

SPARC

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Rationale of project – the beginnings

- Elizabeth Clark Charitable Trust (Sainsbury Family Trust) approached University of Sheffield to *‘improve access to palliative care’*
- **Problems**
 - Equity of access to palliative care is a public health problem
 - Identifying which patients to refer and when to refer is an individual issue
- **Solution**
 - Develop a screening instrument to apply to individual patients
 - Make this freely available to all non-specialists and to potential patients and their carers

Design of 3 year project

Study 1: Item generation: Exploring reasons for referral to specialist palliative care

Study 2: Question development: Developing items into questions

Study 3: Pilot study: Testing the questions and response formats in practice

Study 4: Item analysis and reliability testing

Study 5: Validity testing: Preliminary assessments of validity

Final version of questionnaire

45 questions

Domain	Number of items	Response type
Physical symptoms	21	Distress or bother
Psychological	9	Distress or bother
Religious / spiritual	2	Distress or bother
Independence / activity	3	Distress or bother
Family / social	4	Distress or bother
Treatment issues	2	Distress or bother
Information / communication	3	Yes / No
Personal affairs	1	Yes / No

Sample sections of SPARC

SPARC*

We would like to know a bit more about you and your concerns. Please fill in this questionnaire (with help from a relative or carer if needed) and return it to one of our team. There are no "right" or "wrong" answers. If you are unsure of a question, please leave it blank. THANK YOU.

COMMUNICATION AND INFORMATION ISSUES

1.	Have you been able to talk to any of the following people about your condition?	Yes	No
a.	Your doctor	<input type="checkbox"/>	<input type="checkbox"/>
b.	Community nurse	<input type="checkbox"/>	<input type="checkbox"/>
c.	Hospital nurse	<input type="checkbox"/>	<input type="checkbox"/>
d.	Religious advisor	<input type="checkbox"/>	<input type="checkbox"/>
e.	Social worker	<input type="checkbox"/>	<input type="checkbox"/>
f.	Family	<input type="checkbox"/>	<input type="checkbox"/>
g.	Other people (please state) <input type="text"/>		

PHYSICAL SYMPTOMS

		Please circle <u>one</u> answer per line			
<i>In the past month have you been distressed or bothered by</i>		Not at all	A little bit	Quite a bit	Very much
2.	Pain?	0	1	2	3
3.	Loss of memory?	0	1	2	3
4.	Headache?	0	1	2	3
5.	Dry mouth?	0	1	2	3
6.	Sore mouth?	0	1	2	3
7.	Shortness of breath?	0	1	2	3
8.	Cough?	0	1	2	3

Sample sections of SPARC

9.	Feeling sick (nausea)?	0	1	2	3
10.	Being sick (vomiting)?	0	1	2	3
11.	Bowel problems (eg constipation, diarrhoea or incontinence)?	0	1	2	3
12.	Bladder problems (urinary incontinence)?	0	1	2	3
13.	Feeling weak?	0	1	2	3
14.	Feeling tired?	0	1	2	3
15.	Problems sleeping at night?	0	1	2	3
16.	Feeling sleepy during the day?	0	1	2	3
17.	Loss of appetite?	0	1	2	3
18.	Changes in your weight?	0	1	2	3
19.	Problems with swallowing?	0	1	2	3
20.	Being concerned about changes in your appearance?	0	1	2	3
21.	Feeling restless and agitated?	0	1	2	3
22.	Feeling that your symptoms are not controlled?	0	1	2	3

PSYCHOLOGICAL ISSUES

In the past month have you been distressed or bothered by

23.	Feeling anxious?	0	1	2	3
24.	Feeling as if you are in a low mood?	0	1	2	3
25.	Feeling confused?	0	1	2	3
26.	Feeling unable to concentrate?	0	1	2	3
27.	Feeling lonely?	0	1	2	3
28.	Feeling that everything is an effort?	0	1	2	3
29.	Feeling that life is not worth living?	0	1	2	3
30.	Thoughts about ending it all?	0	1	2	3
31.	The effect of your condition on your sexual life?	0	1	2	3

Sample sections of SPARC

		Please circle <u>one</u> answer per line			
		Not at all	A little bit	Quite a bit	Very much
RELIGIOUS AND SPIRITUAL ISSUES					
<i>In the past month have you been distressed or bothered by</i>					
32.	Worrying thoughts about death or dying?	0	1	2	3
33.	Religious or spiritual needs not being met?	0	1	2	3

INDEPENDENCE AND ACTIVITY					
<i>In the past month have you been distressed or bothered by</i>					
34.	Losing your independence?	0	1	2	3
35.	Changes in your ability to carry out your usual daily activities such as washing, bathing, or going to the toilet?	0	1	2	3
36.	Changes in your ability to carry out your usual household tasks such as cooking for yourself or cleaning the house?	0	1	2	3

FAMILY AND SOCIAL ISSUES					
<i>In the past month have you been distressed or bothered by</i>					
37.	Feeling that people do not understand what you want?	0	1	2	3
38.	Worrying about the effect that your illness is having on your family or other people?	0	1	2	3
39.	Lack of support from your family or other people?	0	1	2	3
40.	Needing more help than your family or other people could give?	0	1	2	3

Sample sections of SPARC

TREATMENT ISSUES

In the past month have you been distressed or bothered by

41.	Side effects from your treatment?	0	1	2	3
42.	Worrying about long term effects of your treatment?	0	1	2	3

PERSONAL ISSUES

		Yes	No
43.	Do you need any help with your personal affairs?	<input type="checkbox"/>	<input type="checkbox"/>
44.	Would you like to talk to another professional about your condition or treatment?	<input type="checkbox"/>	<input type="checkbox"/>
45.	Would you like any more information about the following?		
a.	Your condition	<input type="checkbox"/>	<input type="checkbox"/>
b.	Your care	<input type="checkbox"/>	<input type="checkbox"/>
c.	Your treatment	<input type="checkbox"/>	<input type="checkbox"/>
d.	Other types of support	<input type="checkbox"/>	<input type="checkbox"/>
e.	Financial issues	<input type="checkbox"/>	<input type="checkbox"/>
g.	Other (please state) <input type="text"/>		

Are there any other concerns you would like us to know about?

This form was completed by:

Patient / Carer / Professional*

*circle as appropriate

Date

FOR OFFICE USE ONLY

Why the name?

SPARC

Sheffield Profile for Assessment and Referral for Care

SPARC and national policy

- NICE guidance for cancer services 2004 – need for a sensitive ‘holistic’ assessment tool
- Cancer Peer review requirement

The network’s responsibility for review purposes, for the next two measures, lies jointly with the Chair of the network palliative care group and the network user group. Either both groups are counted as compliant or neither is compliant.

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Methods of Holistic Patient Needs Assessment

1*

The NPC group, with the network user group should agree network-wide guidelines for methods of patient assessment in relation to the following areas of potential need:

- Physical
- Psychological
- Social
- Spiritual
- Information
- Carers' needs

Compliance: The written guidelines agreed by the network palliative care group Chair, and the network user group Chair.

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Communication of Significant News

SPARC and national policy

- Cancer Action Team commissioned Kings College to identify the best assessment tools
- Richardson *et al* reported on the currently available tools in 2005
 - “...SPARC covered all the dimensions in our classification related to health status”

How well is SPARC liked by patients?

- North Trent Cancer Research Network – Supportive and Primary care Oncology Research Group (SPORG) project
 - To investigate consumers' views of SPARC

*Consumer views on a new screening tool for supportive care needs:
A survey of user groups*

- The aim of the study was to examine the views of consumers regarding SPARC used as an assessment of need for supportive care
- 99 local user groups were identified from internet searches, local directories and health service databases

*Consumer views on a new screening tool for supportive care needs:
A survey of user groups*

- 135 questionnaires were returned, representing 38 user groups
- 93% of respondents report SPARC easy to understand and fill in
- 60% found it relevant now
- 47% envisaged it relevant in the future
- 12% found some questions too sensitive

*Consumer views on a new screening tool for supportive care needs:
A survey of user groups*

Comments were analysed and five themes emerged:

- Relevant to a wide range of diagnoses
- Easy to understand
- Quick to fill in
- Relevant for professionals. But will they use it?
- Questions were 'sensitive' – but worthwhile

*Consumer views on a new screening
tool for supportive care needs:
A survey of user groups*

Key findings:

- **Relevant to many diagnoses**
- **Understandable**
- **Acceptable**

How to use SPARC scores?

- SPARC builds up a multidimensional ‘profile’ of various facets of a patient’s life
 - SPARC screens holistically for problems areas – *it does NOT give a clinical diagnosis*
 - SPARC scores are to be seen individually – *NOT to be added up for an ‘overall score’*
 - Professional response to SPARC will depend on individual scores and their chronicity – *NOT on overall scoring*

Using SPARC

- Clinicians should be made aware of scores of 1 or above, eg contact relevant clinician for advice
- Problems with scores of 1 which have lasted since the previous assessment should be treated more urgently
- Scores of 2 or 3 require early attention including detailed assessment and appropriate treatment planning, eg bring to next MDT; call to next clinic
- Requests for help with personal issues or for information should be referred to appropriate agency urgently