	0.497	0.351	1.000	-0.119	0.321
Q34 (T)*	-0.324	-0.171	-0.323	-0.519	-0.292	-0.045	-0.122	-0.570	-0.006	-0.147	-0.102	-0.104	-0.226	-0.191	-0.077	-0.125	0.035	-0.119	1.000	-0.401
Q35 (T)	0.446	0.409	0.565	0.453	0.452	0.370	0.338	0.499	0.497	0.341	0.459	0.483	0.415	0.389	0.372	0.334	0.232	0.321	-0.401	1.000

\* Reverse-keyed

### 2b- Inter-item polychoric correlation- children

Inter-item polychoric Correlations-CHILD																							
	Q5	Q6	Q7_Plus	Q8	Q9_Plus	s	Q13	Q14	s	Q17	Q18	Q19	s	s	s	s	Q25	s	s	s	s	Q30	Q31
Q5	1.000	0.333	0.682	0.410	0.384	0.202	0.270	0.170	0.039	0.224	0.161	0.377	0.249	0.345	0.179	0.463	0.213	0.262	0.231	0.128	-0.053	-0.011	0.517
Q6	0.333	1.000	0.595	0.288	0.466	-0.483	0.098	0.313	0.197	0.380	0.428	0.300	0.254	0.107	0.306	0.126	0.064	0.172	0.148	0.172	0.159	-0.099	0.385
Q7_Plus	0.682	0.595	1.000	0.298	0.615	0.062	0.092	0.421	0.400	0.500	0.358	0.467	0.286	0.226	0.404	0.421	0.209	0.287	0.140	0.182	0.043	-0.143	0.635
Q8	0.410	0.288	0.298	1.000	0.248	0.408	0.206	-0.405	-0.033	0.428	0.401	-0.032	0.273	0.007	0.115	0.030	-0.070	0.068	-0.054	-0.222	-0.620	-0.171	0.393
Q9_Plus	0.384	0.466	0.615	0.248	1.000	0.016	0.257	0.426	0.325	0.398	0.443	0.369	0.169	0.246	0.372	0.228	0.179	0.254	0.218	0.328	-0.029	-0.130	0.333
Q10_Plus	0.202	-0.483	0.062	0.408	0.016	1.000	-0.219	-0.608	0.053	0.173	-0.038	0.079	0.046	0.153	-0.053	-0.058	0.025	0.082	0.170	-0.031	-0.592	-0.013	-0.041
Q13	0.270	0.098	0.092	0.206	0.257	-0.219	1.000	0.460	0.120	-0.164	0.325	0.180	0.356	0.051	0.402	0.342	0.403	-0.087	0.200	0.399	0.280	-0.194	0.539
Q14	0.170	0.313	0.421	-0.405	0.426	-0.608	0.460	1.000	0.434	-0.137	0.144	0.230	-0.053	0.098	0.432	0.419	0.270	-0.086	-0.089	0.228	0.543	-0.099	0.353
Q15_Plus	0.039	0.197	0.400	-0.033	0.325	0.053	0.120	0.434	1.000	-0.262	0.282	0.273	-0.064	0.084	0.434	0.364	0.379	0.101	-0.053	0.131	0.117	-0.345	0.243
Q17	0.224	0.380	0.500	0.428	0.398	0.173	-0.164	-0.137	-0.262	1.000	0.335	0.043	0.344	0.138	0.052	-0.140	-0.042	0.084	0.010	0.056	-0.251	-0.043	0.264
Q18	0.161	0.428	0.358	0.401	0.443	-0.038	0.325	0.144	0.282	0.335	1.000	0.245	0.450	0.286	0.219	0.122	0.240	0.035	0.106	0.345	0.114	-0.200	0.520
Q19	0.377	0.300	0.467	-0.032	0.369	0.079	0.180	0.230	0.273	0.043	0.245	1.000	0.371	0.534	0.376	0.394	0.449	0.455	0.584	0.424	0.361	0.028	0.293
Q21_Plus	0.249	0.254	0.286	0.273	0.169	0.046	0.356	-0.053	-0.064	0.344	0.450	0.371	1.000	0.499	0.363	0.288	0.487	0.359	0.572	0.438	0.373	-0.155	0.526
Q22_Plus	0.345	0.107	0.226	0.007	0.246	0.153	0.051	0.058	0.084	0.138	0.286	0.534	0.499	1.000	0.318	0.491	0.457	0.318	0.555	0.286	0.317	-0.043	0.258
Q23_Plus	0.179	0.306	0.404	0.115	0.372	-0.053	0.402	0.432	0.434	0.052	0.219	0.376	0.363	0.318	1.000	0.262	0.291	0.145	0.266	0.258	0.091	-0.024	0.321
Q24_Plus	0.463	0.126	0.421	0.030	0.228	-0.058	0.342	0.419	0.364	-0.140	0.122	0.394	0.288	0.491	0.262	1.000	0.504	0.277	0.269	0.142	0.303	-0.008	0.324
Q25	0.213	0.064	0.209	-0.070	0.179	0.025	0.403	0.270	0.379	-0.042	0.240	0.449	0.487	0.457	0.291	0.504	1.000	0.207	0.513	0.296	0.530	-0.098	0.438
Q26_Plus	0.262	0.172	0.287	0.068	0.254	0.092	-0.087	-0.086	0.101	0.084	0.035	0.455	0.359	0.318	0.145	0.277	0.207	1.000	0.353	0.254	0.221	-0.033	0.111
Q27_Plus	0.231	0.148	0.140	-0.054	0.218	0.170	0.200	-0.089	-0.053	0.010	0.106	0.584	0.572	0.595	0.266	0.269	0.513	0.353	1.000	0.605	0.387	0.078	0.207
Q28_Plus	0.128	0.172	0.182	-0.222	0.328	-0.031	0.399	0.228	0.131	0.056	0.345	0.424	0.438	0.286	0.258	0.142	0.296	0.254	0.605	1.000	0.427	0.030	0.163
Q29_Plus	-0.053	0.159	0.043	-0.620	-0.029	-0.592	0.280	0.543	0.117	-0.251	0.114	0.361	0.373	0.317	0.091	0.303	0.530	0.221	0.387	0.427	1.000	-0.166	0.302
Q30*	-0.011	-0.099	-0.143	-0.171	-0.130	-0.013	-0.194	-0.099	-0.345	-0.043	-0.200	0.028	-0.155	-0.043	-0.024	-0.008	-0.098	-0.033	0.078	0.030	-0.166	1.000	-0.367
Q31	0.517	0.385	0.635	0.393	0.333	-0.041	0.539	0.353	0.243	0.264	0.520	0.293	0.526	0.258	0.321	0.324	0.438	0.111	0.207	0.163	0.302	-0.367	1.000

\* Reverse-keyed



## 2c- Inter-item polychoric correlation- parents

Inter-item polychoric Correlations-PARENTS																						
	Q3 (T)	Q4 (T)	Q5+ (T)	Q6+ (T)	Q7 (P&A)	Q10 (P)+	Q15 (T)	Q16 (P&A)	Q18+ (T)	Q20 (T)	Q21 (T)	Q22 (T)	Q24+ (T)	Q25+ (T)	Q26+ (T)	Q27+ (T)	Q28 (T)	Q29+ (T)	Q30+ (T)	Q31+ (T)	Q32+ (P&A)	Q34 (T)*
Q3(T)	1.000	0.865	0.688	0.846	0.724	-0.392	0.762	0.710	0.551	0.303	0.493	0.258	0.282	0.240	0.371	0.398	0.303	0.294	0.129	0.095	-0.003	-0.353
Q4 (T)	0.865	1.000	0.691	0.771	0.758	-0.340	0.630	0.645	0.445	0.295	0.364	0.147	0.153	0.034	0.179	0.279	0.139	0.095	-0.057	-0.017	-0.094	-0.291
Q5+ (T)	0.688	0.691	1.000	0.657	0.683	-0.672	0.725	0.685	0.525	0.433	0.603	0.223	0.097	0.059	0.156	0.389	0.344	0.471	-0.061	-0.090	0.149	-0.389
Q6+ (T)	0.846	0.771	0.657	1.000	0.760	-0.372	0.724	0.688	0.465	0.298	0.506	0.321	0.344	0.227	0.219	0.382	0.397	0.248	0.144	0.032	0.014	-0.381
Q7 (P&A)	0.724	0.758	0.683	0.760	1.000	-0.414	0.622	0.674	0.521	0.331	0.525	0.217	0.335	0.209	0.254	0.377	0.247	0.206	0.171	0.010	0.069	-0.300
Q10 (P)+	-0.392	-0.340	-0.672	-0.372	-0.414	1.000	-0.758	-0.753	-0.719	-0.552	-0.662	-0.144	0.231	0.045	-0.014	-0.625	-0.140	-0.152	0.324	0.184	-0.209	-0.076
Q15 (T)	0.762	0.630	0.725	0.724	0.622	-0.758	1.000	0.897	0.758	0.363	0.724	0.437	0.204	0.237	0.227	0.582	0.286	0.289	-0.175	-0.071	-0.016	-0.223
Q16	0.710	0.645	0.685	0.688	0.674	-0.753	0.897	1.000	0.769	0.217	0.707	0.252	0.246	0.157	0.115	0.656	0.130	0.219	-0.133	0.056	0.161	-0.191
Q18+ (T)	0.551	0.445	0.525	0.465	0.521	-0.719	0.758	0.769	1.000	0.365	0.396	0.138	0.155	0.163	0.331	0.662	0.134	0.146	-0.172	0.036	-0.054	0.067
Q20 (T)	0.303	0.295	0.433	0.298	0.331	-0.552	0.363	0.217	0.365	1.000	0.237	0.111	-0.273	-0.131	0.052	0.152	0.096	-0.120	-0.076	-0.104	-0.181	0.108
Q21 (T)	0.493	0.364	0.603	0.506	0.525	-0.662	0.724	0.707	0.396	0.237	1.000	0.065	0.101	0.085	0.065	0.275	0.107	0.318	-0.128	-0.159	0.114	-0.259
Q22 (T)	0.258	0.147	0.223	0.321	0.217	-0.144	0.437	0.252	0.138	0.111	0.065	1.000	0.386	0.574	0.396	0.491	0.612	0.225	0.362	0.198	0.267	-0.142
Q24+ (T)	0.282	0.153	0.097	0.344	0.335	0.231	0.204	0.246	0.155	-0.273	0.101	0.386	1.000	0.476	0.230	0.137	0.415	0.337	0.493	0.356	0.135	-0.147
Q25+ (T)	0.240	0.034	0.059	0.227	0.209	0.045	0.237	0.157	0.163	-0.131	0.085	0.574	1.000	0.600	0.600	0.304	0.402	0.183	0.352	0.346	0.378	0.101
Q26+ (T)	0.371	0.179	0.156	0.219	0.254	-0.014	0.227	0.115	0.331	0.052	0.065	0.396	0.230	0.600	1.000	0.452	0.456	0.200	0.418	0.294	0.134	-0.159
Q27+ (T)	0.398	0.279	0.389	0.382	0.377	-0.625	0.582	0.656	0.662	0.152	0.275	0.491	0.137	0.304	0.452	1.000	0.511	0.044	0.153	0.188	0.478	-0.040
Q28 (T)	0.303	0.139	0.344	0.397	0.247	-0.140	0.286	0.130	0.134	0.096	0.107	0.612	0.415	0.402	0.456	0.511	1.000	0.398	0.476	0.165	0.397	-0.168
Q29+ (T)	0.294	0.095	0.471	0.248	0.206	-0.152	0.289	0.219	0.146	-0.120	0.318	0.225	0.337	0.183	0.200	0.044	0.398	1.000	0.381	0.190	0.288	-0.218
Q30+ (T)	0.129	-0.057	-0.061	0.144	0.171	0.324	-0.175	-0.133	-0.172	-0.076	-0.128	0.362	0.493	0.352	0.418	0.153	0.476	0.381	1.000	0.667	0.493	-0.063
Q31+ (T)	0.095	-0.017	-0.090	0.032	0.010	0.184	-0.071	0.056	0.036	-0.104	-0.159	0.198	0.356	0.346	0.294	0.188	0.165	0.190	0.667	1.000	0.409	0.235
Q32+ (P&A)	-0.003	-0.094	0.149	0.014	0.069	-0.209	-0.016	0.161	-0.054	-0.181	0.114	0.267	0.135	0.378	0.134	0.478	0.397	0.288	0.493	0.409	1.000	0.234
Q34 (T)*	-0.353	-0.291	-0.389	-0.381	-0.300	-0.076	-0.223	-0.191	0.067	0.108	-0.259	-0.142	-0.147	0.101	-0.159	-0.040	-0.168	-0.218	-0.063	0.235	0.234	1.000
Q35+ (T)	0.561	0.469	0.498	0.501	0.514	-0.219	0.533	0.386	0.277	-0.055	0.459	0.315	0.234	0.283	0.313	0.278	0.352	0.268	0.169	0.057	0.138	-0.271

\* Reverse-keyed