

Survey of PIES website usage Letter of invitation

Dear PIES website user,

The University of Sheffield is conducting an evaluation of PIES – a cancer information website for cancer patients and carers within South Yorkshire and parts of Derbyshire and Nottinghamshire. PIES stands for Personalised Information, Education and Support. We have developed a website to assist people in looking for relevant information on the internet. We are very eager to find out how this website is received by its users and as part of this evaluation, we invite you to fill in a questionnaire.

I would be most grateful if you would complete the following questionnaire for us to help ensure that we fully represent the views of patients and other users.

We advise that you read the attached information sheet carefully.

With many thanks in anticipation of your help.

Yours faithfully

Dr Richard Stevens
Research Associate

Telephone 0114 262 0174
Email: r.j.stevens@sheffield.ac.uk

User information sheet for questionnaire

Evaluation of PIES

PIES - A study about Personalised Information, Education and Support
for cancer patients and carers

You are being invited to take part in an evaluation study. Before you decide, it is important for you to understand why the study is being done and what it will involve. Please take time to read the following information carefully, and discuss it with others if you wish. Ask us if there is anything that is not clear or if you would like more information. Take time to decide whether or not you wish to take part. Thank you for reading this.

What is the purpose of this study?

Like you, we think that information is very important, particularly when you or someone close to you is ill. Because we are all different, we have different needs regarding **what** information we need, **when** we want it and **how** to get it.

In the past, most of the information from professionals to patients and carers has been given via leaflets, booklets, and of course in consultations between health care professionals and patients and carers. These are excellent methods that we want to keep using. The internet has recently become another source of information for people, also in relation to finding health information. A positive thing about the internet is that it can provide access to a wealth of information in any possible area. This can however also be a downside, as it can be hard to find exactly what we are looking for and to decide if the information we find is reliable. In this study, we wish to find out more about how people use the internet for information relating to a cancer illness. In particular, we wish to ask about people's views on a new website called PIES, that we are developing with the intention of assisting people in finding reliable and useful information on the internet.

Why have I been chosen?

You have been chosen as someone who has used the PIES website at least once in order to look for information relating to a cancer illness.

Do I have to take part in the study?

No, you are in no way obliged to take part in the study. It is completely voluntary, and even if you do choose to participate, you are not obliged to answer all the questions in the questionnaire. If you choose not to take part, your care and follow-up will not be compromised in any way.

What is involved if I decide to take part?

We invite you to fill in a questionnaire where we ask several questions related to online information. We will specifically ask for your opinion about use of the PIES website in relation to finding relevant information for you. We have also added some questions, which

will give us some background about you. You might wonder how these questions can have anything to do with issues of information. We ask these questions because we are interested in what we call ‘personalised information’ that relates to your needs. In order to find out more about that, we need to know something about you as a person and the type of information you are looking for. This background data will also help us check that we have collected feedback from a variety of different users in the study. You will only need to fill in one questionnaire. It should not take more than 10 – 15 minutes to complete it.

What if I wish to complain about the way in which the study has been conducted?

If you wish to complain, or have any concerns about any aspect of the way you have been approached or treated during the course of this study, the normal National Health Service complaints mechanisms are available to you.

Will the information I give be confidential?

Yes, the questionnaire is anonymous and strictly confidential. We will not ask for your name, and you will not be identified in any way by filling in the questionnaire. The number in the bottom right corner of the questionnaire will only identify the particular place where the questionnaire was handed to you and how many questionnaires has been handed out from that place. It can in no way be traced back to your identity.

What will happen to the results of the study?

The results of this evaluation will be published in various ways by our department after the study has ended. Information about the progress of such publications can be found on our department’s website (<http://www.sheffield-palliative.org.uk>) or can be obtained by contacting the Project Manager.

Who is organising and funding the study?

The study is a collaboration between the [Academic Palliative Medicine Unit](#) and [School of Nursing](#) at the University of Sheffield. It is funded by [Macmillan Cancer Relief](#).

Contact persons are:

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Research Associate

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PIES Project Manager

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Sykes House, Little Common Lane

Sheffield S11 9NE

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Part A: About You

In this section we are asking about you and your information needs.

1. Please tick the box which best describes your circumstances:

- I am a person diagnosed with cancer
- I am a person being investigated for cancer
- I am a husband/wife/partner of a person with cancer
- I am a child of a person with cancer
- Other description - **please write it in here:**

2. Are you male or female?

Male Female

3. My age-group is...

18-24 25-34 35-44 45-54
55-64 65-74 75-84 85 and over

4. Please tick the box which best describes you:

- English is my first language
- English is not my first language but I have no problems understanding what I read
- English is not my first language and I sometimes have problems understanding what I read

5. I would describe my ethnic origin as...

- White
- Black Caribbean
- Black African
- Black other - **please describe:**.....
- Indian
- Pakistani
- Bangladeshi
- Chinese
- Any other ethnic group - **please describe:**.....
- Prefer not to say

6. Please tick the box(es) which best describes your employment situation.

Please tick all boxes that apply

- Full-time employee
- Part-time employee
- Self-employed
- Unemployed
- Full-time student/trainee
- Retired
- Permanently sick
- Home-maker

7. Do you have any disabilities?

Please tick all boxes that apply

- I suffer from dyslexia
- I am blind/partially sighted
- I am deaf/have a hearing impairment
- I am a wheelchair user/have a mobility impairment
- I am a person with learning difficulties
- I have a disability not listed above - **please describe here:**

8. What is the main type(s) of cancer you are looking for information on?

Please tick all boxes that apply

- not one single type, just looking for general information
- cancer of the breast
- cancer of the prostate
- cancer in the gastro-intestinal tract/digestive system
- cancer of the lung
- cancer of the brain
- lymphoma
- female cancer
- cancer of the bladder
- oral, head and neck cancer
- other cancer - **please write it in here:**

.....

.....

.....

.....

9. What kind of cancer information are you looking for at this stage?

Please tick all boxes that apply

- Causes of the illness
- Type of illness
- Treatment choices
- Side effects of treatments
- Control of distressing symptoms
- Complementary therapies (e.g. relaxation)
- Voluntary organisations/self help and support groups
- Financial benefits/social security
- Family issues/close relationships
- Communicating with children about illness
- Body image/sexuality
- Local services
- Other - **please write it in here:**

.....

.....

.....

.....

10. Where do you live? It would help us enormously in classifying responses if you would tell us the area and broad postcode sector in which you live - for example, *Rotherham S60* or *Doncaster DN5*. (Please note - to maintain anonymity of questionnaire data, we are not asking for the last part of your postcode).

Please write it in here:.....

Part B: About your use of the internet

In this section we are asking about how you use the Internet in general.

11. How much experience of using the internet do you have?

- | | | |
|--------------------------|---------------------------|--------------------------|
| Very little experience | Fair amount of experience | Great deal of experience |
| <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
-

12. Do you have access to the Internet at home?

- Yes No Don't know
-

13. Do you have access to the Internet at work, school or college?

- Yes No Don't know Not applicable
-

14. Do you have access to the Internet in a public place near where you live – for example, in a library, community centre, café or shop?

- Yes No Don't know
-

15. How often have you used the Internet for finding medical or health information?

- never on 1 or 2 occasions on 3 or more occasions
-

16. How often have you looked for cancer information on the Internet?

- never on 1 or 2 occasions on 3 or more occasions
-

17. Have you already given us some feedback about PIES via the online questionnaire on the PIES website?

- Yes (Please note: even if you have also given us some feedback via the online questionnaire on the PIES website or otherwise, we would still be very grateful if you also complete this written questionnaire which may give us more detailed information)
- No
- Don't know
-

Part C: About your use of the PIES website

In this section we are asking specifically about your use of the PIES website.

18. When did you first use the PIES website?

- | | | | |
|--------------------------|--------------------------|--------------------------|--------------------------|
| Today | Within the
last week | 2-4 weeks
ago | More than 4
weeks ago |
| <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
-

19. When was the last (i.e. most recent) time you used the PIES website?

- | | | | |
|--------------------------|--------------------------|--------------------------|--------------------------|
| Today | Within the
last week | 2-4 weeks
ago | More than 4
weeks ago |
| <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
-

20. On how many different occasions have you looked at the PIES website?

- 1 occasion only
 - 2-3 occasions
 - 4-5 occasions
 - 6-10 occasions
 - More than 10 occasions
-

21. When you used the PIES website, on average, how long did a typical session last?

- 5 minutes or less
 - More than 5 minutes but less than 30 minutes
 - 30 minutes or more but less than 60 minutes
 - 60 minutes or more
-

22. How do you rate the overall *look* of the PIES website - the colours, text, images, shape of pages etc.?

- | | | | | | |
|--------------------------|--------------------------|--------------------------|--------------------------|--------------------------|--------------------------|
| Very poor | Poor | Fair | Good | Very good | Can't say |
| <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
-

23. How easy or difficult is it to find your way around within the PIES website?

- | | | | | | |
|--------------------------|--------------------------|-------------------------------|--------------------------|--------------------------|--------------------------|
| Very
difficult | Quite
difficult | Neither easy
nor difficult | Quite
easy | Very
easy | Can't
say |
| <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
-

24. Which of these statements best describes the main way you looked for information within the PIES website?

- I mainly browsed around the PIES website (I mainly looked for information by clicking on titles, headings, other text or links)
 - I mainly searched the PIES website (I mainly looked for information by typing words in the search box, then looking at the results)
 - I mainly used a combination of both browsing and searching to look for information.
 - Can't say
-

25. Generally, how do you rate the PIES website to find relevant and reliable information?

- | | | | | | |
|--------------------------|--------------------------|--------------------------|--------------------------|--------------------------|--------------------------|
| Very poor | Poor | Fair | Good | Very good | Can't say |
| <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
-

26. Is there any specific information or particular links you looked for in PIES but could not find?

- No
- Yes - **please write it in here:**

.....

.....

.....

.....

27. Have you used the area of the PIES website that gives a directory of local cancer services?
 Yes No Not sure

28. How do you rate the area of the PIES website that gives a directory of local cancer services?
Very poor Poor Fair Good Very good Can't say

29. How important to you is the principle of the PIES rating system for information (the number of pies which are marked next to some resources to indicate their quality)?
Very Unimportant Quite unimportant Neither important nor unimportant Quite important Very important Can't say

30. How important to you is it to be able to read other users' comments about websites that PIES links to and/or to add your own comments?
Very Unimportant Quite unimportant Neither important nor unimportant Quite important Very important Can't say

31. Have you used the 'My Notebook' facility?
Yes No Don't know

32. How do you rate the 'My Notebook' facility?
Very poor Poor Fair Good Very good Can't say

33. How often have you searched MEDLINE after following the link to PubMed from PIES?
 On 1 occasion only
 On 2-3 occasions
 On 4-5 occasions
 On more than 5 occasions
 Never
 Don't know

34. What sort of personal training or help in how to use the PIES website did you receive?
Tick one box only that best describes your training for use of the PIES website
 None
 Someone gave me a brief demonstration to get me started
 Someone gave me a brief demonstration to get me started, and was also available for extra help while I used PIES
 Someone gave me a brief demonstration to get me started, was also available for extra help while I used PIES, and also supported me step-by-step throughout the training session
 Other - **please describe:**

.....
.....

35. Was the training you received in preparing you to use the PIES website adequate or inadequate?
 Inadequate – **please explain in what way it was inadequate:**.....

.....
.....

Adequate
 Can't say

36. How easy or difficult was it to find cancer information on the Internet before you used PIES?

Very difficult	Quite difficult	Neither easy nor difficult	Quite easy	Very easy	Can't say
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

37. Will you use the Internet for finding cancer information in future?

Yes No Don't know

38. From what you have seen so far, how important to you do you think the PIES website will be for finding cancer information in future?

Very Unimportant	Quite unimportant	Neither important nor unimportant	Quite important	Very important	Can't say
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

39. If you would like to add any other comments about the PIES website please write them here:

.....
.....
.....
.....

40. Please write in today's date: /...../ 2002

Thank you very much for your help.

Please return the completed questionnaire by posting it to us using an envelope with the address below – it does not need a stamp within the UK.

Richard Stevens
University of Sheffield
Trent Palliative Care Centre
FREEPOST SF 1605
Sheffield
S11 8TE

If you have any queries about the questionnaire, please do not hesitate to contact us at the above address or via:

telephone: 0114 262 0174
fax: 0114 236 2916
email: r.j.stevens@sheffield.ac.uk or h.h.ahmedzai@sheffield.ac.uk
web: www.piesforcancer.info

Reply form for potential interview

Evaluation of PIES

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We intend to follow up the questionnaire survey with face to face interviews with some of those who have used the PIES website within the districts of Barnsley, Bassetlaw, Chesterfield, Doncaster, Rotherham or Sheffield.

If you live in one of these areas, would you be prepared to help us further at a later date by being interviewed in person or on the telephone?

If so, please tick the Yes box, fill in your contact details, separate the slip below and return it to Richard Stevens either together with the questionnaire or in a separate envelope if you don't want your name to be connected with the questionnaire.



Please cut along the line, or fold along the line and carefully tear off

Yes, I may be prepared to take part in the interview stage of the PIES evaluation, but I am under no obligation to do so. I would be interested in receiving further information about this and can be contacted as follows:

Title: Mr/Ms/Miss/Mrs/Dr/other.....
(please circle as appropriate, or write in)

My first name is:

My last name is:

My address is:

My telephone number is:

Email address (if you have one):

Please indicate if you have any preference for the way you want to be contacted

.....
.....