

Data Dictionary Codebook

#	Variable / Field Name	Field Label <i>Field Note</i>	Field Attributes (Field Type, Validation, Choices, Calculations, etc.)														
Instrument: PT Survey (pt_survey) ➤ Enabled as survey																	
1	[record_id]	Record ID	text														
2	[consent]	<p>Section Header: <i>[If you are an adult or a minor child who will complete the survey, 'you' means 'you'. If you are a parent/guardian completing the survey for your child, 'you' means 'your child']</i> We are inviting you to participate in a research study. The purpose of the study is to determine which types of airway clearance you use and why you may or may not use them routinely. We are inviting you to be in this study because you have cystic fibrosis. Approximately 200 people will take part in this study at the University of Iowa. If you agree to participate, we would like you to complete the following survey, which will take about 10 minutes. If you do not want to participate, you may exit the survey. You are free to skip any questions you would prefer not to answer. The information you provide may be used in separate future research studies. We will keep the information you provide confidential, however federal regulatory agencies and the University of Iowa Institutional Review Board (a committee that reviews and approves research studies) may inspect and copy records pertaining to this research. None of the information we collect will be able to identify you individually and we will not maintain a link between you and your data. This data can be used for future research, but again, you will not be able to be individually identified. If we write a report about this study we will do so in such a way that you cannot be identified. There are no known risks from being in this study, and you will not benefit personally. However, we hope that others may benefit in the future from what we learn as a result of this study. You will not have any costs for being in this research study. You will not be paid for being in this research study. Taking part in this research study is completely voluntary. If you decide not to be in this study, or if you stop participating at any time, you won't be penalized or lose any benefits for which you otherwise qualify. If you have any questions about the research study itself, please contact Anthony Fischer at 319-356-6992. If you experience a research-related injury, please contact: Anthony Fischer at 319-356-6992. If you have questions about the rights of research subjects, please contact the Human Subjects Office, 105 Hardin Library for the Health Sciences, 600 Newton Rd, The University of Iowa, Iowa City, IA 52242-1098, (319) 335-6564, or e-mail irb@uiowa.edu. To offer input about your experiences as a research subject or to speak to someone other than the research staff, call the Human Subjects Office at the number above. Thank you very much for your consideration. Sincerely, Anthony Fischer, MD</p> <p>Do you agree to participate in this survey? You may withdraw your participation at any time during the survey.</p>	<p>yesno</p> <table border="1"> <tr> <td>1</td> <td>Yes</td> </tr> <tr> <td>0</td> <td>No</td> </tr> </table> <p>Stop actions on 0</p>	1	Yes	0	No										
1	Yes																
0	No																
3	[who_filled_out]	<p>Section Header: <i>Who is filling out this survey?</i></p> <p>Are you the patient or the caregiver (parent / legal guardian)?</p>	<p>radio</p> <table border="1"> <tr> <td>1</td> <td>Patient (17 years or younger)</td> </tr> <tr> <td>2</td> <td>Patient (18 years or older)</td> </tr> <tr> <td>3</td> <td>Parent / Legal Guardian</td> </tr> </table>	1	Patient (17 years or younger)	2	Patient (18 years or older)	3	Parent / Legal Guardian								
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4	[year_of_birth]	<p>Section Header: <i>Demographics</i></p> <p>Patient's Year of Birth</p>	text (integer, Min: 1920, Max: 2020), Identifier														
5	[patient_current_age]	<p>Patient's age in years (whole number)</p> <p>example: if you are 12.5, enter 12</p>	text (integer, Min: 0, Max: 100), Identifier Custom alignment: RH														
6	[gender]	Patient's Gender	<p>radio, Identifier</p> <table border="1"> <tr> <td>1</td> <td>Male</td> </tr> <tr> <td>2</td> <td>Female</td> </tr> <tr> <td>3</td> <td>Non-binary</td> </tr> <tr> <td>4</td> <td>Transgender female</td> </tr> <tr> <td>5</td> <td>Transgender male</td> </tr> <tr> <td>6</td> <td>Other</td> </tr> <tr> <td>7</td> <td>Prefer not to say</td> </tr> </table>	1	Male	2	Female	3	Non-binary	4	Transgender female	5	Transgender male	6	Other	7	Prefer not to say
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7	[chest_binder] Show the field ONLY if: [gender] = '5'	Do you (THE PATIENT) currently use a chest binder?	yesno 1 Yes 0 No
8	[disclaimer1]	For the duration of the survey, "you" or "your" or "I" refers to the patient	descriptive
9	[time_on_treatments]	Section Header: <i>Over the last two weeks:</i> How much time do you spend each day on your treatments?	radio 1 Less than 30 minutes 2 30 minutes to 59 minutes 3 1 to 2 hours 4 More than 2 hours 5 I don't take my treatments 6 I don't take my treatments unless I'm sick 7 I don't know
10	[doing_treatments]	How difficult is it for you to do your treatments (including medications and airway clearance) each day?	radio 1 Not at all 2 A little 3 Moderately 4 Very
11	[treatments_daily_life]	How much do your treatments make your daily life more difficult?	radio 1 Not at all 2 A little 3 Moderately 4 A lot
12	[overall_health]	How is your overall health?	radio 1 Excellent 2 Good 3 Fair 4 Poor
13	[fev_known]	Do you know your percent predicted forced expiratory volume (ppFEV1)?	yesno 1 Yes 0 No
14	[fev] Show the field ONLY if: [fev_known] = '1'	What is your percent predicted forced expiratory volume (ppFEV1)?	text (number)
15	[ever_used]	Section Header: <i>Airway Clearance</i> In your life, which forms of airway clearance have you EVER USED? Select ALL that apply	checkbox 1 ever_used__1 Manual Percussion (Chest PT) 2 ever_used__2 Intrapulmonary Percussive Ventilation (IPV) 3 ever_used__3 High Frequency Chest Wall Oscillation (Vest) 4 ever_used__4 Oscillating Positive Expiratory Pressure (PEP), e.g. Aerobika or Acapella 5 ever_used__5 Vigorous Exercise e.g. running 6 ever_used__6 Huff Coughing 7 ever_used__7 Other 8 ever_used__8 I don't know

16	[clearance_forms]	Which forms of airway clearance have you used in the PAST 30 DAYS? Select ALL that apply	checkbox <table border="1"> <tr> <td data-bbox="1044 111 1068 142">1</td> <td data-bbox="1068 111 1273 142">clearance_forms__1</td> <td data-bbox="1273 111 1524 142">Manual Percussion (Chest PT)</td> </tr> <tr> <td data-bbox="1044 184 1068 216">2</td> <td data-bbox="1068 184 1273 216">clearance_forms__2</td> <td data-bbox="1273 184 1524 216">Intrapulmonary Percussive Ventilation (IPV)</td> </tr> <tr> <td data-bbox="1044 258 1068 289">3</td> <td data-bbox="1068 258 1273 289">clearance_forms__3</td> <td data-bbox="1273 258 1524 289">High Frequency Chest Wall Oscillation (Vest)</td> </tr> <tr> <td data-bbox="1044 331 1068 363">4</td> <td data-bbox="1068 331 1273 363">clearance_forms__4</td> <td data-bbox="1273 331 1524 363">Oscillating Positive Expiratory Pressure (PEP), e.g. Aerobika or Acapella</td> </tr> <tr> <td data-bbox="1044 405 1068 436">5</td> <td data-bbox="1068 405 1273 436">clearance_forms__5</td> <td data-bbox="1273 405 1524 436">Vigorous Exercise e.g. running</td> </tr> <tr> <td data-bbox="1044 478 1068 510">6</td> <td data-bbox="1068 478 1273 510">clearance_forms__6</td> <td data-bbox="1273 478 1524 510">Huff Coughing</td> </tr> <tr> <td data-bbox="1044 552 1068 583">7</td> <td data-bbox="1068 552 1273 583">clearance_forms__7</td> <td data-bbox="1273 552 1524 583">None</td> </tr> <tr> <td data-bbox="1044 625 1068 657">8</td> <td data-bbox="1068 625 1273 657">clearance_forms__8</td> <td data-bbox="1273 625 1524 657">Other</td> </tr> <tr> <td data-bbox="1044 657 1068 688">9</td> <td data-bbox="1068 657 1273 688">clearance_forms__9</td> <td data-bbox="1273 657 1524 688">I don't know</td> </tr> </table>	1	clearance_forms__1	Manual Percussion (Chest PT)	2	clearance_forms__2	Intrapulmonary Percussive Ventilation (IPV)	3	clearance_forms__3	High Frequency Chest Wall Oscillation (Vest)	4	clearance_forms__4	Oscillating Positive Expiratory Pressure (PEP), e.g. Aerobika or Acapella	5	clearance_forms__5	Vigorous Exercise e.g. running	6	clearance_forms__6	Huff Coughing	7	clearance_forms__7	None	8	clearance_forms__8	Other	9	clearance_forms__9	I don't know			
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17	[why_no_like] Show the field ONLY if: [clearance_forms(7)] = '1'	Why don't you perform any of these airway clearance techniques? Select ALL that apply	checkbox <table border="1"> <tr> <td data-bbox="1044 699 1068 730">1</td> <td data-bbox="1068 699 1256 730">why_no_like__1</td> <td data-bbox="1256 699 1524 730">I get short of breath</td> </tr> <tr> <td data-bbox="1044 741 1068 772">2</td> <td data-bbox="1068 741 1256 772">why_no_like__2</td> <td data-bbox="1256 741 1524 772">They take too much time</td> </tr> <tr> <td data-bbox="1044 783 1068 814">3</td> <td data-bbox="1068 783 1256 814">why_no_like__3</td> <td data-bbox="1256 783 1524 814">They are painful</td> </tr> <tr> <td data-bbox="1044 825 1068 856">4</td> <td data-bbox="1068 825 1256 856">why_no_like__4</td> <td data-bbox="1256 825 1524 856">They are uncomfortable</td> </tr> <tr> <td data-bbox="1044 867 1068 898">5</td> <td data-bbox="1068 867 1256 898">why_no_like__5</td> <td data-bbox="1256 867 1524 898">They are less effective than medicine</td> </tr> <tr> <td data-bbox="1044 909 1068 940">6</td> <td data-bbox="1068 909 1256 940">why_no_like__6</td> <td data-bbox="1256 909 1524 940">They do not coordinate easily with other treatments</td> </tr> <tr> <td data-bbox="1044 951 1068 982">7</td> <td data-bbox="1068 951 1256 982">why_no_like__7</td> <td data-bbox="1256 951 1524 982">They are unpleasant or embarrassing</td> </tr> <tr> <td data-bbox="1044 993 1068 1024">8</td> <td data-bbox="1068 993 1256 1024">why_no_like__8</td> <td data-bbox="1256 993 1524 1024">I do not like them</td> </tr> <tr> <td data-bbox="1044 1035 1068 1066">9</td> <td data-bbox="1068 1035 1256 1066">why_no_like__9</td> <td data-bbox="1256 1035 1524 1066">Other</td> </tr> <tr> <td data-bbox="1044 1077 1068 1108">10</td> <td data-bbox="1068 1077 1256 1108">why_no_like__10</td> <td data-bbox="1256 1077 1524 1108">I don't know</td> </tr> </table>	1	why_no_like__1	I get short of breath	2	why_no_like__2	They take too much time	3	why_no_like__3	They are painful	4	why_no_like__4	They are uncomfortable	5	why_no_like__5	They are less effective than medicine	6	why_no_like__6	They do not coordinate easily with other treatments	7	why_no_like__7	They are unpleasant or embarrassing	8	why_no_like__8	I do not like them	9	why_no_like__9	Other	10	why_no_like__10	I don't know
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18	[chest_pt_like] Show the field ONLY if: [ever_used(1)] = '1'	What do you LIKE about Manual Percussion (Chest PT)? Select ALL that apply	checkbox <table border="1"> <tr> <td data-bbox="1044 1224 1068 1255">1</td> <td data-bbox="1068 1224 1240 1255">chest_pt_like__1</td> <td data-bbox="1240 1224 1524 1255">It takes little time</td> </tr> <tr> <td data-bbox="1044 1266 1068 1297">2</td> <td data-bbox="1068 1266 1240 1297">chest_pt_like__2</td> <td data-bbox="1240 1266 1524 1297">It is comfortable</td> </tr> <tr> <td data-bbox="1044 1308 1068 1339">3</td> <td data-bbox="1068 1308 1240 1339">chest_pt_like__3</td> <td data-bbox="1240 1308 1524 1339">It works well with my other treatments</td> </tr> <tr> <td data-bbox="1044 1350 1068 1381">4</td> <td data-bbox="1068 1350 1240 1381">chest_pt_like__4</td> <td data-bbox="1240 1350 1524 1381">It is more effective than other forms of airway clearance</td> </tr> <tr> <td data-bbox="1044 1392 1068 1423">5</td> <td data-bbox="1068 1392 1240 1423">chest_pt_like__5</td> <td data-bbox="1240 1392 1524 1423">It feels good or is healthy</td> </tr> <tr> <td data-bbox="1044 1434 1068 1465">6</td> <td data-bbox="1068 1434 1240 1465">chest_pt_like__6</td> <td data-bbox="1240 1434 1524 1465">Nothing</td> </tr> <tr> <td data-bbox="1044 1476 1068 1507">7</td> <td data-bbox="1068 1476 1240 1507">chest_pt_like__7</td> <td data-bbox="1240 1476 1524 1507">Other</td> </tr> <tr> <td data-bbox="1044 1518 1068 1549">8</td> <td data-bbox="1068 1518 1240 1549">chest_pt_like__8</td> <td data-bbox="1240 1518 1524 1549">I don't know</td> </tr> </table>	1	chest_pt_like__1	It takes little time	2	chest_pt_like__2	It is comfortable	3	chest_pt_like__3	It works well with my other treatments	4	chest_pt_like__4	It is more effective than other forms of airway clearance	5	chest_pt_like__5	It feels good or is healthy	6	chest_pt_like__6	Nothing	7	chest_pt_like__7	Other	8	chest_pt_like__8	I don't know						
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19	[other_like_chest_pt] Show the field ONLY if: [chest_pt_like(7)] = '1'	Please explain what you LIKE about Manual Percussion (Chest PT)	notes																														

20	<p>[ipv_like]</p> <p>Show the field ONLY if: [ever_used(2)] = '1'</p>	<p>What do you LIKE about Intrapulmonary Percussive Ventilation (IPV)? Select ALL that apply</p>	<p>checkbox</p> <table border="1"> <tr> <td>1</td> <td>ipv_like__1</td> <td>It takes little time</td> </tr> <tr> <td>2</td> <td>ipv_like__2</td> <td>It is comfortable</td> </tr> <tr> <td>3</td> <td>ipv_like__3</td> <td>It works well with my other treatments</td> </tr> <tr> <td>4</td> <td>ipv_like__4</td> <td>It is more effective than other forms of airway clearance</td> </tr> <tr> <td>5</td> <td>ipv_like__5</td> <td>It feels good or is healthy</td> </tr> <tr> <td>6</td> <td>ipv_like__6</td> <td>Nothing</td> </tr> <tr> <td>7</td> <td>ipv_like__7</td> <td>Other</td> </tr> <tr> <td>8</td> <td>ipv_like__8</td> <td>I don't know</td> </tr> </table>	1	ipv_like__1	It takes little time	2	ipv_like__2	It is comfortable	3	ipv_like__3	It works well with my other treatments	4	ipv_like__4	It is more effective than other forms of airway clearance	5	ipv_like__5	It feels good or is healthy	6	ipv_like__6	Nothing	7	ipv_like__7	Other	8	ipv_like__8	I don't know
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22	<p>[vest_like]</p> <p>Show the field ONLY if: [ever_used(3)] = '1'</p>	<p>What do you LIKE about High Frequency Chest Wall Oscillation (Vest)? Select ALL that apply</p>	<p>checkbox</p> <table border="1"> <tr> <td>1</td> <td>vest_like__1</td> <td>It takes little time</td> </tr> <tr> <td>2</td> <td>vest_like__2</td> <td>It is comfortable</td> </tr> <tr> <td>3</td> <td>vest_like__3</td> <td>It works well with my other treatments</td> </tr> <tr> <td>4</td> <td>vest_like__4</td> <td>It is more effective than other forms of airway clearance</td> </tr> <tr> <td>5</td> <td>vest_like__5</td> <td>It feels good or is healthy</td> </tr> <tr> <td>6</td> <td>vest_like__6</td> <td>Nothing</td> </tr> <tr> <td>7</td> <td>vest_like__7</td> <td>Other</td> </tr> <tr> <td>8</td> <td>vest_like__8</td> <td>I don't know</td> </tr> </table>	1	vest_like__1	It takes little time	2	vest_like__2	It is comfortable	3	vest_like__3	It works well with my other treatments	4	vest_like__4	It is more effective than other forms of airway clearance	5	vest_like__5	It feels good or is healthy	6	vest_like__6	Nothing	7	vest_like__7	Other	8	vest_like__8	I don't know
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24	<p>[pep_like]</p> <p>Show the field ONLY if: [ever_used(4)] = '1'</p>	<p>What do you LIKE about Oscillating Positive Expiratory Pressure (PEP), e.g. Aerobika or Acapella? Select ALL that apply</p>	<p>checkbox</p> <table border="1"> <tr> <td>1</td> <td>pep_like__1</td> <td>It takes little time</td> </tr> <tr> <td>2</td> <td>pep_like__2</td> <td>It is comfortable</td> </tr> <tr> <td>3</td> <td>pep_like__3</td> <td>It works well with my other treatments</td> </tr> <tr> <td>4</td> <td>pep_like__4</td> <td>It is more effective than other forms of airway clearance</td> </tr> <tr> <td>5</td> <td>pep_like__5</td> <td>It feels good or is healthy</td> </tr> <tr> <td>6</td> <td>pep_like__6</td> <td>Nothing</td> </tr> <tr> <td>7</td> <td>pep_like__7</td> <td>Other</td> </tr> <tr> <td>8</td> <td>pep_like__8</td> <td>I don't know</td> </tr> </table>	1	pep_like__1	It takes little time	2	pep_like__2	It is comfortable	3	pep_like__3	It works well with my other treatments	4	pep_like__4	It is more effective than other forms of airway clearance	5	pep_like__5	It feels good or is healthy	6	pep_like__6	Nothing	7	pep_like__7	Other	8	pep_like__8	I don't know
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26	<p>[exercise_like]</p> <p>Show the field ONLY if: [ever_used(5)] = '1'</p>	<p>What do you LIKE about Vigorous Aerobic Exercise? Select ALL that apply</p>	<p>checkbox</p> <table border="1"> <tr> <td>1</td> <td>exercise_like__1</td> <td>It takes little time</td> </tr> <tr> <td>2</td> <td>exercise_like__2</td> <td>It is comfortable</td> </tr> <tr> <td>3</td> <td>exercise_like__3</td> <td>It works well with my other treatments</td> </tr> <tr> <td>4</td> <td>exercise_like__4</td> <td>It is more effective than other forms of airway clearance</td> </tr> <tr> <td>5</td> <td>exercise_like__5</td> <td>It feels good or is healthy</td> </tr> <tr> <td>6</td> <td>exercise_like__6</td> <td>Nothing</td> </tr> <tr> <td>7</td> <td>exercise_like__7</td> <td>Other</td> </tr> <tr> <td>8</td> <td>exercise_like__8</td> <td>I don't know</td> </tr> </table>	1	exercise_like__1	It takes little time	2	exercise_like__2	It is comfortable	3	exercise_like__3	It works well with my other treatments	4	exercise_like__4	It is more effective than other forms of airway clearance	5	exercise_like__5	It feels good or is healthy	6	exercise_like__6	Nothing	7	exercise_like__7	Other	8	exercise_like__8	I don't know			
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27	<p>[other_like_exercise]</p> <p>Show the field ONLY if: [exercise_like(7)] = '1'</p>	<p>Please explain what you LIKE about Vigorous Aerobic Exercise</p>	<p>notes</p>																											
28	<p>[huff_cough_like]</p> <p>Show the field ONLY if: [ever_used(6)] = '1'</p>	<p>What do you LIKE about Huff Coughing? Select ALL that apply</p>	<p>checkbox</p> <table border="1"> <tr> <td>1</td> <td>huff_cough_like__1</td> <td>It takes little time</td> </tr> <tr> <td>2</td> <td>huff_cough_like__2</td> <td>It is comfortable</td> </tr> <tr> <td>3</td> <td>huff_cough_like__3</td> <td>It works well with my other treatments</td> </tr> <tr> <td>4</td> <td>huff_cough_like__4</td> <td>It is more effective than other forms of airway clearance</td> </tr> <tr> <td>5</td> <td>huff_cough_like__5</td> <td>It feels good or is healthy</td> </tr> <tr> <td>6</td> <td>huff_cough_like__6</td> <td>Nothing</td> </tr> <tr> <td>7</td> <td>huff_cough_like__7</td> <td>Other</td> </tr> <tr> <td>8</td> <td>huff_cough_like__8</td> <td>I don't know</td> </tr> </table>	1	huff_cough_like__1	It takes little time	2	huff_cough_like__2	It is comfortable	3	huff_cough_like__3	It works well with my other treatments	4	huff_cough_like__4	It is more effective than other forms of airway clearance	5	huff_cough_like__5	It feels good or is healthy	6	huff_cough_like__6	Nothing	7	huff_cough_like__7	Other	8	huff_cough_like__8	I don't know			
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<p>32</p> <p>[chest_pt_where]</p> <p>Show the field ONLY if: [chest_pt_dislike(3)] = '1' or [chest_pt_dislike(4)] = '1' or [chest_pt_dislike(7)] = '1'</p>	<p>Where on your body does Manual Percussion (Chest PT) bother you? Select ALL that apply</p>	<p>checkbox</p> <table border="1"> <tr><td>1</td><td>chest_pt_where__1</td><td>head</td></tr> <tr><td>2</td><td>chest_pt_where__2</td><td>mouth</td></tr> <tr><td>3</td><td>chest_pt_where__3</td><td>throat</td></tr> <tr><td>4</td><td>chest_pt_where__4</td><td>neck</td></tr> <tr><td>5</td><td>chest_pt_where__5</td><td>back</td></tr> <tr><td>6</td><td>chest_pt_where__6</td><td>chest</td></tr> <tr><td>7</td><td>chest_pt_where__7</td><td>armpits</td></tr> <tr><td>8</td><td>chest_pt_where__8</td><td>breasts</td></tr> <tr><td>9</td><td>chest_pt_where__9</td><td>stomach/abdomen</td></tr> <tr><td>10</td><td>chest_pt_where__10</td><td>my port or PICC line</td></tr> <tr><td>11</td><td>chest_pt_where__11</td><td>my arms or legs</td></tr> <tr><td>12</td><td>chest_pt_where__12</td><td>other</td></tr> </table>	1	chest_pt_where__1	head	2	chest_pt_where__2	mouth	3	chest_pt_where__3	throat	4	chest_pt_where__4	neck	5	chest_pt_where__5	back	6	chest_pt_where__6	chest	7	chest_pt_where__7	armpits	8	chest_pt_where__8	breasts	9	chest_pt_where__9	stomach/abdomen	10	chest_pt_where__10	my port or PICC line	11	chest_pt_where__11	my arms or legs	12	chest_pt_where__12	other
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<p>33</p> <p>[ipv_dislike]</p> <p>Show the field ONLY if: [ever_used(2)] = '1'</p>	<p>What do you DISLIKE about Intrapulmonary Percussive Ventilation (IPV)? Select ALL that apply</p>	<p>checkbox</p> <table border="1"> <tr><td>1</td><td>ipv_dislike__1</td><td>I get short of breath</td></tr> <tr><td>2</td><td>ipv_dislike__2</td><td>It takes too long</td></tr> <tr><td>3</td><td>ipv_dislike__3</td><td>It is painful</td></tr> <tr><td>4</td><td>ipv_dislike__4</td><td>It is uncomfortable</td></tr> <tr><td>5</td><td>ipv_dislike__5</td><td>It is less effective than other forms of airway clearance</td></tr> <tr><td>6</td><td>ipv_dislike__6</td><td>It does not work well with my other treatments</td></tr> <tr><td>7</td><td>ipv_dislike__7</td><td>It is unpleasant or embarrassing</td></tr> <tr><td>8</td><td>ipv_dislike__8</td><td>Nothing</td></tr> <tr><td>9</td><td>ipv_dislike__9</td><td>I don't know</td></tr> </table>	1	ipv_dislike__1	I get short of breath	2	ipv_dislike__2	It takes too long	3	ipv_dislike__3	It is painful	4	ipv_dislike__4	It is uncomfortable	5	ipv_dislike__5	It is less effective than other forms of airway clearance	6	ipv_dislike__6	It does not work well with my other treatments	7	ipv_dislike__7	It is unpleasant or embarrassing	8	ipv_dislike__8	Nothing	9	ipv_dislike__9	I don't know									
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<p>34</p> <p>[ipv_follow_up]</p> <p>Show the field ONLY if: [ipv_dislike(3)] = '1' or [ipv_dislike(4)] = '1' or [ipv_dislike(7)] = '1'</p>	<p>Why is Intrapulmonary Percussive Ventilation (IPV) painful, uncomfortable or unpleasant?</p>	<p>text</p>																																				
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36	<p>[vest_dislike]</p> <p>Show the field ONLY if: [ever_used(3)] = '1'</p>	<p>What do you DISLIKE about High Frequency Chest Wall Oscillation (Vest)? Select ALL that apply</p>	<p>checkbox</p> <table border="1"> <tr> <td>1</td> <td>vest_dislike__1</td> <td>I get short of breath</td> </tr> <tr> <td>2</td> <td>vest_dislike__2</td> <td>It takes too long</td> </tr> <tr> <td>3</td> <td>vest_dislike__3</td> <td>It is painful</td> </tr> <tr> <td>4</td> <td>vest_dislike__4</td> <td>It is uncomfortable</td> </tr> <tr> <td>5</td> <td>vest_dislike__5</td> <td>It is less effective than other forms of airway clearance</td> </tr> <tr> <td>6</td> <td>vest_dislike__6</td> <td>It does not work well with my other treatments</td> </tr> <tr> <td>7</td> <td>vest_dislike__7</td> <td>It is unpleasant or embarrassing</td> </tr> <tr> <td>8</td> <td>vest_dislike__8</td> <td>Nothing</td> </tr> <tr> <td>9</td> <td>vest_dislike__9</td> <td>I don't know</td> </tr> </table>	1	vest_dislike__1	I get short of breath	2	vest_dislike__2	It takes too long	3	vest_dislike__3	It is painful	4	vest_dislike__4	It is uncomfortable	5	vest_dislike__5	It is less effective than other forms of airway clearance	6	vest_dislike__6	It does not work well with my other treatments	7	vest_dislike__7	It is unpleasant or embarrassing	8	vest_dislike__8	Nothing	9	vest_dislike__9	I don't know									
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<p>42</p>	<p>[exercise_dislike] Show the field ONLY if: [ever_used(5)] = '1'</p>	<p>What do you DISLIKE about Vigorous Aerobic Exercise? Select ALL that apply</p>	<p>checkbox</p> <table border="1"> <tr><td>1</td><td>exercise_dislike__1</td><td>I get short of breath</td></tr> <tr><td>2</td><td>exercise_dislike__2</td><td>It takes too long</td></tr> <tr><td>3</td><td>exercise_dislike__3</td><td>It is painful</td></tr> <tr><td>4</td><td>exercise_dislike__4</td><td>It is uncomfortable</td></tr> <tr><td>5</td><td>exercise_dislike__5</td><td>It is less effective than other forms of airway clearance</td></tr> <tr><td>6</td><td>exercise_dislike__6</td><td>It does not work well with my other treatments</td></tr> <tr><td>7</td><td>exercise_dislike__7</td><td>It is unpleasant or embarrassing</td></tr> <tr><td>8</td><td>exercise_dislike__8</td><td>Nothing</td></tr> <tr><td>9</td><td>exercise_dislike__9</td><td>I don't know</td></tr> </table>	1	exercise_dislike__1	I get short of breath	2	exercise_dislike__2	It takes too long	3	exercise_dislike__3	It is painful	4	exercise_dislike__4	It is uncomfortable	5	exercise_dislike__5	It is less effective than other forms of airway clearance	6	exercise_dislike__6	It does not work well with my other treatments	7	exercise_dislike__7	It is unpleasant or embarrassing	8	exercise_dislike__8	Nothing	9	exercise_dislike__9	I don't know									
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<p>43</p>	<p>[exercise_follow_up] Show the field ONLY if: [exercise_dislike(3)] = '1' or [exercise_dislike(4)] = '1' or [exercise_dislike(7)] = '1'</p>	<p>Why is Vigorous Aerobic Exercise painful, uncomfortable or unpleasant?</p>	<p>text</p>																																				
<p>44</p>	<p>[exercise_where] Show the field ONLY if: [exercise_dislike(3)] = '1' or [exercise_dislike(4)] = '1' or [exercise_dislike(7)] = '1'</p>	<p>Where on your body does Vigorous Aerobic Exercise bother you? Select ALL that apply</p>	<p>checkbox</p> <table border="1"> <tr><td>1</td><td>exercise_where__1</td><td>head</td></tr> <tr><td>2</td><td>exercise_where__2</td><td>mouth</td></tr> <tr><td>3</td><td>exercise_where__3</td><td>throat</td></tr> <tr><td>4</td><td>exercise_where__4</td><td>neck</td></tr> <tr><td>5</td><td>exercise_where__5</td><td>back</td></tr> <tr><td>6</td><td>exercise_where__6</td><td>chest</td></tr> <tr><td>7</td><td>exercise_where__7</td><td>armpits</td></tr> <tr><td>8</td><td>exercise_where__8</td><td>breasts</td></tr> <tr><td>9</td><td>exercise_where__9</td><td>stomach/abdomen</td></tr> <tr><td>10</td><td>exercise_where__10</td><td>my port or PICC line</td></tr> <tr><td>11</td><td>exercise_where__11</td><td>my arms or legs</td></tr> <tr><td>12</td><td>exercise_where__12</td><td>other</td></tr> </table>	1	exercise_where__1	head	2	exercise_where__2	mouth	3	exercise_where__3	throat	4	exercise_where__4	neck	5	exercise_where__5	back	6	exercise_where__6	chest	7	exercise_where__7	armpits	8	exercise_where__8	breasts	9	exercise_where__9	stomach/abdomen	10	exercise_where__10	my port or PICC line	11	exercise_where__11	my arms or legs	12	exercise_where__12	other
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<p>45</p> <p>[huff_cough_dislike]</p> <p>Show the field ONLY if: [ever_used(6)] = '1'</p>	<p>What do you DISLIKE about Huff Coughing? Select ALL that apply</p>	<p>checkbox</p> <table border="1"> <tr> <td>1</td> <td>huff_cough_dislike__1</td> <td>I get short of breath</td> </tr> <tr> <td>2</td> <td>huff_cough_dislike__2</td> <td>It takes too long</td> </tr> <tr> <td>3</td> <td>huff_cough_dislike__3</td> <td>It is painful</td> </tr> <tr> <td>4</td> <td>huff_cough_dislike__4</td> <td>It is uncomfortable</td> </tr> <tr> <td>5</td> <td>huff_cough_dislike__5</td> <td>It is less effective than other forms of airway clearance</td> </tr> <tr> <td>6</td> <td>huff_cough_dislike__6</td> <td>It does not work well with my other treatments</td> </tr> <tr> <td>7</td> <td>huff_cough_dislike__7</td> <td>It is unpleasant or embarrassing</td> </tr> <tr> <td>8</td> <td>huff_cough_dislike__8</td> <td>Nothing</td> </tr> <tr> <td>9</td> <td>huff_cough_dislike__9</td> <td>I don't know</td> </tr> </table>	1	huff_cough_dislike__1	I get short of breath	2	huff_cough_dislike__2	It takes too long	3	huff_cough_dislike__3	It is painful	4	huff_cough_dislike__4	It is uncomfortable	5	huff_cough_dislike__5	It is less effective than other forms of airway clearance	6	huff_cough_dislike__6	It does not work well with my other treatments	7	huff_cough_dislike__7	It is unpleasant or embarrassing	8	huff_cough_dislike__8	Nothing	9	huff_cough_dislike__9	I don't know									
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<p>46</p> <p>[huff_cough_follow_up]</p> <p>Show the field ONLY if: [huff_cough_dislike(3)] = '1' or [huff_cough_dislike(4)] = '1' or [huff_cough_dislike(7)] = '1'</p>	<p>Why is Huff Coughing painful, uncomfortable or unpleasant?</p>	<p>text</p>																																				
<p>47</p> <p>[huff_cough_where]</p> <p>Show the field ONLY if: [huff_cough_dislike(3)] = '1' or [huff_cough_dislike(4)] = '1' or [huff_cough_dislike(7)] = '1'</p>	<p>Where on your body does Huff Coughing bother you? Select ALL that apply</p>	<p>checkbox</p> <table border="1"> <tr> <td>1</td> <td>huff_cough_where__1</td> <td>head</td> </tr> <tr> <td>2</td> <td>huff_cough_where__2</td> <td>mouth</td> </tr> <tr> <td>3</td> <td>huff_cough_where__3</td> <td>throat</td> </tr> <tr> <td>4</td> <td>huff_cough_where__4</td> <td>neck</td> </tr> <tr> <td>5</td> <td>huff_cough_where__5</td> <td>back</td> </tr> <tr> <td>6</td> <td>huff_cough_where__6</td> <td>chest</td> </tr> <tr> <td>7</td> <td>huff_cough_where__7</td> <td>armpits</td> </tr> <tr> <td>8</td> <td>huff_cough_where__8</td> <td>breasts</td> </tr> <tr> <td>9</td> <td>huff_cough_where__9</td> <td>stomach/abdomen</td> </tr> <tr> <td>10</td> <td>huff_cough_where__10</td> <td>my port or PICC line</td> </tr> <tr> <td>11</td> <td>huff_cough_where__11</td> <td>my arms or legs</td> </tr> <tr> <td>12</td> <td>huff_cough_where__12</td> <td>other</td> </tr> </table>	1	huff_cough_where__1	head	2	huff_cough_where__2	mouth	3	huff_cough_where__3	throat	4	huff_cough_where__4	neck	5	huff_cough_where__5	back	6	huff_cough_where__6	chest	7	huff_cough_where__7	armpits	8	huff_cough_where__8	breasts	9	huff_cough_where__9	stomach/abdomen	10	huff_cough_where__10	my port or PICC line	11	huff_cough_where__11	my arms or legs	12	huff_cough_where__12	other
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<p>48</p> <p>[treatments_maintain]</p>	<p>Section Header: <i>My CF Treatments</i></p> <p>Which treatments do you currently use to maintain your health? Select ALL that apply</p>	<p>checkbox</p> <table border="1"> <tr> <td>1</td> <td>treatments_maintain__1</td> <td>Inhaled Antibiotics: e.g. Tobramycin (TOBI), Aztreonam (Cayston), etc.</td> </tr> <tr> <td>2</td> <td>treatments_maintain__2</td> <td>Oral Antibiotics: e.g. Azithromycin, Augmentin, Bactrim, Cephalexin, Ciprofloxacin, etc.</td> </tr> <tr> <td>3</td> <td>treatments_maintain__3</td> <td>Mucus thinners: e.g. Hypertonic Saline, Dornase Alfa (Pulmozyme), etc.</td> </tr> <tr> <td>4</td> <td>treatments_maintain__4</td> <td>None of these</td> </tr> </table>	1	treatments_maintain__1	Inhaled Antibiotics: e.g. Tobramycin (TOBI), Aztreonam (Cayston), etc.	2	treatments_maintain__2	Oral Antibiotics: e.g. Azithromycin, Augmentin, Bactrim, Cephalexin, Ciprofloxacin, etc.	3	treatments_maintain__3	Mucus thinners: e.g. Hypertonic Saline, Dornase Alfa (Pulmozyme), etc.	4	treatments_maintain__4	None of these																								
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<p>49</p> <p>[pt_effects]</p>	<p>How does airway clearance affect your health?</p>	<p>radio</p> <table border="1"> <tr> <td>1</td> <td>It improves it</td> </tr> <tr> <td>2</td> <td>It does not change / no effect</td> </tr> <tr> <td>3</td> <td>It worsens it</td> </tr> </table>	1	It improves it	2	It does not change / no effect	3	It worsens it																														
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50	[theratype]	Do you currently take any of these medications?	radio <table border="1"> <tr><td>1</td><td>ivacaftor (kalydeco)</td></tr> <tr><td>2</td><td>lumacaftor/ivacaftor (orkambi)</td></tr> <tr><td>3</td><td>tezacaftor/ivacaftor (symdeko)</td></tr> <tr><td>4</td><td>elexacaftor/tezacaftor/ivacaftor (trikafta)</td></tr> <tr><td>5</td><td>None of these</td></tr> </table>	1	ivacaftor (kalydeco)	2	lumacaftor/ivacaftor (orkambi)	3	tezacaftor/ivacaftor (symdeko)	4	elexacaftor/tezacaftor/ivacaftor (trikafta)	5	None of these
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51	[clearance_perform1] Show the field ONLY if: [theratype] = '1'	Which statement best describes your current airway clearance use since starting ivacaftor (kalydeco)?	radio <table border="1"> <tr><td>1</td><td>I perform more airway clearance now</td></tr> <tr><td>2</td><td>I perform the same amount of airway clearance now</td></tr> <tr><td>3</td><td>I perform less airway clearance now</td></tr> </table>	1	I perform more airway clearance now	2	I perform the same amount of airway clearance now	3	I perform less airway clearance now				
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52	[clearance_perform2] Show the field ONLY if: [theratype] = '2'	Which statement best describes your current airway clearance use since starting lumacaftor/ivacaftor (orkambi)?	radio <table border="1"> <tr><td>1</td><td>I perform more airway clearance now</td></tr> <tr><td>2</td><td>I perform the same amount of airway clearance now</td></tr> <tr><td>3</td><td>I perform less airway clearance now</td></tr> </table>	1	I perform more airway clearance now	2	I perform the same amount of airway clearance now	3	I perform less airway clearance now				
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53	[clearance_perform3] Show the field ONLY if: [theratype] = '3'	Which statement best describes your current airway clearance use since starting tezacaftor/ivacaftor (symdeko)?	radio <table border="1"> <tr><td>1</td><td>I perform more airway clearance now</td></tr> <tr><td>2</td><td>I perform the same amount of airway clearance now</td></tr> <tr><td>3</td><td>I perform less airway clearance now</td></tr> </table>	1	I perform more airway clearance now	2	I perform the same amount of airway clearance now	3	I perform less airway clearance now				
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54	[clearance_perform4] Show the field ONLY if: [theratype] = '4'	Which statement best describes your current airway clearance use since starting elexacaftor/tezacaftor/ivacaftor (trikafta)?	radio <table border="1"> <tr><td>1</td><td>I perform more airway clearance now</td></tr> <tr><td>2</td><td>I perform the same amount of airway clearance now</td></tr> <tr><td>3</td><td>I perform less airway clearance now</td></tr> </table>	1	I perform more airway clearance now	2	I perform the same amount of airway clearance now	3	I perform less airway clearance now				
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55	[mod_clearance_more] Show the field ONLY if: [clearance_perform1] = '1' or [clearance_perform2] = '1' or [clearance_perform3] = '1' or [clearance_perform4] = '1'	Why do you perform more airway clearance now?	notes										
56	[mod_clearance_same] Show the field ONLY if: [clearance_perform1] = '2' or [clearance_perform2] = '2' or [clearance_perform3] = '2' or [clearance_perform4] = '2'	Why do you perform the same amount of airway clearance now as you did prior to starting your modulator?	notes										
57	[mod_clearance_less] Show the field ONLY if: [clearance_perform1] = '3' or [clearance_perform2] = '3' or [clearance_perform3] = '3' or [clearance_perform4] = '3'	Why do you perform less airway clearance now?	notes										
58	[ranking_modulators] Show the field ONLY if: [theratype] = '1' or [theratyp e] = '2' or [theratype] = '3' or [theratype] = '4'	Section Header: <i>Please indicate how important each of the following are for maintaining your health:</i> CFTR Modulators Kalydeco, Orkambi, Symdeko or Trikafta	slider Slider labels: Least Important, , Most Important Custom alignment: RH										
59	[ranking_inhaled_anti] Show the field ONLY if: [treatments_maintain(1)] = '1'	Inhaled Antibiotics e.g. Tobramycin (TOBI), Aztreonam (Cayston), etc.	slider Slider labels: Least Important, , Most Important Custom alignment: RH										
60	[ranking_oral_anti] Show the field ONLY if: [treatments_maintain(2)] = '1'	Oral Antibiotics e.g. Azithromycin, Augmentin, Bactrim, Cephalexin, Ciprofloxacin, etc.	slider Slider labels: Least Important, , Most Important Custom alignment: RH										

61	[ranking_mucus] Show the field ONLY if: [treatments_maintain(3)] = '1'	Mucus thinners e.g. Hypertonic Saline or Dornase Alfa (Pulmozyme), etc.	slider Slider labels: Least Important , Most Important Custom alignment: RH																								
62	[ranking_airway]	Airway clearance techniques e.g. Manual Chest PT, IPV, Vest, or PEP (aerobika or acapella)	slider Slider labels: Least Important , Most Important Custom alignment: RH																								
63	[ranking_exercise]	Exercise	slider Slider labels: Least Important , Most Important Custom alignment: RH																								
64	[ranking_nutrition]	Nutrition	slider Slider labels: Least Important , Most Important Custom alignment: RH																								
65	[race] Show the field ONLY if: [who_filled_out] = '1' or [who_filled_out] = '2'	Section Header: <i>Demographics</i> What is your race? Select ALL that apply	checkbox <table border="1"> <tr><td>1</td><td>race__1</td><td>American Indian or Alaska Native</td></tr> <tr><td>2</td><td>race__2</td><td>Asian</td></tr> <tr><td>3</td><td>race__3</td><td>Black or African American</td></tr> <tr><td>4</td><td>race__4</td><td>Hispanic or Latino</td></tr> <tr><td>5</td><td>race__5</td><td>Native Hawaiian or Other Pacific Islander</td></tr> <tr><td>6</td><td>race__6</td><td>White</td></tr> <tr><td>7</td><td>race__7</td><td>Other (not represented above)</td></tr> <tr><td>8</td><td>race__8</td><td>Prefer not to answer</td></tr> </table>	1	race__1	American Indian or Alaska Native	2	race__2	Asian	3	race__3	Black or African American	4	race__4	Hispanic or Latino	5	race__5	Native Hawaiian or Other Pacific Islander	6	race__6	White	7	race__7	Other (not represented above)	8	race__8	Prefer not to answer
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66	[race2] Show the field ONLY if: [who_filled_out] = '3'	What is THE PATIENT'S race? Select ALL that apply	checkbox <table border="1"> <tr><td>1</td><td>race2__1</td><td>American Indian or Alaska Native</td></tr> <tr><td>2</td><td>race2__2</td><td>Asian</td></tr> <tr><td>3</td><td>race2__3</td><td>Black or African American</td></tr> <tr><td>4</td><td>race2__4</td><td>Hispanic or Latino</td></tr> <tr><td>5</td><td>race2__5</td><td>Native Hawaiian or Other Pacific Islander</td></tr> <tr><td>6</td><td>race2__6</td><td>White</td></tr> <tr><td>7</td><td>race2__7</td><td>Other (not represented above)</td></tr> <tr><td>8</td><td>race2__8</td><td>Prefer not to answer</td></tr> </table>	1	race2__1	American Indian or Alaska Native	2	race2__2	Asian	3	race2__3	Black or African American	4	race2__4	Hispanic or Latino	5	race2__5	Native Hawaiian or Other Pacific Islander	6	race2__6	White	7	race2__7	Other (not represented above)	8	race2__8	Prefer not to answer
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67	[patient_household_size]	How many people are currently living in your household, including yourself?	text																								
68	[patient_household_child ren]	How many children ≤18 years old live in your house, including yourself?	text																								
69	[patient_education] Show the field ONLY if: [who_filled_out] = '1' or [who_filled_out] = '2'	What is the highest grade you have completed?	radio <table border="1"> <tr><td>1</td><td>Preschool or Younger</td></tr> <tr><td>2</td><td>Elementary (Kindergarten - 5th Grade)</td></tr> <tr><td>3</td><td>Middle School (6th - 8th Grade)</td></tr> <tr><td>4</td><td>High School: (9th - 12th grade)</td></tr> <tr><td>5</td><td>College/Junior College</td></tr> <tr><td>6</td><td>Graduate School or Beyond</td></tr> </table>	1	Preschool or Younger	2	Elementary (Kindergarten - 5th Grade)	3	Middle School (6th - 8th Grade)	4	High School: (9th - 12th grade)	5	College/Junior College	6	Graduate School or Beyond												
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70	[patient_education_2] Show the field ONLY if: [who_filled_out] = '3'	What is the highest grade your child (THE PATIENT) has completed?	radio <table border="1"> <tr><td>1</td><td>Preschool or Younger</td></tr> <tr><td>2</td><td>Elementary (Kindergarten - 5th Grade)</td></tr> <tr><td>3</td><td>Middle School (6th - 8th Grade)</td></tr> <tr><td>4</td><td>High School: (9th - 12th grade)</td></tr> <tr><td>5</td><td>College/Junior College</td></tr> <tr><td>6</td><td>Graduate School or Beyond</td></tr> </table>	1	Preschool or Younger	2	Elementary (Kindergarten - 5th Grade)	3	Middle School (6th - 8th Grade)	4	High School: (9th - 12th grade)	5	College/Junior College	6	Graduate School or Beyond												
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6	Graduate School or Beyond																										

71	[parent_degree_2] Show the field ONLY if: [who_filled_out] = '1'	What is the highest degree your parent or caregiver has earned?	radio 1 Some high school or less 2 High school diploma or equivalency (GED) 3 Associate degree (junior college) or vocational degree/license 4 Bachelor's degree 5 Master's degree 6 Doctorate, Professional (MD, JD, DDS, PhD, etc) 7 None of the above
72	[parent_degree] Show the field ONLY if: [who_filled_out] = '3'	What is the highest degree you (THE PARENT/CAREGIVER) earned?	radio 1 Some high school or less 2 High school diploma or equivalency (GED) 3 Associate degree (junior college) or vocational degree/license 4 Bachelor's degree 5 Master's degree 6 Doctorate, Professional (MD, JD, DDS, PhD, etc) 7 None of the above
73	[work_status] Show the field ONLY if: [who_filled_out] = '1' or [who_filled_out] = '2'	What is your current work or school status?	radio 1 Attending school outside the home 2 Attending classes from home 3 Working full or part time (either outside the home or at a home-based business) 4 Not attending school or working due to my health 5 Not working for other reasons 6 Too young for school, attending day care outside of home 7 Too young for school, attending day care within the home
74	[work_status_2] Show the field ONLY if: [who_filled_out] = '3'	What is your child's (THE PATIENT'S) current work or school status?	radio 1 Attending school outside the home 2 Attending classes from home 3 Working full or part time (either outside the home or at a home-based business) 4 Not attending school or working due to my health 5 Not working for other reasons 6 Too young for school, attending day care outside of home 7 Too young for school, attending day care within the home
75	[who_completed]	Who completed this survey? Select ALL that apply	checkbox 1 who_completed__1 Patient 2 who_completed__2 Patient's Parent / Caregiver 3 who_completed__3 Patient's Spouse 4 who_completed__4 Other
76	[pt_survey_complete]	Section Header: <i>Form Status</i> Complete?	dropdown 0 Incomplete 1 Unverified 2 Complete

