Pathway to diagnosis of type 1 diabetes in children questionnaire

We are interested in your experience of the time before your child was diagnosed with diabetes. We know that recognising the symptoms of diabetes is difficult and we really want to know what you noticed and what made you first ask for medical advice from a doctor or nurse. The symptoms are different for every child so don't worry if your child didn't have all the symptoms mentioned. We are hoping to also find out how long children have symptoms for before they are diagnosed so please try to add dates wherever possible and be as accurate as you can. We have included a calendar on the next page with school holidays and bank holidays on it so please use this and your own diaries to help you remember.

Section 1 - Information about your child and family

In this section we are interested in details about your child and family. This allows us to make sure that we have included children of different ages and from different places to make the results as useful as possible.

Gender of your child: Male ☐ Female ☐ Date of birth of your child: DD/MM/YY

Ethnic background? White ☐ Asian ☐ Black ☐ Chinese ☐ Mixed ☐ Other _____

Does your child have any other medical problems? Yes ☐ No ☐ (If yes, please give details)

_____

_____

Does your child take any medication other than for diabetes? Yes ☐ No ☐ (If yes, please give details)

_____

_____

Does anyone else in the family have diabetes?

	Type 1	Type 2
Child's parent (s)	☐	☐
Child's brother or sister?	☐	☐
Other (please specify)		
_____	☐	☐
_____	☐	☐

Is anyone in the family medical / healthcare trained? e.g. a doctor, a nurse or a paramedic

Yes ☐ No ☐ (If yes, please give details)

_____

_____

What are the child's parents' current occupations?

Child's mother _____

Child's father _____

Before your child was diagnosed did you know what the symptoms of diabetes in children are?

Yes ☐ No ☐ (If yes, please give details of those symptoms you knew of)

_____

_____

What is your postcode?

__ __ __ __ __ __ __

How many other children live in the same house as your child?

0 ☐ 1 ☐ 2 ☐ 3 ☐ 4 + ☐

Calendar

This calendar shows the school holidays and bank holidays. We have included it to help you remember when you noticed symptoms and other dates relating to your child's diagnosis. You may find it helpful to add important family dates such as birthdays and holidays.

August 2012

Mon	Tue	Wed	Thu	Fri	Sat	Sun
30	31	1	2	3	4	5
6	7	8	9	10	11	12
13	14	15	16	17	18	19
20	21	22	23	24	25	26
27	28	29	30	31	1	2
3	4	5	6	7	8	9

27th - Bank holiday
27th July – 12th August - Olympics

September 2012

Mon	Tue	Wed	Thu	Fri	Sat	Sun
27	28	29	30	31	1	2
3	4	5	6	7	8	9
10	11	12	13	14	15	16
17	18	19	20	21	22	23
24	25	26	27	28	29	30
1	2	3	4	5	6	7

3rd – school term starts

October 2012

Mon	Tue	Wed	Thu	Fri	Sat	Sun
1	2	3	4	5	6	7
8	9	10	11	12	13	14
15	16	17	18	19	20	21
22	23	24	25	26	27	28
29	30	31	1	2	3	4
5	6	7	8	9	10	11

29th Oct – 2nd Nov - half term
31st - Halloween

November 2012

Mon	Tue	Wed	Thu	Fri	Sat	Sun
29	30	31	1	2	3	4
5	6	7	8	9	10	11
12	13	14	15	16	17	18
19	20	21	22	23	24	25
26	27	28	29	30	1	2
3	4	5	6	7	8	9

29th Oct – 2nd Nov - half term
5th – Guy Fawkes day

December 2012

Mon	Tue	Wed	Thu	Fri	Sat	Sun
26	27	28	29	30	1	2
3	4	5	6	7	8	9
10	11	12	13	14	15	16
17	18	19	20	21	22	23
24	25	26	27	28	29	30
31	1	2	3	4	5	6

21st - school term ends
25th – Christmas Day

January 2013

Mon	Tue	Wed	Thu	Fri	Sat	Sun
31	1	2	3	4	5	6
7	8	9	10	11	12	13
14	15	16	17	18	19	20
21	22	23	24	25	26	27
28	29	30	31	1	2	3
4	5	6	7	8	9	10

8th – school term starts

February 2013

Mon	Tue	Wed	Thu	Fri	Sat	Sun
28	29	30	31	1	2	3
4	5	6	7	8	9	10
11	12	13	14	15	16	17
18	19	20	21	22	23	24
25	26	27	28	1	2	3
4	5	6	7	8	9	10

11th – 15th Half term

March 2013

Mon	Tue	Wed	Thu	Fri	Sat	Sun
25	26	27	28	1	2	3
4	5	6	7	8	9	10
11	12	13	14	15	16	17
18	19	20	21	22	23	24
25	26	27	28	29	30	31
1	2	3	4	5	6	7

28th - school term ends
31st - Easter Sunday

April 2013

Mon	Tue	Wed	Thu	Fri	Sat	Sun
1	2	3	4	5	6	7
8	9	10	11	12	13	14
15	16	17	18	19	20	21
22	23	24	25	26	27	28
29	30	1	2	3	4	5
6	7	8	9	10	11	12

1st – Easter Monday
15th – school term starts

May 2013

Mon	Tue	Wed	Thu	Fri	Sat	Sun
29	30	1	2	3	4	5
6	7	8	9	10	11	12
13	14	15	16	17	18	19
20	21	22	23	24	25	26
27	28	29	30	31	1	2
3	4	5	6	7	8	9

27th – 31st - half term
6th and 27th- Bank holidays
11th – FA cup final

June 2013

Mon	Tue	Wed	Thu	Fri	Sat	Sun
27	28	29	30	31	1	2
3	4	5	6	7	8	9
10	11	12	13	14	15	16
17	18	19	20	21	22	23
24	25	26	27	28	29	30
1	2	3	4	5	6	7

24th June – 7th July - Wimbledon

July 2013

Mon	Tue	Wed	Thu	Fri	Sat	Sun
1	2	3	4	5	6	7
8	9	10	11	12	13	14
15	16	17	18	19	20	21
22	23	24	25	26	27	28
29	30	31	1	2	3	4
5	6	7	8	9	10	11

24th June – 7th July - Wimbledon
23rd - school term ends

Section 2 – Information about the symptoms you noticed before your child was diagnosed

In this section we are interested in all the symptoms your child had in the weeks or months leading up to when they were diagnosed with diabetes.

For each symptom please tick yes or no to indicate whether you noticed that symptom. If you did notice it, please add the date you first noticed it and what you thought the symptom was due to at the time.

Symptom	Did you notice this symptom?	If yes, when did you notice this symptom?	What did you think the symptom was due to at the time?
Drinking more than usual	YES ☐ NO ☐	DD/MM/YY	
Weeing (passing urine) more than usual	YES ☐ NO ☐	DD/MM/YY	
Changes in appetite	YES ☐ NO ☐	DD/MM/YY	
Going to the loo at night more than usual	YES ☐ NO ☐	DD/MM/YY	
Being more tired than usual	YES ☐ NO ☐	DD/MM/YY	
Wetting the bed at night	YES ☐ NO ☐	DD/MM/YY	
Losing weight	YES ☐ NO ☐	DD/MM/YY	
Vomiting	YES ☐ NO ☐	DD/MM/YY	
Having accidents when passing urine	YES ☐ NO ☐	DD/MM/YY	
Tummy pain	YES ☐ NO ☐	DD/MM/YY	
Fever	YES ☐ NO ☐	DD/MM/YY	
Constipation	YES ☐ NO ☐	DD/MM/YY	
Different smelling breath	YES ☐ NO ☐	DD/MM/YY	
Skin infections	YES ☐ NO ☐	DD/MM/YY	
Faster breathing	YES ☐ NO ☐	DD/MM/YY	
Other changes in behaviour / mood (please give details) _____ _____	YES ☐ NO ☐	DD/MM/YY	
Other (please specify) _____ _____	YES ☐ NO ☐	DD/MM/YY	

Still thinking about the symptoms that you noticed at the time before your child was diagnosed with diabetes, when you first noticed each symptom, how much did each of them concern you?

Symptom	Not applicable, my child did not have this symptom	Not at all	A little	Quite a lot	Very much
Drinking more than usual	☐	☐	☐	☐	☐
Weeing (passing urine) more than usual	☐	☐	☐	☐	☐
Changes in appetite	☐	☐	☐	☐	☐
Going to the loo at night more than usual	☐	☐	☐	☐	☐
Being more tired than usual	☐	☐	☐	☐	☐
Wetting the bed at night	☐	☐	☐	☐	☐
Losing weight	☐	☐	☐	☐	☐
Vomiting	☐	☐	☐	☐	☐
Having accidents when passing urine	☐	☐	☐	☐	☐
Tummy pain	☐	☐	☐	☐	☐
Fever	☐	☐	☐	☐	☐
Constipation	☐	☐	☐	☐	☐
Different smelling breath	☐	☐	☐	☐	☐
Skin infections	☐	☐	☐	☐	☐
Faster breathing	☐	☐	☐	☐	☐
Other changes in behaviour/mood	☐	☐	☐	☐	☐
Other (please specify) _____	☐	☐	☐	☐	☐

Section 3 – Information about what made you decide to seek medical advice

In this section we are interested in what made you decide to seek medical advice and where you went for that advice.

Did you look for information about the symptoms your child had in any of the places below?

Books	☐	Magazines	☐
The internet	☐	Other _____	☐

If you have ticked any of the boxes above, please give details below of where you looked and what information you read _____

_____

_____

Did you discuss the symptoms your child had with any of the following groups of people? (Please tick all that apply)

Family members	☐	School / nursery / play group	☐
Friends	☐	Other _____	☐

If you have ticked any of the boxes above, please give details below of who you spoke to and what advice they gave _____

_____

_____

When did you first think about seeking medical advice about the symptoms? DD/MM/YY

When did you decide to seek medical advice about the symptoms? DD/MM/YY

What was it that made you decide to seek medical advice then?

_____

Where did you go **first** for that medical advice?

GP	☐	Out of hours GP	☐	Emergency department	☐
NHS Direct	☐	Health visitor	☐	Other _____	☐
Pharmacy	☐	Minor illness centre	☐		

Where did you **first** see a doctor or nurse?

GP	☐	Out of hours GP	☐	Emergency department	☐
Minor illness centre	☐	Other _____	☐		

When was that first appointment with a doctor or nurse? DD/MM/YY

What was the main concern that you mentioned at that first appointment?

_____

_____

Had you considered diabetes at that stage? Yes ☐ No ☐ If yes, please explain what had made you think it might be diabetes

_____

_____

Thinking about your decision to seek medical advice, how much do you think each of the following made you seek medical advice **sooner**?

	Not at all	A little	Quite a lot	Very much
Concern there was something serious wrong	☐	☐	☐	☐
The symptoms were getting worse	☐	☐	☐	☐
The symptoms were not getting any better	☐	☐	☐	☐
Wanting reassurance from a doctor	☐	☐	☐	☐
Comments from other family members	☐	☐	☐	☐
Comments from school	☐	☐	☐	☐
Comments from friends	☐	☐	☐	☐
Written information from books, magazines, posters or the internet	☐	☐	☐	☐

And how much do you think each of the following made you wait and seek medical advice **later**?

	Not at all	A little	Quite a lot	Very much
Difficulty getting an appointment with a doctor or nurse	☐	☐	☐	☐
Waiting to get an appointment with a particular doctor or nurse	☐	☐	☐	☐
Concern about having to wait at the surgery to see a doctor or nurse	☐	☐	☐	☐
Worry about wasting the time of the doctor or nurse	☐	☐	☐	☐
Fear of getting a serious diagnosis	☐	☐	☐	☐
Worry that the doctor would not take you seriously	☐	☐	☐	☐
The symptoms weren't very serious	☐	☐	☐	☐
Hope that the symptoms would go away	☐	☐	☐	☐

Section 4 – Information about the diagnosis

In this section we are interested who made the diagnosis, how the diagnosis was made and how your child was at the time.

Was the diagnosis of diabetes made or suggested at that first appointment? Yes ☐ No ☐

If not, how many more times did you see a health professional before you were told your child might have diabetes?

1 ☐ 2 ☐ 3 ☐ 4 ☐ 5+ ☐

When were you told your child had diabetes? DD/MM/YY

Who told you your child might have diabetes?

GP	☐	Out of hours GP	☐	Emergency department	☐
Hospital doctor	☐	Health visitor	☐	Other _____	

Which of the following tests did your child have <u>before</u> the diagnosis?

Urine dipstick	☐	Finger prick blood test	☐	Fasting blood test	☐

Did your child need to have fluids through a tube (a drip)? Yes ☐ No ☐

How long did your child stay in hospital after the diagnosis was made? _____ nights

Did your child have diabetic ketoacidosis? Yes ☐ No ☐ I don't know ☐

Section 5 – Other information

In your opinion, do you feel there was anything that prolonged you finding out that your child has diabetes? (Please continue over the page if you need more space)

Do you have any other comments about the symptoms your child had or how the diagnosis was made? (Please continue over the page if you need more space)

Thank you very much for completing this questionnaire.

Please now put it in the pre-paid envelope and return it to:
Dr Juliet Usher-Smith, University of Cambridge, Dept. Public Health & Primary Care, Strangeways Research Laboratory, 2 Worts Causeway, Cambridge CB1 8RN.

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