



Collecting Clinical Data in the Cyber Age

The transition from paper to on-line
Clinical Questionnaires for a
Paediatric Pain Service

Dave Anderson



Why should Complex Pain Services Collect Data?



Collecting ***clinically significant*** patient data has a number of benefits for Complex Pain Services:

- Pre-assessment Questionnaires can provide clinically significant data scores for numerous domains of chronic pain;
 - Psychosocial stressors
 - Level of function
 - Psychological factors
 - Opioid usage
- This information can be used to triage referrals
- Can be used as a guide for clinical interviews



- Sending out follow up Questionnaires can be used to measure patient progress
- Include a feedback section in follow up to collect Quality Improvement data
- Benchmarking against other Pain Services to improve outcomes
 - Guide best practice
- Data can be used for clinical research projects



Traditionally Data Collection is carried out using pen and paper questionnaires.

What are the drawbacks to using this method?



- Printing and Postage (+ return) of the Questionnaires
- Poor patient compliance and data often missing
- Labour intensive local data entry of the returned Questionnaires to get any clinical scoring or significance
- Often only have a local database in Excel or Access formats with limited ability to do in-depth data analysis
- Very difficult to share data with other centres
- Difficult to use to guide best practice
- Poor follow up



Traditionally, in multi-center studies, questionnaires in paper format are forwarded from patients and centres to central database hosting facilities, where data are manually transformed into electronic databases. This multi-step process is time and labour-consuming and prone to errors (Wolters, et al., 2005).



**What can we do to overcome
these limitations?**

&

Why is the internet our friend?



- In May 1991, Tim Berners-Lee and Robert Cailliau, two physicists working at the CERN laboratory in Switzerland, released a new document format called Hyper-Text Markup Language (HTML) and an accompanying document retrieval protocol called Hyper-Text Transfer Protocol (HTTP)
- Following its introduction, the HTML standard rapidly incorporated extensions that allowed programmers to add multimedia capabilities, searching, purchasing and other complex interactions between the Internet user and a web site (Mowery & Simcoe, 2002).



- HTML pivotal in advancing on line data collection
- Once the internet had the capability to allow forms to be filled in... then companies could make money
- This led to rapid and substantial improvements in the software that was available for non computer experts to create web sites to sell their products
- Which was quickly followed by the market research industry creating on line survey utilities



- Ideally, HTML survey forms enhance data collection, compared with conventional surveys, because of their use of colour, innovative screen designs, question formatting, and other features not available with paper questionnaires.
- They can prohibit multiple or blank responses by not allowing the participant to continue on or to submit the survey without first correcting the response error. (Schleyer & Forrest, 2000)
- In 2000, the cost of administering the same questionnaire via the normal printing and posting when compared to online was reported to be 38% cheaper using online forms. (HTML expert employed to create forms)



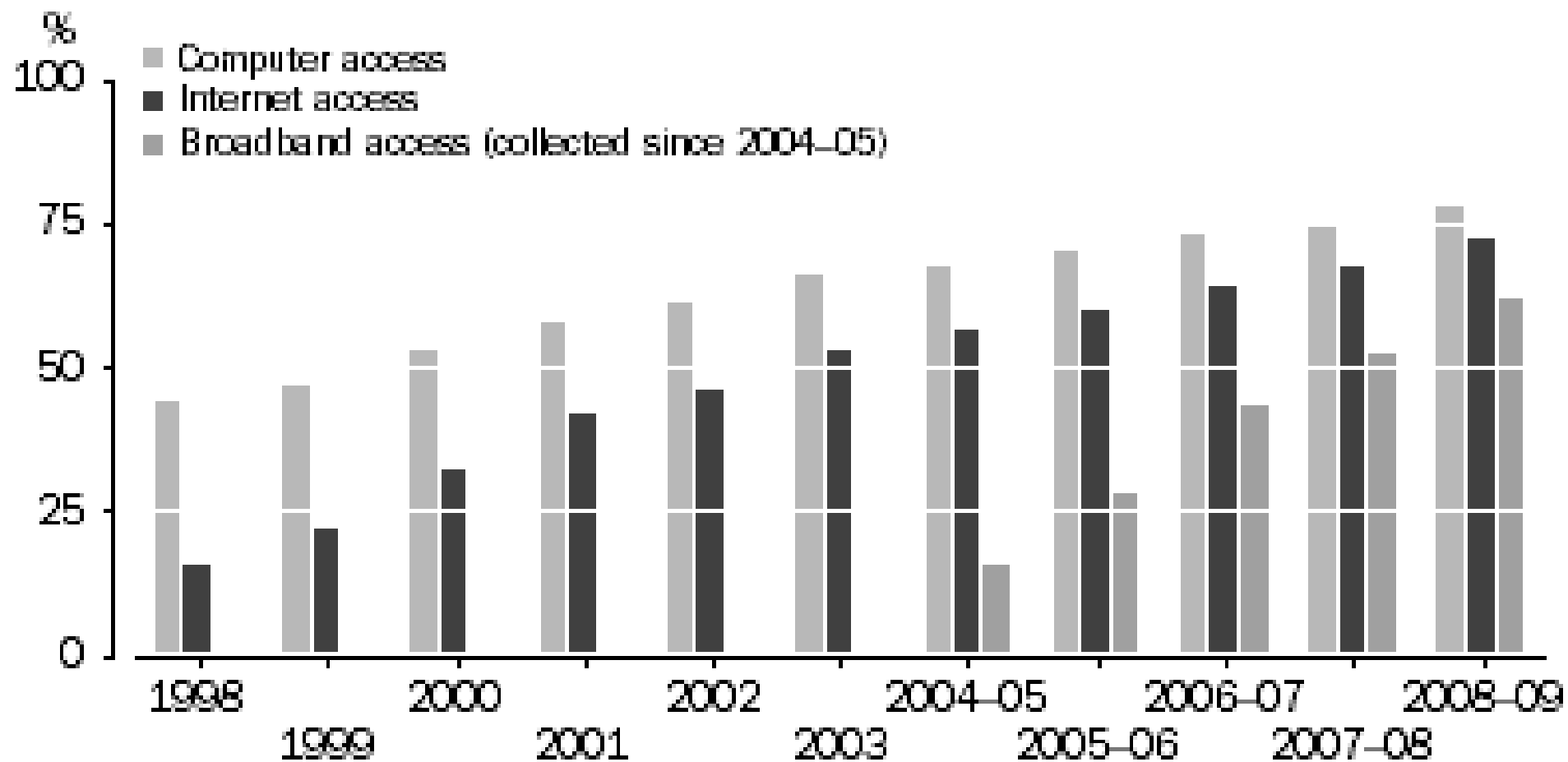
- The Internet is at once a world-wide broadcasting capability, a mechanism for information dissemination, and a medium for collaboration and interaction between individuals and their computers without regard for geographic location (Leiner, et al., 2003).
- The advantages of using the world wide web to collect behavioural data include rapid access to numerous potential respondents and previously hidden populations, respondent openness and full participation, opportunities for student research, and reduced research costs. (Rhodes, Bowie & Hergenrather 2003)



- The Australian Bureau of Statistics have been collecting data on access to computer and internet resources since 1988
- Over the 20 years to the last survey in 2009 there has been a steady and sustained increase in household access to computers and the internet.
- Over 75% of households have access to a computer
- With nearly 70% having internet connections the majority of which are broadband connections



FIGURE 1.1: HOUSEHOLD COMPUTER OR INTERNET ACCESS,
Proportion of all households—1998 to 2008–09





How can we as Pain Services use this technology to collect data?

- Which survey company to use?
- What are the limitations of that company?
- How secure is your data?
- What format does the data come in?
- How easy is it to get good analysis of your data?



- There are numerous free, survey companies available e.g. www.surveypirate.com, www.surveymonkey.com, www.kwiksurveys.com.
 - No knowledge of HTML needed
 - Good for simple anonymous surveys
 - Lack sophistication needed for quality clinical data
 - ? Security of sensitive patient data
 - Often restrict the number of responses



- Wide variety of commercial survey companies:
www.keysurvey.com, www.creativedatasolutions.com.au,
[www.**qualtrics**.com](http://www.qualtrics.com)
 - More sophisticated and suitable for clinical data collection
 - Expert backup from tech-support
 - Secure data servers to protect sensitive data
 - No restrictions on returns or numbers
 - Professional looking and able to incorporate company/Health Service “Branding”
 - Wide choice of data download formats
 - SPSS/PASW, EXCEL, HTML



Data Collection at Sydney Children's Hospital – Randwick

Our journey into Cyber Space.



- Child/Adolescent Baseline: 9 pages of questions covering a wide variety of domains:
 - Pain location, Intensity, Duration
 - Sleep disturbance, Tiredness
 - Catastrophising, Social Interactions, Family Stress
 - Functional Disability, Social Consequences, Depression
- Parent Baseline: 20 pages of questions
 - All of the above, Plus
 - Parental Responses, Marital & Financial stressors
 - Expectations, Knowledge of Chronic Pain
 - Level of Child's Self Efficacy in Managing Pain



How I get along with others (problems with...)	Never	Almost never	Sometimes	Often	Almost Always
1. I have trouble getting along with other kids	0	1	2	3	4
2. Other kids do not want to be my friend	0	1	2	3	4
3. Other kids tease me	0	1	2	3	4
4. I cannot do things that other kids my age can do	0	1	2	3	4
5. It is hard to keep up with other kids	0	1	2	3	4

		Never	Once in a while	Some-times	Often	Always
1.	Do you stay home from school?	0	1	2	3	4
2.	Does your Mum or Dad spend more time than usual with you?	0	1	2	3	4
3.	Do you sleep later than usual in the morning?	0	1	2	3	4
4.	Do you get behind in your schoolwork?	0	1	2	3	4
5.	Does your Mum or Dad tell you not to make such a fuss about your pain?	0	1	2	3	4
6.	Do you spend less time with other kids?	0	1	2	3	4
7.	Do you get special food or drinks?	0	1	2	3	4
8.	Do you sleep or rest somewhere special, like in your parents' room or on the couch?	0	1	2	3	4
9.	Does your Mum or	0	1	2	3	4



How our survey tool works.



My Surveys

- Create Survey
- Edit Survey
- Distribute Survey
- View Results
- Polls
- Library
- Panels
- Administration

- Create Survey
- Email Survey
- View Results
- Message Center

Survey Search...
Show More

Get Help [Ask a Question](#)

All Surveys (13) [Manage Folders](#)

★	Active	Name	Responses	Tasks
★	<input type="checkbox"/>	parental follow-up Modified on: May 27, 2011	0	Edit Results Send View Collaborate Copy Translate Delete
★	<input type="checkbox"/>	PARENT ED EVAL Modified on: May 24, 2011	0	Edit Results Send View Collaborate Copy Translate Delete
★	<input type="checkbox"/>	parent ed Modified on: May 25, 2011	3	Edit Results Send View Collaborate Copy Translate Delete
★	<input checked="" type="checkbox"/>	Patient Baseline Modified on: May 10, 2011	7	Edit Results Send View Collaborate Copy Translate Delete
★	<input type="checkbox"/>	test2 Modified on: Mar 30, 2011	0	Edit Results Send View Collaborate Copy Translate Delete
★	<input checked="" type="checkbox"/>	Patient Baseline - Test Modified on: Apr 11, 2011	2	Edit Results Send View Collaborate Copy Translate Delete
★	<input type="checkbox"/>	Qualtrics Demo Survey Modified on: Feb 23, 2011	0	Edit Results Send View Collaborate Copy Translate Delete



My Surveys

Create Survey

Edit Survey

Distribute Survey

View Results

Polls

Library

Panels

Administration

How do you want to build your survey?



Quick Survey Builder

Looking for a fast and easy way to build a powerful survey?
Try our survey builder to accelerate your survey creation and start gathering results!

[Click to Continue](#) ➔



Create from Copy

Use this tool to help you create a survey based on an existing survey.

[Click to Continue](#) ➔



Survey Library

Don't know where to start? Pick a survey template from a variety of categories.

[Click to Continue](#) ➔



- My Surveys
- Create Survey
- Edit Survey
- Distribute Survey
- View Results
- Polls
- Library**
- Panels
- Administration

Library Overview

Survey Library

Question Library

Graphics Library

Files Library

Message Library

Get Help [Ask a Question](#)

Current Library:

Survey Libraries

Dave Anderson	0 Categories	0 Surveys
Qualtrics Library	21 Categories	283 Surveys

Question Libraries

Dave Anderson	0 Categories	0 Questions
Qualtrics Library	21 Categories	90 Questions

Graphics Libraries

Dave Anderson	1 Categories	13 Graphics
Qualtrics Library	5 Categories	546 Graphics

Files Libraries

Dave Anderson	0 Categories	0 Files
Qualtrics Library	0 Categories	0 Files

Message Libraries

	Invite Emails	Reminder	Thank You	End of Survey	Inactive Survey	General
Dave Anderson	5	0	0	4	0	0
Qualtrics Library	1	0	0	0	0	0

Q40

PCS-C - Thoughts and feelings during pain

Q41

We are interested in what you think and how strong the feelings are when your child is in pain.

Below are 2 blocks of sentences of different thoughts and feelings you may have when your child is in pain.

Try to show us as clearly as possible what you think and feel by clicking on how strongly each thought applies to you.



	Not at all	Mildly	Moderately	Severely	Extremely
When my child is in pain, I worry all the time about whether the pain will end	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
When my child is in pain, I feel I can't go on like this much longer	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
When my child is in pain, it's terrible and I think it's never going to get better	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
When my child is in pain, it's awful and I feel that it overwhelms me	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
When my child is in pain, I can't stand it anymore	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
When my child is in pain, I become afraid that the pain will get worse	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
When my child is in pain, I keep thinking of other painful events	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Q42

Try to show us as clearly as possible what you think and feel by clicking on how strongly each thought applies to you.

	Not at all	Mildly	Moderately	Severely	Extremely
When my child is in pain, I want the pain to go away	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
When my child is in pain, I can't keep it out of my mind	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Change Item Type



Matrix Table

Statements

- 7 +

 Automatic Statements

Scale Points

- 5 +

 Automatic Scale Points

Matrix Type

 Likert

 Bipolar

[More](#)

Answers

 Single Answer

 Multiple Answer

 Dropdown List

Options

 Transpose Table

 Position Text Above

 Repeat Headers

 Add White Space

Validation Options

 Force Response

Validation Type

 None

 [Custom Validation](#)
[Add Page Break](#)
[Add Display Logic](#)
[Add Skip Logic](#)
[Copy Question](#)



Matrix Table

Statements

- 6 +

 Automatic Statements

Scale Points

- 5 +

 Automatic Scale PointsQ42

Try to show us as clearly as possible what you think and feel by clicking on how strongly each thought applies to you.

Not at all

Mildly

Moderately

Severely

Extremely

When my child is in pain, I

Recode Values

 Recode Values Variable Naming Question Export Tags

1

2

3

4

5

Not at all

Mildly

Moderately

Severely

Extremely

When my child is in pain, I want the pain to go away

When my child is in pain, I can't keep it out of my mind

When my child is in pain, I keep thinking about how much they are suffering

When my child is in pain, I keep thinking about how much I want the pain to stop

When my child is in pain, there is nothing I can do to stop the pain

When my child is in pain, I wonder whether something serious may happen

Close

Q43

Sleep disturbance

Q44

How much does the pain disturb your child's sleep?

Validation Type

 None Custom Validation

Add Page Break

Add Display Logic

Add Skip Logic

Copy Question

Yes

No



Q8

Do you have any other children?

Yes

No

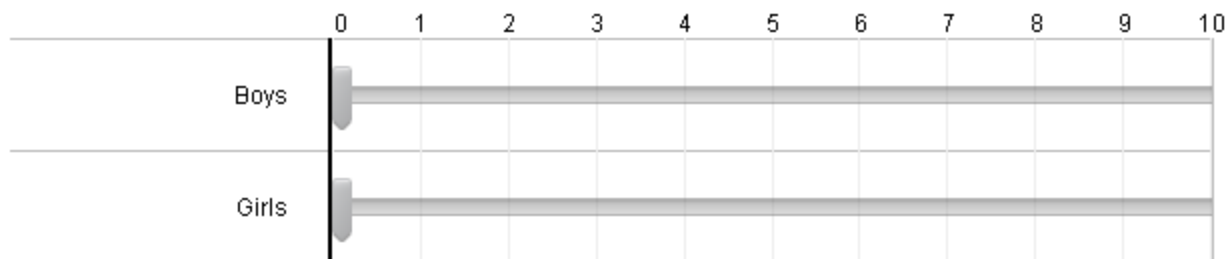


Display This Question:

If **Do you have any other children?** **Yes** Is **Selected** [Edit](#)

Q9

How many children do you have including the child you are completing this questionnaire about?



Q10

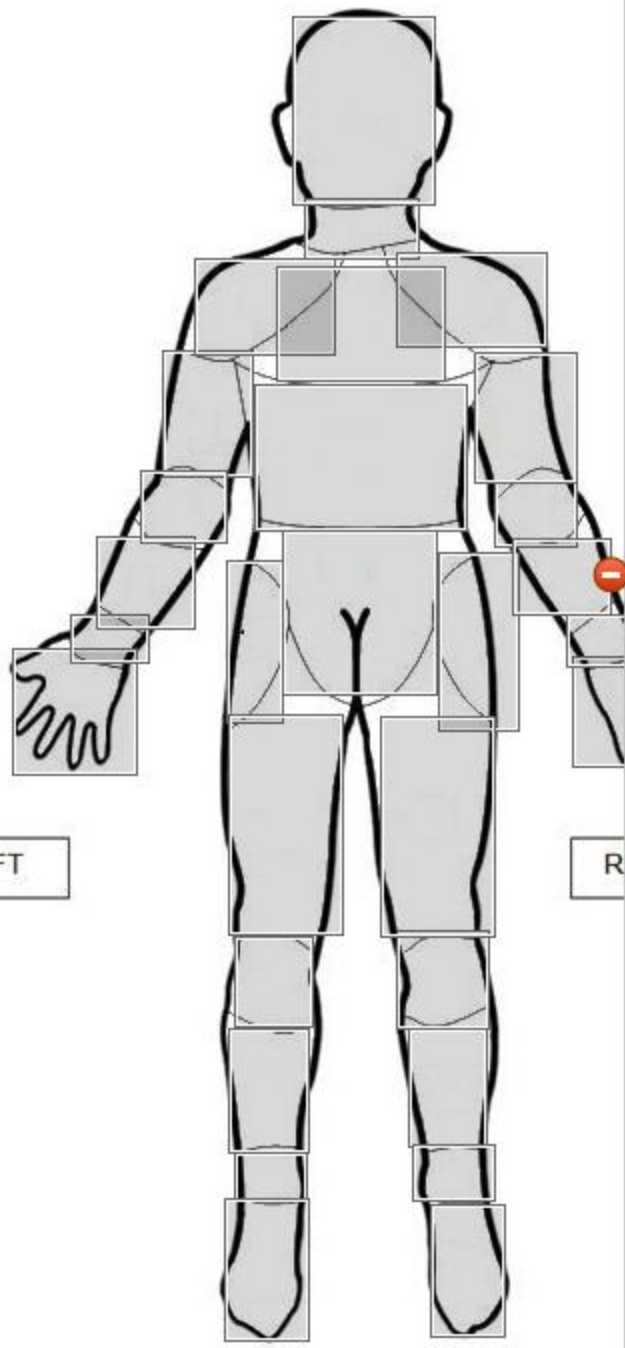
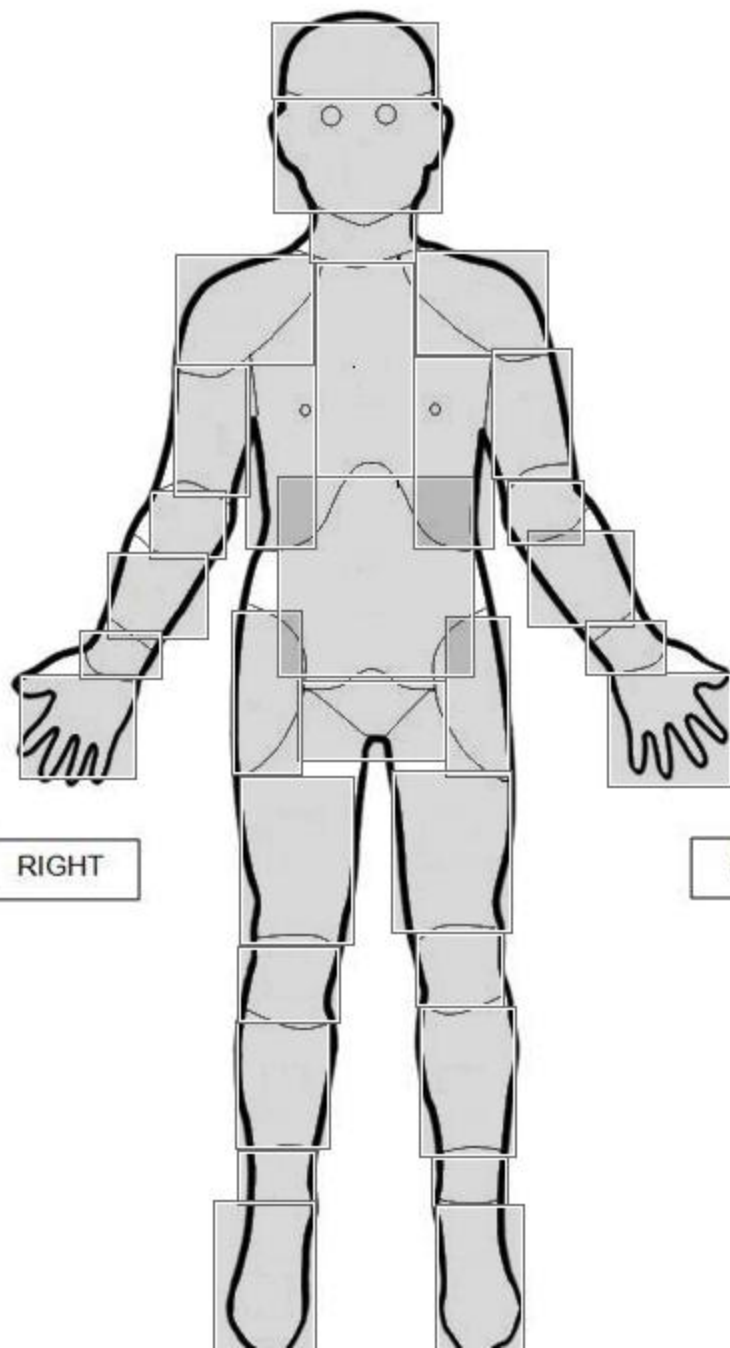
Your child's pain

Q11

Please give a brief description of how your child's pain started

FRONT VIEW

BACK VIEW



RIGHT

LEFT


R





- My Surveys
- Create Survey
- Edit Survey
- Distribute Survey**
- View Results
- Polls
- Library
- Panels
- Administration

- Survey Link
- Email Survey
- Email History
- Social Media
- In-Page Popup
- Website Feedback
- Survey Director
- Preview Survey

 Need more respondents? Use the Qualtrics Panel. [Click here](#) to get a quote.

Get Help [Ask a Question](#)

Current Survey: parental baseline -t

parental baseline -test

Your Anonymous Survey Link:

https://sesiahs.qualtrics.com/SE/?SID=SV_blgmsVnM06u8TcM

You can copy this link, then paste it into an email or website.

Note: This will not track identifying information. If needed, try our [Survey Mailer](#)

[Custom Link](#)



Panels



Panel Members



Sample Management






Get Help

[Ask a Question](#)Current Panel Library:

Panels

My Panels: Dave Anderson

[+ Create New Panel](#)Select: [All](#) [None](#) With Selected: [Delete](#)

	Panel	Last Used	Members	Panel Actions
Unassigned				
<input type="checkbox"/>	2011-03-17 11:58:10	Mar 17, 2011 11:01AM	1	 Export Panel  Embedded Data  Move Panel  Send Email
<input type="checkbox"/>	Aherne	Jun 2, 2011 2:52PM	1	 Export Panel  Embedded Data  Move Panel  Send Email
<input type="checkbox"/>	Belford	Jun 2, 2011 2:54PM	1	 Export Panel  Embedded Data  Move Panel  Send Email
<input type="checkbox"/>	Bruce	Apr 13, 2011 8:32AM	1	 Export Panel  Embedded Data  Move Panel  Send Email
<input type="checkbox"/>	Cindy	Mar 30, 2011 12:00PM	1	 Export Panel  Embedded Data  Move Panel  Send Email

parental baseline -test

To: Please Select... ▾

Enter Email Addresses...

Use Email Addresses From a Library

When: My Library: Dave Anderson ▶

Search...

Message:

From Name: Dave Anderson

Reply-To Email Address: david.anderson@sesiahs.hee

Subject:

Load a Saved Message ▾



Follow this link to the Survey:

`\${!://SurveyLink?d=Take the Survey}`

Or copy and paste the URL below into your internet browser...

`\${!://SurveyURL}`

Follow the link to opt out of future emails:

`\${!://OptOutLink?d=Click here to unsubscribe}`

New Panel...

2011-03-17 11:58:10 ▶

Aherne ▶

Belford ▶

Bruce ▶

Cindy ▶

dave a ▶

Duncan ▶

Evengelo ▶

Galanopoulos ▶

Gladman ▶

[Next](#)

|

Select Entire Panel

Select a Panel Sample ▶

Select an Individual

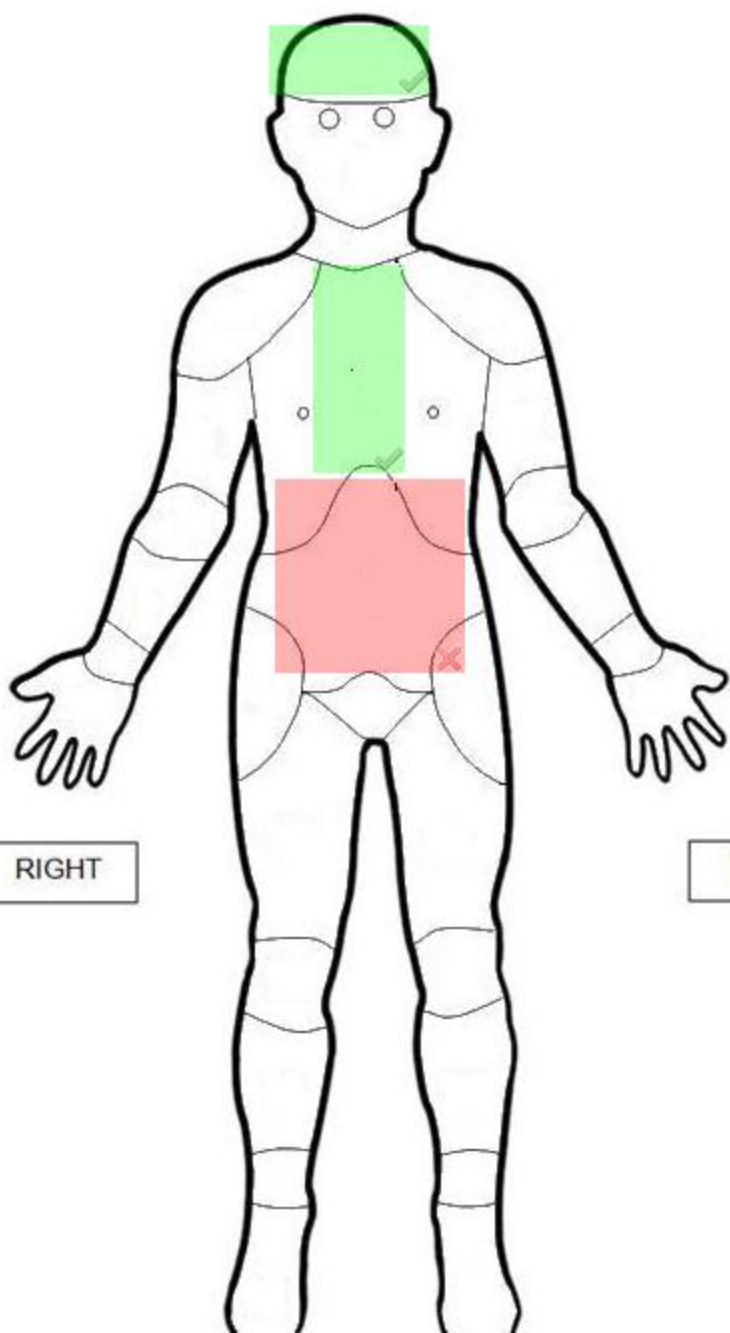
tsbdaves@gmail.com

Save

Save As...

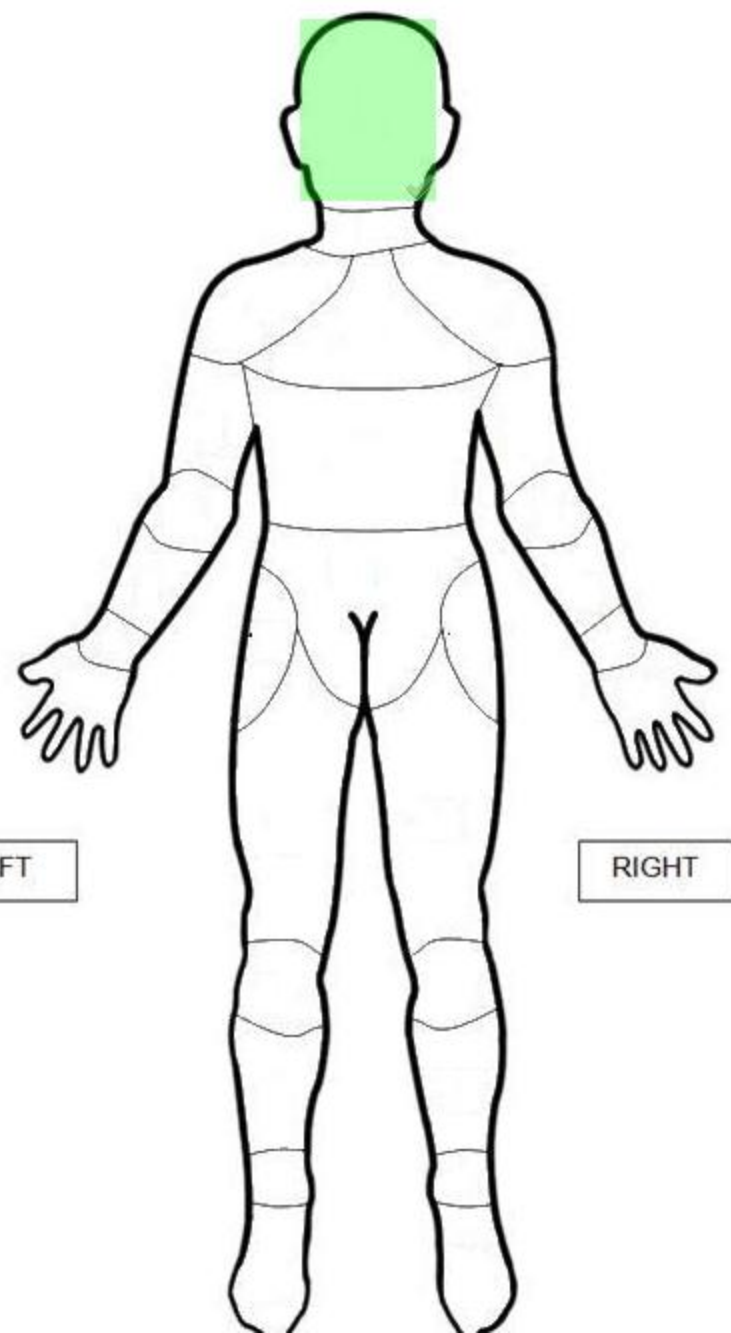
FRONT VIEW

BACK VIEW



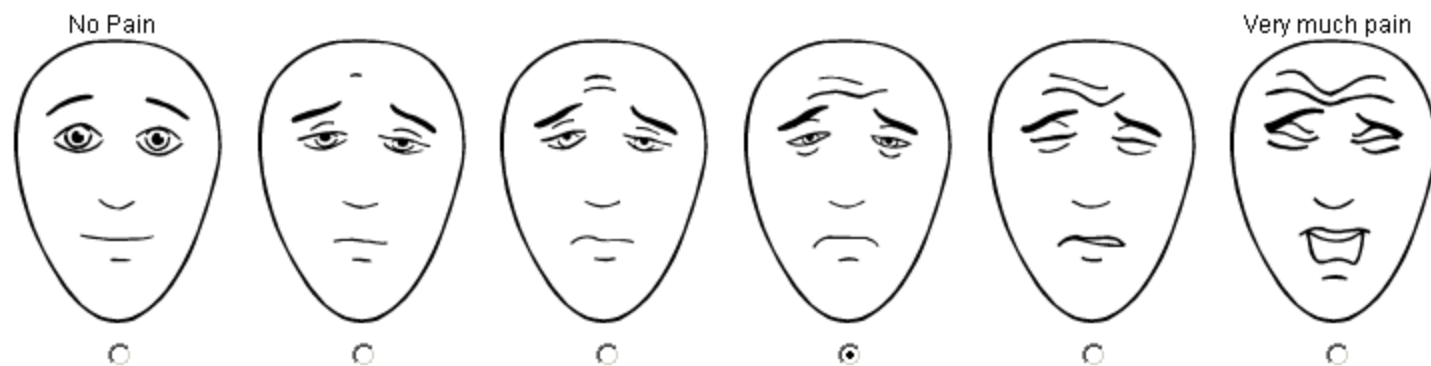
RIGHT

LEFT



RIGHT

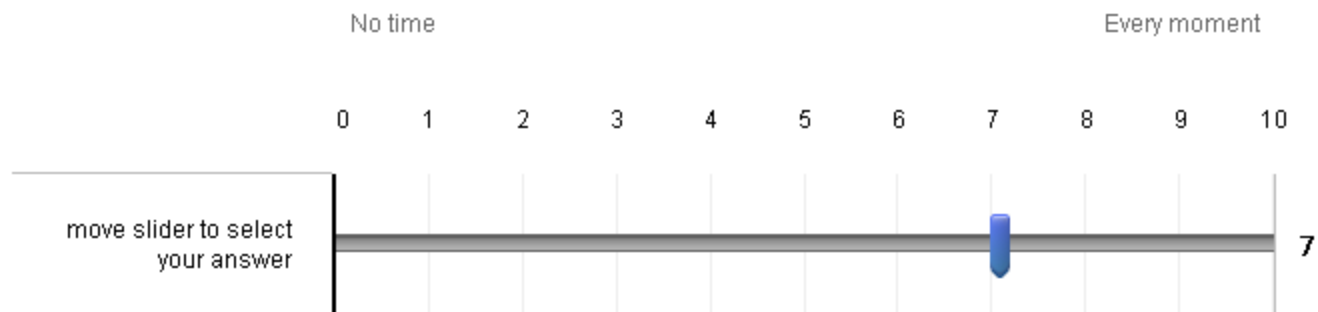
Here are 6 faces that show how much something can hurt. The face on the left shows no pain. The faces show more and more pain up to the face on the right which shows very much pain. Click on the button below the face that represents the *worst* pain your child had during the last week



What were they doing at the time?

playing with sister

How much of your child's awake time is bothered by pain?



4. Lately, how many days a week is your child pain-free or not bothered by the pain?

- Never
- 1 day a week



Functioning (FDI)

When people are sick or not feeling well, it is sometimes difficult for them to do their regular activities. In the last few days would your child have had any physical trouble or difficulties doing these activities Please click on one response to each question

	No trouble	A little trouble	Some trouble	A lot of trouble	Impossible
Walking to the bathroom	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Walking up stairs	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Doing something with a friend	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Doing chores at home	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Eating regular meals	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Being up all day without a nap or rest	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Riding the school bus or travelling in the car	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Being at school all day	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Doing the activities in gym class (or playing sports)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Reading or doing homework	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Watching TV	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Walking the length of a football field	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Running the length of a football field	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Going shopping	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Getting to sleep at night and staying asleep	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>



PCS-C - Thoughts and feelings during pain

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When my child is in pain, I feel I can't go on like this much longer	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
When my child is in pain, it's terrible and I think it's never going to get better	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
When my child is in pain, it's awful and I feel that it overwhelms me	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
When my child is in pain, I can't stand it anymore	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
When my child is in pain, I become afraid that the pain will get worse	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
When my child is in pain, I keep thinking of other painful events	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Try to show us as clearly as possible what you think and feel by clicking on how strongly each thought applies to you.



View Reports



Responses



Download Data



Cross Tabulation

Surveys Started: 2

Surveys Completed: 2

Get Help

[Ask a Question](#)

Current Survey: parental baseline -test

Recorded Responses

Responses in Progress

Current Filters From ReportResponse Set: **Old Q responses**

Subgroup: -

Response Search CriteriaResponse Type: From Date: First Name: Email Address: Response ID: to End Date: Last Name: External Reference: Select: [All](#) [None](#) With Selected: [View](#) [Delete](#)**Advanced Options** ▼

	Response ID	Respondent	Response Type	Start Time	End Time	Duration	Action
<input type="checkbox"/>	R_e4ImGyhRy6MIFdQ	10.131.38.208	IP Address	11 Apr 2011 03:38 PM	11 Apr 2011 04:06 PM	28m 2s	▼
<input type="checkbox"/>	R_efigFVxk5FMwVMA	10.131.38.208	IP Address	15 Apr 2011 01:24 PM	15 Apr 2011 02:02 PM	38m 6s	▼



View Reports



Responses



Download Data



Cross Tabulation

Get Help

[Ask a Question](#)Current Survey: **Current Filters From Report**Response Set: **Old Q responses**

Subgroup: -

Questions:

All Questions

Chronic Pain Clinic Parent Baseline Questionnaire

Please enter your child's full name

How old is your child?

Please enter your name

Representation: Answers as Values Answers as Labels**Export tags:** Yes No**Recode Values:** Recode Seen but Unanswered Questions as **Date range:**From: To: **Format:****CSV**

This is a Comma Separated Values format of the raw data that can be easily imported into Excel, Access, or other programs. Each value in the response is separated by a comma, and each response is separated by a newline character.

SPSS

Statistical Package for the Social Sciences (SPSS) is one of the most widely used software packages for survey analysis. This is an SPSS sav data file with raw data, variable and value labels. [Download SPSS Syntax File](#)

[Download](#)[Download SPSS .sav File](#)

Options

String Width: [Having problems with international characters?](#)**XML**

A	B	C	D	E	F	G	H	I	J	K	L	M
V1	V2	V3	V4	V5	V6	V7	V8	V9	V10	SC0_0	SC0_1	SC0_2
Response	Response	Name	ExternalID	EmailAddr	IPAddress	Status	StartDate	EndDate	Finished	Grade-sun	Grade-we	Grade
R_cD93RU	New Q res	Anonymous			10.136.13	0	#####	#####	1	220	2.5	

Page Break Preview Ruler Formula Bar
 Page Layout Gridlines Headings
 Full Screen Message Bar
 Workbook Views Show/Hide

Zoom 100% Zoom to Selection
 Zoom

New Window Split Hide
 Arrange All Hide
 Freeze Panes Unhide
 Window

Save Workspace Switch Windows
 Save Switch Windows
 Macros

IF17 fx =SUM(DC17:DQ17)

IF	IG	IH	II	IJ	IK	IL	IM	IN
10	31	15	2	14	60	1.5	1.8	3.375
11	40	14	9	17	51	1.4375	0.2	3.375
12	8	6	0	2	71	2.5625	0.2	3.625
21	28	14	2	12	51	1.25	0.8	3.375
35	17	9	2	6	46	1.8125	0.4	1.875
8	16	10	3	3	44	0.9375	0.8	3.125
22	10	5	0	5	35	0.8125	0.6	2.375
48	21	7	4	10	45	1.25	0	3.125
39	31	12	6	13	50	1.5	0.8	2.75
29	13	7	2	4	49	1.25	0.6	3.25
31	35	11	7	17	43	1.25	0.6	2.5
37	31	15	3	13	41	1.125	0	2.875
15	23	10	4	9	55	1.375	2	2.875
43	27	12	5	10	63	1.75	1.4	3.5

PATIENT PARENT

Average: 18.5166667 Count: 9 Sum: 166.65 167%

In... Th... Da... Mi... 2 A... En... Mi... Desktop CP-Ortho-Pain Study 12:18 PM



Home Insert Page Layout Formulas Data Review View Developer

Normal Page Break Preview Custom Views Full Screen Workbook Views

Ruler Formula Bar
 Gridlines Headings
 Message Bar Show/Hide

Zoom 100% Zoom to Selection

New Window Split Arrange All Hide Freeze Panes Unhide Save Workspace Switch Windows

Macros

IF17 fx =SUM(DC17:DQ17)

	IF	IG	IH	II	IJ	IK	IL	IM	IN
4	10	31	15	2	14	60	1.5	1.8	3
5	11	40	14	9	17	51	1.4375	0.2	3
6	12	8	6	0	2	71	2.5625	0.2	3
7	21	28	14	2	12	51	1.25	0.8	3
8	35	17	9	2	6	46	1.8125	0.4	1
9	8	16	10	3	3	44	0.9375	0.8	3
10	22	10	5	0	5	35	0.8125	0.6	2
11	48	21	7	4	10	45	1.25	0	3
12	39	31	12	6	13	50	1.5	0.8	
13	29	13	7	2	4	49	1.25	0.6	
14	31	35	11	7	17	43	1.25	0.6	
15	37	31	15	3	13	41	1.125	0	2
16	15	23	10	4	9	55	1.375	2	2
17	43	27	12	5	10	63	1.75	1.4	
18	3	7	3	0	4	43	1.125	0.4	2



PAIN CLINIC QUESTIONNAIRE – CLIENT RECORD FORM

Note to clinicians and allied health workers:

Please make sure you look at descriptive responses in the questionnaire battery as they are not recorded on this form. This form provides client scores for numerical and standardized measures only. This form should not be used to replace qualitative clinical assessment of the client's pain syndrome. We recommend that the pain clinic questionnaire should be used in conjunction with a clinical and medical interview to guide and facilitate treatment formulation.

MRN:

Name:

DOB/Age:

Gender: Male Female

PARENT PAIN CLINIC QUESTIONNAIRE

Administration Initial 3Mth 6 mth 12 mth
date:

Parent/Guardian name:

Relationship:

Parent Scales	Initial	3months	6months	12months
A. Satisfaction (5mths follow-up question, pg 2) 1. Satisfaction with <u>pain management</u> program = SP ; range (not at all satisfied = 0; Extremely satisfied = 10) 2. Satisfaction with <u>explanations</u> for pain = SE ; range (not at all satisfied = 0; Extremely satisfied = 10) 3. Satisfaction with <u>approach</u> by pain team = SA ; range (Not at all satisfied = 0; Extremely satisfied = 10).		SP: <input type="text"/>	SP: <input type="text"/>	SP: <input type="text"/>
		SE: <input type="text"/>	SE: <input type="text"/>	SE: <input type="text"/>
		SA: <input type="text"/>	SA: <input type="text"/>	SA: <input type="text"/>
A5. Faces Pain Scale Revised (FPS-R) in the last week; range (0 - 10). CS: ≥ 3	CS <input type="checkbox"/>	CS <input type="checkbox"/>	CS <input type="checkbox"/>	CS <input type="checkbox"/>
C. Adverse Reactions d) How well was adverse reaction managed; range (not at all = 0; extremely well = 10)		<input type="text"/>	<input type="text"/>	<input type="text"/>
B6. Family stress; range (no stress = 0; extreme stress = 10). Note. In D1. of 6mths FU questionnaire	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>
B7. Marital stress; range (no stress = 1; extreme stress = 10)	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>
C. Functional Disability Inventory (FDI); range (0 - 60) Moderate: 5-10; CS: ≥ 11	CS <input type="checkbox"/>	CS <input type="checkbox"/>	CS <input type="checkbox"/>	CS <input type="checkbox"/>



PAIN CLINIC QUESTIONNAIRE – CLIENT RECORD FORM

D. Impact of Pain 1. (I) Pain-related days off school (days/term) (II) Other reasons days off school (days/term) 2. Days off paid work because of child's pain (days/mth) 3. Days off unpaid work because of child's pain KEY (1=None, 2=less than 5, 3=5-10, 4=10-15, 5=15-20, 6=more than 20) 4. Cost of pain treatment (\$/6mths) 5. Financial burden; range (no burden = 0; huge burden = 10)	1(I) <input type="text"/>	1(I) <input type="text"/>	1(I) <input type="text"/>	1(I) <input type="text"/>
	1(II) <input type="text"/>	1(II) <input type="text"/>	1(II) <input type="text"/>	1(II) <input type="text"/>
	2. <input type="text"/>	2. <input type="text"/>	2. <input type="text"/>	2. <input type="text"/>
	3. <input type="text"/>	3. <input type="text"/>	3. <input type="text"/>	3. <input type="text"/>
	4.5 <input type="text"/>	4.5 <input type="text"/>	4.5 <input type="text"/>	4.5 <input type="text"/>
5. <input type="text"/>	5. <input type="text"/>	5. <input type="text"/>	5. <input type="text"/>	
E. Pain catastrophizing scale – Parent version (total range: 0 - 52) R = Rumination; range (0 - 16) CS: ≥ 12 M = Magnification; range (0 - 12) CS: ≥ 5 H = Helplessness; range (0 - 24) CS: ≥ 15	Tot: <input type="text"/>	Tot: <input type="text"/>	Tot: <input type="text"/>	Tot: <input type="text"/>
	R: <input type="text"/>	R: <input type="text"/>	R: <input type="text"/>	R: <input type="text"/>
	CS <input type="checkbox"/>	CS <input type="checkbox"/>	CS <input type="checkbox"/>	CS <input type="checkbox"/>
	M: <input type="text"/>	M: <input type="text"/>	M: <input type="text"/>	M: <input type="text"/>
	CS <input type="checkbox"/>	CS <input type="checkbox"/>	CS <input type="checkbox"/>	CS <input type="checkbox"/>
H: <input type="text"/>	H: <input type="text"/>	H: <input type="text"/>	H: <input type="text"/>	
CS <input type="checkbox"/>	CS <input type="checkbox"/>	CS <input type="checkbox"/>	CS <input type="checkbox"/>	
F. Sleep Disturbance = D (0-10) Falling asleep = FA (0 - 10) Wake during sleep = W (0 - 10) Tiredness = T (0 - 10)	D: <input type="text"/>	D: <input type="text"/>	D: <input type="text"/>	D: <input type="text"/>
	FA: <input type="text"/>	FA: <input type="text"/>	FA: <input type="text"/>	FA: <input type="text"/>
	W: <input type="text"/>	W: <input type="text"/>	W: <input type="text"/>	W: <input type="text"/>
	T: <input type="text"/>	T: <input type="text"/>	T: <input type="text"/>	T: <input type="text"/>
G. Adult responses to children's symptoms (ARCS) P = Protect CS: ≥ 1.5 M = Minimise CS: ≥ 0.8 EM = Encourage & monitor CS: ≥ 2.6 NB: ARCS takes an average score. Therefore, all ranges should be 0 - 4, based on 5-point Likert scale	TOT: <input type="text"/>	TOT: <input type="text"/>	TOT: <input type="text"/>	TOT: <input type="text"/>
	P: <input type="text"/>	P: <input type="text"/>	P: <input type="text"/>	P: <input type="text"/>
	CS <input type="checkbox"/>	CS <input type="checkbox"/>	CS <input type="checkbox"/>	CS <input type="checkbox"/>
	M: <input type="text"/>	M: <input type="text"/>	M: <input type="text"/>	M: <input type="text"/>
	CS <input type="checkbox"/>	CS <input type="checkbox"/>	CS <input type="checkbox"/>	CS <input type="checkbox"/>
EM: <input type="text"/>	EM: <input type="text"/>	EM: <input type="text"/>	EM: <input type="text"/>	
CS <input type="checkbox"/>	CS <input type="checkbox"/>	CS <input type="checkbox"/>	CS <input type="checkbox"/>	



In Conclusion



■ On line data collection should be:

- Clinically relevant
- Cost effective – no postage or printing
- Green - No trees killed in the process
- Labour saving- (download and score takes 5 mins V's 2 people up to 45 mins)
- Quick and easy access to the data
- Easy to track who has been sent Questionnaires
- Easy to schedule follow up Questionnaires



- The data should be available in a variety of formats depending on need
- Data stored on server must be secure
- Data should be easy to share with other centres using the same questionnaires to increase the power of any research or analysis
- Incorporate benchmarking with other services to improve on best practice