Patient Experience of Diabetes Services (PEDS) Survey

Guidance notes to help you implement the PEDS Survey locally

November 2013

Record your PEDS Survey Unique Service ID here:

This ID was included in the email sent with this pack, and is needed on all questionnaires submitted by your patients.

Please ensure your diabetes patients and colleagues know this ID when asked to complete questionnaires.
About this guidance document

This guidance booklet has been provided to assist you in managing the PEDS survey within your service.

It outlines the process involved for contacting people about the survey, with recommendations about how to make participation as easy and rewarding as possible. The more people who complete the PEDS survey, the more insightful and valuable the final survey report will be.

Timelines and key dates

The checklists included in this booklet provide an overview of key dates and associated tasks to help you keep the PEDS survey on track. These are provided as guidance only, as you may need to alter some of the timescales to fit with local needs. Some of the dates in the ‘Date due’ column of the checklist have therefore been left blank for you to complete.

However, the following dates are fixed:

**14th November 2013.** The online survey goes ‘live’ and patients will be able to complete the online survey from 9am on this date

**13th December 2013.** Final deadline for registering your organisation to participate in the PEDS Survey

**31st January 2014.** The online survey will close at 5pm on this date.

Participating services will receive their individualised local reports in Summer 2014.

Contact information

For latest news and information, and downloaded promotional materials, please visit the PEDS WebPages at [http://www.hscic.gov.uk/PEDS](http://www.hscic.gov.uk/PEDS)

For general enquiries, email [PEDS@hscic.gov.uk](mailto:PEDS@hscic.gov.uk)
Introduction

The PEDS survey is a new and exciting addition to the National Diabetes Audit (NDA) portfolio. This survey of patient experience will measure the diabetes healthcare service experiences of people with diabetes. This will then help you compare your service with national standards and against other services. It will highlight areas of good practice and also those where there is potential to improve.

The PEDS survey is commissioned by the Healthcare Quality Improvement Partnership (HQIP) and delivered by the Health and Social Care Information Centre (HSCIC), working in collaboration with Diabetes UK and Public Health England.

The PEDS pilot

During 2013-14, we are testing the PEDS survey using a web-based online questionnaire across diabetes healthcare providers in England and Wales.

The PEDS pilot aims to assess whether the approach used yields sufficient numbers of respondents from each service to provide robust data, both at service level and nationally. We also want to gain a better understanding of the barriers to participation and some measure of who isn’t completing the online questionnaire and what additional support they might need.

PEDS survey pilot will be formally evaluated at the end of the survey period and the NDA team will be in touch with you to get some feedback about your participation in February 2014.

In the meantime, it would really help with the evaluation process if you could keep a note of what has happened with the PEDS survey within your service. A template form has been provided to help you keep notes. A copy of the form is in Appendix A.

Areas covered by the PEDS Survey

The main aspects of care covered in the PEDS Survey are:

- Is communication at consultations effective?
- Does care planning take place as recommended?
- What is the experience of accessing care?
- How engaged are people with diabetes in their care?

A copy of the questionnaire is included in Appendix B.
RUNNING THE PEDS SURVEY IN YOUR SERVICE

Below outlines the stages of making contact and offering support to ensure that participation rates are high and people with diabetes find it a rewarding experience.

Asking people with diabetes to complete the PEDS questionnaire

In order to complete the PEDS survey for your service, people will need two important pieces of information:

1. The web link or URL, which is

   clinicalaudit.ic.nhs.uk/peds/welcome

2. Your unique service ID. This was provided to you in the go ‘live’ email, which was sent to your with these guidance notes.

   NOTE: This unique service ID will be the way we link questionnaire responses back to your services. Patients will not be able to access the questionnaire without a valid service ID.

You can provide this information to people with diabetes in any way that works for your service. We have provided some materials to help promote the PEDS survey and provide this information to your patients. These include:

- A template letter – to hand out or to send by post. This is a word document and a space has been provided to type in your unique service ID before printing the letter off. See below:

- A promotional poster. As with the letter template, a space has been provided to hand write in your unique service ID
• A promotional A6 card template. Again, a space has been provided to type in your unique service ID. These can then be printed off and cut to size for display or handing out in your practice/clinic

Promoting the PEDS survey and inviting people with diabetes to take part

You can promote the PEDS survey in any way that is appropriate to your service and encouraging to people with diabetes. You can develop your own information or use the materials/templates provided, as suggested below:

By letter
You may wish to use the template letter provided or write your own letter (please ensure the web link and unique service ID are included). The letter can be posted to people with diabetes attending your service and/or given out during clinics

Using handouts or flyers
You may wish to use the promotional A6 card template to make cards which can be handed out during clinics and/or left in the waiting room and/or reception desk.

If you prefer, you can develop your own flyers or handouts as long as the web link and unique service ID are included.

Posters
A promotional poster has been provided as part of the PEDS survey pack. Please display this in waiting rooms, reception areas and anywhere else where patients may see the information.

Raise awareness amongst key staff
In order to maximise response rates, it will be important that all staff who come into contact with people with diabetes are aware of the PEDS survey and that they have enough information to both promote it and answer any queries. Including information about PEDS in all staff emails or talking about the survey at staff meetings are just some of the ways you might do this.

Other ideas for promoting the PEDS survey and encouraging participation:

- Promoting via your services website, electronic noticeboards and in-service kiosks
- Emailing people with diabetes attending your service (ensuring that you only use an email address that people have approved you using for correspondence about your treatment)
- Texting people with diabetes attending your service (ensuring that you only use mobile phone numbers that people have approved you using for correspondence about their treatment)
- Including information on repeat prescriptions for people with diabetes
- Including an invitation to take part on any appointment letters that are sent to people with diabetes
- Providing information to people with diabetes who are attending for their flu jab or other vaccinations

**Support during the survey period**

We hope that the supporting information we have provided will make it as straightforward as possible for you to encourage patients to complete the survey and ensure maximum participation and response rates.

During the survey period, you will be able to keep track of how many of your patients have completed the survey via your Single Sign-On (SSO) account. This is the account you set up when you first registered to take part.

Some Frequently Asked Questions are provided at the end of this document, which hopefully will answer most further queries.

Copies of all the documents and further information about PEDS are available on the PEDS webpage at [www.hscic.gov.uk/peds](http://www.hscic.gov.uk/peds).

If you have any queries during the survey period, please email PEDS@hscic.gov.uk
Frequently Asked Questions

Is the PEDS survey for children and adults?
A. Any person with diabetes is eligible to complete the survey regardless of age.

How many patients do we need to select to complete the PEDS survey?
A. We would recommend that you promote the survey amongst all people who attend your service and encourage as many as possible to participate. However, in order to ensure your service has enough responses to produce a service level report, we would expect the following targets to be reached:

- If your service has less than 200 patients, at least 10% of your patients need to complete
- If your service has more than 200 patients, at least 5% of your patients need to complete

How long does it take for people with diabetes to complete the survey?
A. 10-15 minutes

What questions are asked in the PEDS survey?
A. The PEDS survey asks about the patients’ experience of their diabetes care, including care planning, communications about treatments and what care they have received. A copy of the questionnaire used can be found in the Appendix B

Are the results confidential to the service?
A. No. The survey findings for each participating service will be published on the Health and Social Care Information Centre (HSCIC) website.

When will the PEDS survey results be published?
A. Results from the survey will be published in summer 2014. You will be informed of exact publication dates by email once these have been confirmed.

Why is the survey only being done online?
A. The NDA team want to develop a survey tool that is cost-effective and sustainable, and one which provides the least burden to the healthcare providers who participate. Following an options appraisal, it was concluded that an online survey approach to gathering patient experience information is both the least burdensome and most cost-effective.

The purpose of this current PEDS survey is to test whether an online survey approach provides a viable solution for future surveys about diabetes patient experience.

Can we compare our performance against other services?
A. Yes. The findings for each participating service will be published, along with a CCG level report and a national report. The analysis will compare and benchmark each participating site against the CCG and national findings.

**How can we ensure that those completing the survey reflect the overall survey population?**

A. By encouraging all people with diabetes who use your service to complete the survey. If you use a combination of approaches to promoting the survey, you have more chance of reaching more people – including face-to-face, targeted invitations, general promotion etc.

We acknowledge that some people either don’t have access to, or are unfamiliar with using, the internet. The PEDS survey can be accessed from any computer, as long as the person has the web address and unique service ID. Encourage friends, relatives and carers to help with access and completion.

**Thank you, and good luck!**
Template Forms and Letters:

a) Template invitation letter (to post)

b) Template invitation letter (to handout)

c) Template monitoring form (for evaluation)
Dear Name of diabetes patient (we recommend you personalise the letters as they are more likely to ensure questionnaires are completed),

What do you think about your diabetes care?

We are getting in touch with you to ask for your feedback on the care you have received for your diabetes from insert name of GP practice or clinic.

We are taking part in a national survey called the Patient Experience of Diabetes’ Services (PEDS) survey. The survey is collecting views from people with diabetes, in England and Wales, about their experience of diabetes care.

Your feedback will help us to know what we are doing well and what we need to do better. The questionnaire does not ask any personal information, so your feedback will be completely anonymous.

How to take part

The survey is collecting feedback via an online questionnaire, which will only take about 10 minutes to complete. The survey can be completed anytime between 14th November 2013 and 31st January 2014.

To access the online questionnaire, go to: clinicalaudit.ic.nhs.uk/peds/welcome

Or scan:

clinicalaudit.ic.nhs.uk/peds/welcome

And then enter the following code in the box provided on the welcome page:

If you would like to find out more about the PEDS survey, please go to www.hscic.gov.uk/PEDS.

Yours sincerely,
Dear Name of diabetes patient (we recommend you personalise the letters as they are more likely to ensure questionnaires are completed),

What do you think about your diabetes care?

We would like to invite you to take part in a survey about the diabetes care you have received from insert name of GP practice or clinic.

We are taking part in a national survey called the Patient Experience of Diabetes’ Services (PEDS) survey. The survey is collecting views from people with diabetes, in England and Wales, about their experience of diabetes care.

Your feedback will help us to know what we are doing well and what we need to do better. The questionnaire does not ask any personal information, so your feedback will be completely anonymous.

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Please enter the following code in the box provided on the welcome page:

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Yours sincerely,

Name of GP practice or clinic
PEDS Survey – Monitoring Form

This form is for your own use to keep a record of progress. You will not need to submit this form, but it will be useful to keep a copy for the PEDS evaluation

| How many patients are you targeting? Eg. All or a % | □ Post (template letter) |
| How did you invite patients to take part | □ Post (own letter) |
| | □ Handout (template letter) |
| | □ Handout (using template cards) |
| | □ Other (please specify) |

| When did you start to promote the PEDS survey and invite patients? | Start date: |
| | End date: |

| Please keep a note of any feedback from staff about the PEDS survey | |

| Please keep a note of any feedback from patients about the PEDs survey | |
| - In general? | |
| - About completing the questionnaire? | |
APPENDIX B:

Patient Experience of Diabetes Services (PEDS) Survey
Online Questionnaire

**NOTE:** This is for information only. We are unable to accept paper copies of completed questionnaires.

The questionnaire must be completed online at
https://clinicalaudit.ic.nhs.uk/peds/welcome
PLANNING YOUR DIABETES CARE

1. In the last 12 months, how many times have you visited <name of service> for your diabetes care?
   1. □ Once
   2. □ Twice
   3. □ Three or four times
   4. □ More than four times
   5. □ Can’t remember / Not sure

THINKING ABOUT THE DIABETES APPOINTMENTS YOU HAVE ATTENDED IN THE LAST YEAR AT <name of service>?

2. Did you discuss your ideas and goals about the best way to manage your diabetes with the clinic staff?
   1. □ Yes, completely
   2. □ Yes, to some extent but not enough
   3. □ No, but I would have liked to
   4. □ No, but I did not want to
   5. □ Can’t remember / Not sure

3. Did you discuss the food that you eat and any changes you could make to your diet?
   1. □ Yes, definitely
   2. □ Yes, I was given some advice but I wanted more
   3. □ No, but I would have liked help/advice
   4. □ No, but I did not need any help/advice
   5. □ Can’t remember / Not sure

4. Did you discuss your levels of physical activity and any changes that you could make?
   1. □ Yes, definitely
   2. □ Yes, I was given some advice but I wanted more
   3. □ No, but I would have liked help/advice
   4. □ No, but I did not need any help/advice
   5. □ Can’t remember / Not sure

5. During your last diabetes appointment, did you discuss and agree a plan about how to manage your diabetes until your next appointment?
   1. □ Yes ➔ Go to Question 6
   2. □ No ➔ Go to Question 7
   3. □ Can’t remember / Not sure ➔ Go to Question 6

6. Were you offered a written, printed or electronic copy of your care plan?
   1. □ Yes
   2. □ No, but I would have liked one
   3. □ No, but I did not want one

7. Do you feel the health professional listened carefully to what you had to say?
   1. □ Yes, definitely
   2. □ Yes, to some extent
   3. □ No
8. Did the health professional explain things clearly?
   1 □ Yes
   2 □ No

9. As a result of your diabetes appointments in the last 12 months, do you feel confident about managing your diabetes?
   1 □ Yes, definitely
   2 □ Yes, to some extent
   3 □ No

B. PROVIDING YOUR DIABETES CARE

10. Sometimes, one health professional will say one thing and another will say something quite different. In the last 12 months, has this happened to you?
    1 □ Yes, often
    2 □ Yes, sometimes
    3 □ No

11. In the last 12 months, have you needed to provide the same important information to clinic staff that you had already provided during a previous visit?
    1 □ Yes
    2 □ No

12. Do you have a contact number to call if you are worried about your diabetes?
    1 □ Yes
    2 □ No

13. In the last 12 months, have you had the nine annual diabetes checks listed below

<table>
<thead>
<tr>
<th>Annual diabetes checks</th>
<th>Yes</th>
<th>No</th>
<th>Can’t remember/not sure</th>
</tr>
</thead>
<tbody>
<tr>
<td>Weight or Body Mass Index (BMI)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Blood pressure measurement</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Blood test to look at your long-term glucose level. This test is called HbA1c.</td>
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<td></td>
<td></td>
</tr>
<tr>
<td>Blood test to check your Cholesterol level</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Blood test to check your kidney function (sometimes called blood creatinine test)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Urine test to check for protein, which may be a sign of kidney problems (sometimes called microalbumin or urine albumin creatinine ratio)</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
Foot examination (sensation, circulation) to assess risk of getting ulceration (wounds)

Eye screening using a specialized digital camera to look for any changes to the retina (sometimes called retinal screening)

Check on whether you are smoking and advice if you are a smoker

**FILTER If people tick yes, then taken to a table which only lists those items ticked yes**

14. Have the results of your diabetes health checks been explained to you?

<table>
<thead>
<tr>
<th>Annual diabetes checks</th>
<th>Yes - definitely</th>
<th>Yes – to some extent</th>
<th>No</th>
<th>Don’t know/not sure</th>
</tr>
</thead>
<tbody>
<tr>
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</tr>
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</table>
FILTER If yes – definitely/to some extent, then taken to the following question

15. Do you feel that you understand what the results of each of the checks mean for you?

<table>
<thead>
<tr>
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<th>Yes - definitely</th>
<th>Yes – to some extent</th>
<th>No</th>
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</tr>
</tbody>
</table>

16. Do you know why you are prescribed each of the medications for your blood glucose control?

1 □ Yes, definitely
2 □ Yes, to some extent but not enough
3 □ No, but I would like to know
4 □ No, but I do not want to know
5 □ I do not take any medication for my blood glucose
6 □ Don’t know / Not sure
17. Do you know about the wide range of different treatments (diet, exercise and/or medications) available to you to manage your diabetes?

1 □ Yes, definitely
2 □ Yes, to some extent but not enough
3 □ No
4 □ Don’t know / Not sure

18. Do you know about how these different treatments will affect your present and future health?

1 □ Yes, definitely
2 □ Yes, to some extent but not enough
3 □ No
4 □ Don’t know / Not sure

19. Have you been offered a formal diabetes education programme?

(formal means a special course about your kind of diabetes with a minimum of 3 hours tuition run by nurses, dietitians or doctors. Examples of formal courses are DAFNE or BERTIE for Type 1; DESMOND or XPERT for Type 2)

1 □ Yes
2 □ No
3 □ Don’t know / Not sure

IF YES, ANSWER Q19.

20. Have you attended a formal diabetes education programme?

1 □ Yes
2 □ No
3 □ Don’t know / Not sure

If yes, please write year e.g. 2004
ABOUT YOU

What Type of diabetes do you have?
1. □ Type 1
2. □ Type 2
3. □ Other (e.g. MODY, due to pancreatitis)
4. □ Don’t know / Not sure

Are you male or female (this will be changed to gender national groupings)
1. □ Male
2. □ Female

What was your year of birth?
(Please write in) e.g. 1 9 3 4

POSTCODE

The following question asks for your postcode. If you choose to provide your postcode, you are consenting to allow this information to be used by the Health and Social Care Information Centre (HSCIC) to find out more information about the part of England or Wales in which you live with respect to this survey.

The HSCIC will convert the postcode you provide into a code that cannot be traced back to you. They will then securely destroy the postcode provided.

If you do not wish to provide this information, then please leave this question blank.

What is your postcode?
ETNIC GROUP

The following question asks for your ethnic group. People from different ethnic groups may have very different experiences of diabetes. This information will not be used at an individual level. If you do not wish to provide this information, then please leave this question blank.

To which of these ethnic groups would you say you belong? (Tick one only)

White British
White Irish
White Any other White background

Mixed White and Black Caribbean
Mixed White and Black African
Mixed White and Asian
Mixed Other mixed background

Asian or Asian British Indian
Asian or Asian British Pakistani
Asian or Asian British Bangladeshi
Asian or Asian British Any other Asian Background

Black or Black British Caribbean
Black or Black British African
Black or Black British Other Black background

Other Chinese
Other Any Other
Not Stated
Not Known
OTHER COMMENTS

If there is anything else you would like to say about the diabetes care you have received from this clinic, over the past year, please do so here.

Was there anything particularly good about your diabetes care?

Was there anything that could have been improved?

Any other comments?

Thank you very much for your feedback.

All of the feedback received from people with diabetes will be analysed and written up in local and national reports. These reports will be published in summer 2014. You will be able to access these reports from [www.hscic.gov.uk/PEDS](http://www.hscic.gov.uk/PEDS).

For more information about diabetes and living with diabetes, visit Diabetes UK’s website [www.diabetes.org.uk](http://www.diabetes.org.uk) or call Diabetes UK’s Careline on 0845 120 2960 for advice and support.