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ORIGINAL ARTICLE

A pilot randomised controlled trial of a holistic needs assessment questionnaire in a supportive and palliative care service.

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Abstract

Context. At present there is no widely used systematic, evidence-based holistic approach to assessment of patients' supportive and palliative care needs.

Objectives. To determine whether the use of a holistic needs assessment questionnaire, SPARC, will lead to improved health care outcomes for patients referred to a palliative care service.

Methods. Open pragmatic randomised controlled trial. 182 patients referred to the palliative care service were randomised to receive SPARC at baseline (n=87) or after a period of two weeks (waiting list control n=95). Primary outcome measure: Difference in score between MYCAW patient-nominated concern 1 on the patient self-scoring visual analogue scale at baseline and the two-week follow up. Secondary: difference in scores in the MYCAW, EQ-5D, and PEI scores at weeks 2, 4 and 6.

Results. There was a significant association between change in MYCAW score and whether the patients were in the intervention or control group (χ^2_{trend} = 5.51; df = 1; p = 0.019). A higher proportion of patients in the control group had an improvement in MYCAW score from baseline to Week 2: Control: 34/70 (48.6%) vs. Intervention: 19/66 (28.8%). There were no significant differences (no detectable effect) between the control and intervention groups in the scores for EQ5D and PEI at 2, 4, or 6 weeks follow up.

Conclusion. This trial result identifies a potential negative effect of SPARC in specialist palliative care services, raising questions that standardised holistic needs assessment questionnaires may be counter-productive if not integrated with a clinical assessment that informs the care plan.

***Key Words*:** Palliative care, holistic needs assessment questionnaire, SPARC, MYCAW, EQ5D.
Running Title: Palliative Care Holistic Needs Assessment RCT.

Abstract: 250 words

Introduction

The Sheffield Profile for Assessment and Referral for Care (SPARC) (**Appendix 1**) is a multidimensional holistic needs assessment questionnaire, designed to identify patients who may benefit from additional supportive or palliative care, regardless of diagnosis or stage of disease. SPARC is intended for use by primary care, hospital teams or other services to improve patient management, either by current professional carers or by referral to a specialist team. The patient-rated (self-complete) 45-item questionnaire reflects nine dimensions of need and as such represents a comprehensive early needs assessment or holistic questionnaire.[1] It is capable of being completed by patients unassisted, or, for those prevented by disability from reading or writing responses, with the help of their informal or professional carers.[2]. Despite rigorous psychometric development, preliminary field-testing, and validation[1,2,3,4,5,6], the clinical utility of SPARC has yet to be established, either as an aid to specialist clinical assessment or as a screening tool. [7]

There is evidence to suggest that patients with cancer and non-malignant chronic progressive illnesses can experience distressing symptoms and concerns, which may remain unrecognised.[7,8,9,10] Previous research has highlighted that distressing symptoms and concerns can be managed, provided they are identified in a timely manner and systems are in place for a prompt referral to specialist teams.[11,12,13,14,15,16] The timely identification of needs and prompt referral to specialist teams could reduce the burden of suffering and lead to earlier discharge. Similarly, earlier detection of these problems in out-patients or the community might prevent unnecessary admissions. These potential health gains might accrue for a relatively small investment.[7] However, at present there is no widely used systematic, evidence-based holistic approach to assessing patients for supportive and palliative care needs. There is a lack of studies on the clinical utility of tools.[1,7]

We conducted a pilot pragmatic, randomised, controlled trial to determine whether the use of SPARC leads to improved health care outcomes (health-related quality of life and self-identified concerns) for patients referred to a palliative care service, to guide the development of a definitive multicentre study. This study represents a development of SPARC for use as an early holistic needs assessment questionnaire within a specialist service. This study does not test the utility of SPARC as a screening questionnaire for specialist palliative care. Palliative care interventions are complex, and in light of this, the SPARC study was developed, piloted, evaluated, reported and implemented in accordance with the Medical Research Council framework for developing and evaluating complex interventions (new guidance).[17,18,19]

Methods

The trial is reported in accordance with the CONSORT 2010 statement.[20]

Trial design and recruitment

This open, randomised, controlled trial employed a waiting-list control design.[21] All patients referred to the supportive and palliative care service that met the study inclusion criteria were invited to take part in the study. Invitations to participate were sent by post (outpatients and those in the community), or given face to face (inpatients and day care patients). Patients who consented to taking part in the study were randomised to receive the SPARC questionnaire at baseline (Intervention group) or after a two-week period (Control group).

Participants

Inclusion criteria

1. Any diagnosis (cancer and non-cancer).
2. Any referral to the palliative care service in any care setting.
3. Patients 18 years old or above.
4. Patients able to give informed consent.

Exclusion criteria

1. Patients incapable of giving informed consent.
2. Patients incapable of completing SPARC even with the help of a relative or informal carer.
3. Patients under 18 years old.

Stratification

Baseline quality of life may confound response to an intervention by reversion to the mean, so patients were stratified for baseline EQ-5D thermometer score. Thus, patients completing the consent form were also asked to complete the EQ-5D thermometer (score) before randomisation. Based on previous work[22,23], the research team set the EQ-5D thermometer score at 40. Patients scoring 40 or above at baseline were placed in the median and above (MA) group, and those scoring less than 40 were placed in the below median (BM) group.

Sheffield palliative care service context and settings

Patients were recruited from the whole range of settings (in-patients, outpatients, day care and from the community) which included the two hospitals within the city, a palliative care unit, a hospice and from the community via a team of community specialist nurses. Over 2000 patients a year are referred to these services, including those with long-term conditions and cancer survivors as well as those needing end of life care.

Intervention (SPARC)

Those patients who consented were randomised to receive the SPARC questionnaire (**Table 1:** follow up procedure) at baseline (intervention group), or after a two-week waiting list period (control group). All patients received on-going care as usual. A completed paper copy of SPARC was sent to the health care professional (HCP) caring for the patient to prompt

action on needs identified by SPARC. The SPARC questionnaire data was also kept in the patients' notes and a copy was kept on the electronic clinical record. Follow-up study questionnaires were administered either face to face or by post. The 2-week point was selected as the crucial follow-up measure following baseline in order to minimize attrition.

Outcome measures

Study participants were required to complete three validated brief self-complete research outcome measures namely; the MYCAW (Measure Yourself Concerns and Wellbeing); the EQ-5D (measure of health-related quality of life) and PEI (The Patient Enablement Instrument) at baseline, week 2, week 4 and week 6 respectively **(Appendix 2).** The rationale for the choice of outcome measures is presented in **Table 2.**[24-30]

Primary outcome:

- The change in MYCAW score between the first MYCAW patient nominated concern at baseline and the two-week follow up. This is the nominated first concern.

Secondary outcomes:

- The change in scores in the EQ-5D at the two time points.
- Changes in the enablement scores (PEI) at the two time points.
- Comparisons of MYCAW patient nominated concerns, EQ-5D, and the PEI at baseline between patient groups.
- The pattern of actions taken and referrals made as a result administering the SPARC screening tool were examined by analysis of the clinical record (to be reported elsewhere).

Randomisation

A set of sequentially-numbered, opaque, sealed, A4 envelopes containing all study documents were set up for each care setting (henceforth called the study pack). The randomisation process was undertaken by a member of the study team (MW), who then identified which study packs were for the intervention arm and which were for the control arm of the study. A copy of the SPARC questionnaire (**Appendix 1**) was added to the study packs for the intervention arm and 182 patients were randomised with computer generated random numbers in pre-paid sealed envelopes to receive SPARC at baseline (n=87) or after a period of two weeks (waiting list control n=95).

Recruitment

For inpatients, and day-care patients, a health care professional informed the patient about the study and asked whether they were willing to participate in the study. Contact details of patients who indicated that they were willing to participate were then passed to a member of the study team. Community patients and outpatients were sent study packs via medical secretaries (the list of patients was first agreed with the health care professional with responsibility for the care of these patients). Upon receiving consent, the researcher (NA), who was blinded to the study collected the next sequentially-numbered, opaque, sealed

envelope and hand-delivered it to inpatients, or sent it via post to community patients and outpatients.

Statistical methods and analysis

Primary end-point analysis

The primary outcome measure was the difference in score between the patient nominated concern (MYCAW, concern 1) on the patient self-scoring visual analogue scale at baseline and the two-week follow up. Assuming the changes in the score (baseline to week 2) would be normally distributed, it was planned to carry out a *t*-test to test the null hypothesis that the difference between the intervention and control groups in the mean score on the first symptom nominated on the scale at baseline and two weeks is 0. However, because the data were not normally distributed, the Mann Whitney test was used to test for difference in the two groups in the rankings of the Week 2, 4, and 6 scores and the rankings of the change in scores from Baseline to Weeks 2, 4 and 6.

Statistical power

To detect a medium-sized difference between two independent sample means at alpha = 0.05, beta = 0.80 required a minimum of 64 individuals in each group with scores at baseline and two weeks.[31] Therefore, a total of 128 patients would have to be recruited.

The power of the study was based on the RCT with the group of patients from whom it would be possible to obtain follow up data. Differences between the control and intervention groups were tested using t-tests to compare the mean scores at Weeks 2, 4, 6, and the mean change in scores from Baseline to Week 2, 4 and 6.

Secondary and exploratory analysis

Statistical analysis of the comparisons between patient groups for the secondary outcomes involved both descriptive analyses and statistical tests. A qualitative content analysis[32, 33] of the nominated first concern and the nominated second concern was undertaken at baseline. The concerns named in MYCAW were analysed qualitatively using a summative content analysis approach. Stated concerns were examined for keywords and themes, with the context taken into account for the final interpretation. Analysis of the data from patient semi-structured interviews, health care professional interviews[34], case note reviews and from the supplementary question about patients' experience of completing SPARC will be presented elsewhere (process evaluation).

Results

Recruitment and attrition rates

A total of 850 patients were invited to take part in the study, of which 225 consented to take part (225/850=26.5% response rate), 182 patients completed baseline questionnaires, 152 completed the 2 week questionnaires, 126 completed the 4 week questionnaires, and 120 completed the 6 week questionnaires. The critical point in the analysis was the 2 week point, the point at which patients in Group A (intervention arm) had already received the SPARC intervention, and patients in Group B (control arm) had not yet received the SPARC intervention. Seven patients did not complete the trial, citing questionnaire completion and

taking part in the trial too burdensome as reasons for not continuing to take part. Two patients expressed concern around issues of data collection, and had anticipated more face-to-face contact visits as opposed to receiving postal questionnaires. At the end of the trial (eight weeks after completion of baseline questionnaires), 23 patients had died, and 159 patients were alive. There was no significant difference in the number of deaths between the intervention and control groups. In Group A (Intervention), nine people (10.3%) died within the 8-week study period and in Group B (Control), fourteen people (14.7%) died within the 8-week study period. A summary of the recruitment is presented in **Figure 1**.

Participants and settings

Baseline data

Of the 182 study participants, 84 were male (46.2%) and 98 were female (53.8%). The mean age of the participants on trial registration was 64.47 years (median = 66.00 years; SD = 12.57; minimum age = 27 years; maximum age = 90 years). There were 87 (47.8%) participants in the intervention arm (Group A), and 95 (52.2%) participants in the control arm (Group B) of the study; there was no significant difference in the partnership status of patients in Groups A vs. B. The majority of patients were married (n=118; 64.8%), and of White-British ethnicity (n=173; 95.1%). No significant differences were observed between the intervention and control groups with respect to age distribution, the gender distribution, in the baseline scores for MYCAW, EQ5D and PEI, or in any other study parameters. Demographic characteristics of participants are summarised in **Table 3**.

MYCAW: Comparison of Groups from Baseline to Week 2, Week 4 and Week 6

The mean MYCAW Concern 1 score for both groups improved over 6 weeks (**Table 4**). The overall mean change in score from baseline to Week 2 was 0.368 (median = 0; SD = 1.39). The overall mean change in score from baseline to Week 4 was 0.430 (median = 0; SD = 1.66). The overall mean change in score from baseline to Week 6 was 0.462 (median = 0; SD = 1.59). There were no significant differences (no detectable effect) between the control and intervention groups in the change in mean MYCAW 1 scores at 2, 4, or 6 weeks follow up.

There was, however, a significant difference in the rankings for the change in MYCAW Concern 1 score [baseline to Week 2] of patients in Groups A (Intervention: mean rank of patients: 61.21) and B (Control: mean rank of patients: 75.37) (Mann Whitney Z = -2.192; p = 0.028; n = 136). Overall patients in Group B (Control) showed greater improvement or less deterioration in the MYCAW score than patients in Group A (Intervention). The mean change in MYCAW Concern 1 score [baseline to Week 2] in Group A (Intervention) was 0.15 (SD = 1.32; median = 0) [a small improvement] vs. Group B (Control) was 0.57 (SD = 1.44; median = 0). When the scores for changes in MYCAW Concern 1 score for the patients were re-coded [baseline to week 2] into groups for deterioration/ no change / improvement, there was a statistically significant association between the change in MYCAW Concern 1 score and study arm (χ^2_{trend} = 5.51; *df* = 1; *p* = 0.019). A higher proportion of patients in Group B (Control: 34/70 (48.6%) had an improvement in the MYCAW Concern 1 score [baseline to Week 2] compared with patients in Group A (Intervention: 19/66 (28.8%). A

higher proportion of patients in Group A (Intervention:16/66; 24.2%) showed a deterioration in the MYCAW Concern 1 score [baseline to Week 2], compared with patients in Group B (Control: 10/70 (14.3%). A higher proportion of patients in Group B (Control:34/70; 48.6%) showed an improvement in the MYCAW Concern 1 score [baseline to Week 2], compared with patients in Group A (Intervention: 19/66 (28.8%). There was a no significant difference in the rankings for the change in MYCAW Concern 1 score from Baseline to Week 4, or from Baseline to Week 6.

MYCAW concerns at baseline

Of the 182 patients completing baseline questionnaires, 173 (173/182, 95.1%) respondents nominated and scored a primary concern and 125 (125/182, 68.7%) nominated and scored a secondary concern. For both MYCAW primary and secondary concerns physical symptoms, condition and disability predominated, but other concerns such as apprehension for themselves or others, concerns about disease progression and dying, feelings of loss of function or purpose, and on help needed are also prominent. Similarities were marked, in that for all groups, symptoms, condition and disability feature most strongly. For cancer survivors, and those receiving end of life cancer care, all concerns were named: apprehension for themselves or others; concerns related to the progression of disease; psychological concerns; concerns related to loss or existential issues; concerns about needing help; the effect on their social life; work or financial issues; and treatment effects.

EQ5D variables

Comparison of Groups from Baseline to week 2, week 4 and week 6

There were no meaningful or significant associations between any of the EQ5D domains for Groups A (Intervention) and B (Control) at baseline, Weeks 2, 4 or 6. **Table 5** shows the frequency of responses for the EQ5D domains at baseline and Weeks 2, 4 and 6. It is also worth noting that, in this analysis, the mean EQ5D scores are not changing in any significant or meaningful way.

PEI scores

Comparison of Groups from Baseline to week 2, week 4 and week 6

Table 6 shows the distribution of responses for the PEI questions at baseline and Weeks 2, 4 and 6 respectively in Groups A (Intervention) and B (Control), and in the total sample. There were no meaningful or significant associations between the PEI responses to the questions for the two groups A (Intervention) and B (Control) or in the total sample (A plus B) at any of the time points.

Discussion

The unexpected negative finding that a higher proportion of patients in the control group (34/70; 48.6%) showed an improvement in their MYCAW score from baseline to Week 2 compared with patients in the intervention group (19/66; 28.8%) ($p=0.019$*)* raises questions about the application of SPARC and possibly other holistic needs assessment questionnaires in the context of a specialist palliative care service.

No positive effect of the intervention on either the primary or secondary outcome measures was observed at two, four or six weeks, suggesting that the intervention did not have a detectable beneficial effect at any point and the difference between arms was obliterated when the control arm received SPARC.

Data that indicate that most patients felt that no particular action or benefit followed from the completion of SPARC will be reported elsewhere. There were no meaningful or significant differences between the control and intervention groups in the scores for health-related quality of life as recorded in the general measure EQ5D. This measure did not significantly change over the six weeks, as would be expected of patients attending palliative care service. However, in contrast, there appears to be improvement in the most important concern as recorded in MYCAW, this suggests that 'usual' palliative care is having a beneficial effect in this respect.

Results in context of other studies

Several other studies have examined the clinical utility of some holistic needs assessment tools. These tools include: 1) Palliative Care Assessment Tool (PACA),[35, 36] 2) The Initial Health Assessment (IHA),[37] and 3) Needs at the End of Life Screening Tool (NEST).[38] Although the studies have measured changes in clinical outcomes following needs assessment, no controlled study has demonstrated an improvement in clinical or patient reported outcomes as result of the intervention. Although many of these studies demonstrated an improvement in documentation of needs, uptake of findings and action following the assessment of needs have been described as poor, with no significant overall improvements in care outcomes. The reasons for these results are unclear but could be due to the following; inadequate power to detect a change; the tools not being comprehensive enough for holistic needs assessments; outcomes chosen may have been inappropriate; health care professionals' attitudes, knowledge or skills[39]; as well as timing of and the availability/non availability of services.[38] It is also possible that standardised needs assessments will never supplement the quality of care unless properly integrated with the clinical methods and routine care planning procedures of the clinical team. Scandrett et al, 2010[38] proposed that new methods to achieve practice change should be considered and evaluated when assessing such interventions.[7]

Limitations of the study

Our poor recruitment of patients within the hospital support service meant our study sample had fewer patients with conditions other than cancer and a smaller proportion of patients acutely ill than the whole population of patients referred to the palliative care service.

The context of a specialist palliative care service is possibly the most difficult environment to test an assessment intervention, in that the existing holistic needs assessments may be sufficient to detect all issues that require attention. The SPARC pilot trial focussed primarily on outcomes, not on the processes involved in implementing the intervention. The MRC framework requires an evaluation of the pilot study and a process evaluation is underway and

will be reported elsewhere, in order to elucidate the precise mechanism by which this result came about.

Conclusions

This trial result identifies a potential negative effect of SPARC in specialist palliative care services, raising questions that standardised holistic needs assessment questionnaires may be counter-productive if not integrated with a clinical assessment that informs the care plan. It may raise expectations that are not subsequently met.

We can, however, conclude that a larger trial with more power to detect an effect is highly unlikely to be positive. A larger trial in specialist outpatient or home care services, employing the same design and outcome measures is unlikely to demonstrate any benefit.

It is nevertheless possible that SPARC has utility for the original purpose for which it was designed, as a screening tool, in primary care or general medical care for selection of patients who may benefit from a referral to specialist palliative care. It is also possible that were SPARC to be included, in the routine clinical assessment that informs a care plan within a specialist service then immediate benefit might follow within an effective supportive or palliative care service.

Disclosures and Acknowledgements

This work was undertaken as part of a doctoral study and is written by NA. The co-authors made suggestions for improvement to the paper. The development of SPARC was previously funded by the Elizabeth Clark Charitable Trust.[4] The authors were part of a team that were involved with the development of SPARC. [2,4,7,8]

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Table 1 Follow up procedure

baseline	**Randomisation**	
	Group A **intervention group** MYCAW; EQ-5D; PEI **SPARC**	**Group B** **waiting–list control** (waiting list) MYCAW; EQ-5D; PEI
2 weeks	MYCAW; EQ-5D; PEI Invitation for patient interview	MYCAW; EQ-5D; PEI; **SPARC**
4 weeks	MYCAW; EQ-5D; PEI plus supplementary question on experience of completing the SPARC	MYCAW; EQ-5D; PEI Invitation for patient interview
6 weeks	MYCAW; EQ-5D; PEI	MYCAW; EQ-5D; PEI plus supplementary question on experience of completing the SPARC
8 weeks	Case Note Reviews Semi-Structured Interviews with Patients Semi-Structured Interviews with Health Care Professionals	

SPARC: *Sheffield Profile for Assessment and Referral for Care*
MYCAW: *Measure Yourself Concerns and Wellbeing*
EQ-5D: *Standardised outcome measure of Health Related Quality of Life*
PEI: *Patient Enablement Instrument*

Figure 1 Summary of recruitment for the SPARC trial

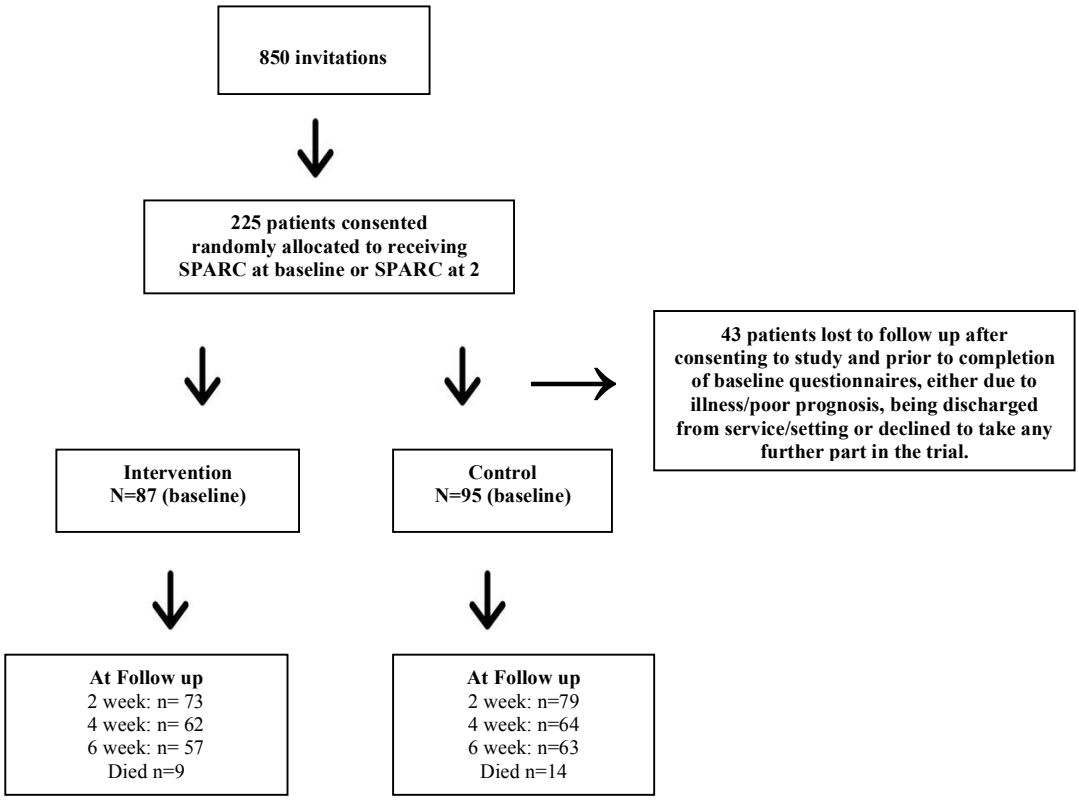


Figure 1: Summary of recruitment for the SPARC trial

There was no significant difference in the number of deaths between the intervention and control groups. In Group A (Intervention), nine people (10.3%) died within the 8-week study period and in Group B (Control), 14 people (14.7%) died within the 8-week study period ($\chi^2 = 0.445; df = 1; p = 0.504$).

Table 2 Research questionnaires: Rationale for choice of outcome measures

MYMOP **(Measure Yourself Medical Outcomes Profile)**	**MYCAW** **(Measure Yourself Concerns and Wellbeing)** Slightly modified version of MYCAW used	**EQ-5D** **(Health-related quality of life outcome measure)**	**PEI** **(Patient Enablement Instrument)** Slightly modified version of PEI used
▪ A precursor of MYCAW. ▪ Demonstrated sensitivity to change. ▪ Used in a range of contexts. ▪ Patient self-complete, outcome questionnaire, problem-specific (includes general wellbeing). ▪ Applicable to all symptomatic patients. ▪ Brief and simple questionnaire to administer. ▪ MYCAW used in preference to MYMOP because concerns raised could be of any kind, and not restricted to symptoms or activity (may be of significance when comparing the information from the three groups: cancer survivors, people with long term conditions and people needing end-of-life care). ▪ For the purposes of this study it was important to use an outcome measure which covered the diversity in the patient group. ▪ A slightly modified version of MYCAW was used (the sentence "*Please write down one or two concerns or problems which you would most like us to help you with*" was replaced with "*Please write down one or two concerns or problems that bother you most*"). ***References*** **24,25,26**	▪ Developed from a validated tool MYMOP, simple to use and sensitive enough to show any changes with time. ▪ Patients nominate concerns, which may or may not be medical (MYCAW) or symptoms (MYMOP) of importance to them (two concerns/symptoms can be identified). ▪ They then score these on a scale of 0 (not bothering me at all) - 6 (bothers me greatly). ▪ Patients are also asked to rate their general feeling of wellbeing on a scale of 0 (as good as it could be) - 6 (as bad as it could be). ▪ The follow-up form asks patients to re-score the concerns/symptoms, and rate their general feeling of wellbeing they previously nominated, thus capturing any changes over time that are important to the patient. ▪ However, HRQoL may not be sensitive enough to changes in the short term, possibly because people adjust their expectations. ▪ Work by Guyatt et al (1998) indicates that in seven-point scales of this kind, a shift of one point corresponds to a moderately important change for a patient. ▪ Is an additional element of needs assessment, stated concerns, are truly patient generated, reflecting an accurate expression of need at that time. ***References*** **25,26,27**	▪ Outcome measure of health-related quality of life. ▪ Patient self-complete. ▪ Five questions (3 varying response categories): on mobility, self-care, usual activities (e.g. work, study, housework, family, or leisure activities), pain/discomfort and anxiety/depression. ▪ A further question (EQ-5D thermometer scale) asks people to mark their current health status on a scale of 0 (worst imaginable health state)-100 (best imaginable health state). ▪ Used extensively in studies where quality of life is compared between patient groups. ***References*** **23,28**	▪ Outcome measure of a patient's ability to cope with life and their illness and the confidence and ability to help themselves (as a result of visiting a doctor or health professional). ▪ Patient self-complete. ▪ One main question "*thinking about the last time you saw a doctor or nurse from palliative care, do you feel you are*:...(6 sub-questions with 4 varying response categories). ▪ Studies in general practice to assess quality of consultations using PEI, have shown it to be a crucial outcome measure, with enablement correlating best with the length of consultation and how well the patient knew the doctor. ▪ PEI scores consultations in cancer clinics, independently of quality of life and scores higher when sufficient time is allocated or when staff have communication skills training (our own unpublished work). ▪ PEI may detect an effect of SPARC (if any) on the quality of subsequent consultations with the clinical team. ▪ A measure of consultation quality was included in order to detect an effect on communication between patients and professionals. However, we overestimated the intensity of contact between patients and professionals and palliative care services in the duration of this trial. ***References*** **29,30**

Table 3: Information relating to baseline demographic characteristics of participants in Group A (Intervention), Group B (Control) and in Total Sample (A plus B).

Characteristic	Intervention Group A n, (%)	Control Group B n, (%)	All patients, n	Notes A vs B *p*
Age (mean age in years) on registration	63.90 years (median = 65.00 years; SD = 11.68; minimum age = 28 years; maximum age = 87 years).	64.99 years (median = 67.00 years; SD = 13.34; minimum age = 27 years; maximum age = 90 years).	64.47 years (median = 66.00 years; SD = 12.57; minimum age = 27 years; maximum age = 90 years).	No significant difference (Mann-Whitney Z = -0.865; p = 0.387).
Gender				No significant difference ($\chi^2 = 1.183; df = 1; p = 0.277$).
Male	36 (41.4%)	48 (50.5%)	84 (46.2%)	
Female	51 (58.6%)	47 (49.5%)	98 (53.8%)	
Total	87 (47.8%)	95 (52.2%)	182	
Partnership / Marital status				No significant difference ($\chi^2 = 1.706; df = 3; p = 0.636$). The majority of patients were married (n=118; 64.8%).
Married	56 (64.4)	62 (65.3)	118 (64.8)	
Single	10 (11.5)	7 (7.5)	17 (9.5)	
Divorced/parted/separated	5 (5.8)	9 (.7)	14 (7.8)	
Widowed	15 (17.4)	15 (16.1)	30 (16.8)	
Total	86 (100)	93 (100)	179 (100) Unknown: 3 (……)	
Ethnicity				
White – British	83 (95.4)	90 (94.7)	173 (95.1)	The low numbers in many of the groups meant that it was not possible to test for differences.
White – other background	2 (2.3)	0 (-)	2 (1.1)	
Black or Black British Caribbean	1 (1.1)	0 (-)	1 (0.5)	
Asian or Asian British-Indian	0 (-)	1 (1.1)	1 (0.5)	
Information withheld/not documented	1 (1.1)	4 (4.2)	5 (2.7)	
Total	87 (100)	95 (100)	182 (100)	
Living arrangements				The majority of patients were living at home (n=177; 97.3%), three patients were living in a care or nursing home (1.6%), and for two patients (1.1%) it was not known where they were living.
Home	83 (96.5)	94 (100)	177 (98.3)	
Care home/nursing home	3 (3.5)	0 (-)	3 (1.7)	
Total	86 (100)	94 (100)	180 (100)	
Patient lives alone				No significant difference in the proportions of patients living alone ($\chi^2 = 0.020; df = 1; p = 0.887$).
Living alone	15 /73 (20.5%)	20/88 (22.7%)	35 (19.2%)	
Religion				The majority of the patients (n=115; 63.2%) gave their religious denomination as Church of England.
Church of England	56 (64.4)	59 (62.1)	115 (63.2)	
Roman Catholic	6 (6.9)	5 (5.3)	11 (6.0)	
Christian	5 (5.7)	7 (7.4)	12 (6.6)	
Jewish	2 (2.3)	2 (2.1)	4 (2.2)	
Methodist	3 (3.4)	4 (4.2)	7 (3.8)	
Protestant	1 (1.1)	1 (1.1)	2 (1.1)	
Humanist	1 (1.1)	0 (-)	1 (0.5)	
Anglican	1 (1.1)	0 (-)	1 (0.5)	
Agnostic	0 (-)	2 (2.1)	2 (1.1)	
Quaker	1 (1.1)	2 (2.1)	3 (1.6)	
Church of Scotland	1 (1.1)	0 (-)	1 (0.5)	
None	10 (11.5)	13 (13.7)	23 (12.6)	
Total	87 (100)	95 (100)	182 (100)	

Table 4 Shows the distribution of scores for MYCAW concern 1 at baseline and at 2, 4 and 6-week follow-up in Group A (Intervention), Group B (Control) and for the Total Sample (Group A plus Group B).

MYCAW Concern 1 score	n (%)											
	Baseline			Week 2			Week 4			Week 6		
	A	B	Total	A	B	Total	A	B	Total	A	B	Total
0	2 (2.5)	3 (3.2)	5 (2.9)	2 (2.9)	2 (2.9)	4 (2.9)	3 (5.1)	6 (10.0)	9 (7.6)	2 (3.6)	3 (5.6)	5 (4.6)
1	1 (1.2)	4 (4.3)	5 (2.9)	1 (1.4)	8 (11.4)	9 (6.5)	2 (3.4)	3 (5.0)	5 (4.2)	3 (5.5)	4 (7.4)	7 (6.4)
2	6 (7.4)	6 (6.5)	12 (6.9)	6 (8.7)	11 (15.7)	17 (12.2)	4 (6.8)	4 (6.7)	8 (6.7)	4 (7.3)	4 (7.4)	8 (7.3)
3	7 (8.6)	9 (9.7)	16 (9.2)	14 (20.3)	11 (15.7)	25 (18.0)	9 (15.3)	10 (16.7)	19 (16.0)	11 (20.0)	11 (20.4)	22 (20.2)
4	20 (24.7)	20 (21.5)	40 (23.0)	13 (18.8)	11 (15.7)	24 (17.3)	14 (23.7)	14 (23.3)	28 (23.5)	9 (16.4)	15 (27.8)	24 (22.0)
5	19 (23.5)	21 (22.6)	40 (23.0)	16 (23.2)	11 (15.7)	27 (19.4)	11 (18.6)	13 (21.7)	24 (20.2)	10 (18.2)	7 (13.0)	17 (15.6)
6	26 (32.1)	30 (32.3)	56 (32.2)	17 (24.6)	16 (22.9)	33 (23.7)	16 (27.1)	10 (16.7)	26 (21.8)	16 (29.1)	10 (18.5)	26 (23.9)
Total	81 (100)	93 (100)	174 (100)	69 (100)	70 (100)	139 (100)	59 (100)	60 (100)	119 (100)	55 (100)	54 (100)	109 (100)

Table 5 Frequency of EQ5D responses in Groups A (Intervention) and B (Control) and Total Sample (A plus B) at Baseline, Weeks 2, 4 and 6.

Domain	**Response n (%)**	**Baseline**			**Week 2**			**Week 4**			**Week 6**		
Group		A	B	Total	A	B	Total	A	B	Total	A	B	Total
Mobility	I have no problems in walking about	13 (15.7)	9 (9.5)	22 (12.4)	11 (15.1)	10 (13.0)	21 (14.0)	10 (16.9)	8 (12.5)	18 (14.6)	8 (14.3)	5 (7.9)	13 (10.9)
	I have some problems in walking about	66 (79.5)	85 (89.5)	151 (84.8)	60 (82.2)	64 (83.1)	124 (82.7)	48 (81.4)	53 (82.8)	101 (82.1)	45 (80.4)	56 (88.9)	101 (55.5)
	I am confined to bed	4 (4.8)	1 (1.1)	5 (2.8)	2 (2.7)	3 (3.9)	5 (3.3)	1 (1.7)	3 (4.7)	4 (3.3)	3 (5.4)	2 (3.2)	5 (2.7)
	Total	83 (100)	95 (100)	178 (100)	73 (100)	77 (100)	150 (100)	59 (100)	64 (100)	123 (100)	56 (100)	63 (100)	119 (100)
Self-care	I have no problems with self care	43 (53.1)	43 (45.3)	86 (48.9)	37 (51.4)	36 (46.8)	73 (49.0)	34 (57.6)	28 (44.4)	62 (50.8)	31 (55.4)	27 (42.9)	58 (48.7)
	I have some problems washing or dressing myself	33 (40.7)	48 (50.5)	81 (46.0)	31 (43.1)	36 (46.8)	67 (45.0)	22 (37.3)	33 (52.4)	55 (45.1)	20 (35.7)	33 (52.4)	53 (44.5)
	I am unable to wash or dress myself	5 (6.2)	4 (4.2)	9 (5.1)	4 95.6)	5 (6.5)	9 (6.0)	3 (5.1)	2 (3.2)	5 (4.1)	5 (8.9)	3 (4.8)	8 (6.7)
	Total	81 (100)	95 (100)	176 (100)	72 (100)	77 (100)	149 (100)	59 (100)	63 (100)	122 (100)	56 (100)	63 (100)	119 (100)
Usual Activities	I have no problems with performing my usual activities	7 (8.4)	6 (6.5)	13 (7.4)	7 (9.7)	8 (10.3)	15 (10.0)	3 (5.1)	8 (12.5)	11 (8.9)	4 (7.4)	7 (11.1)	11 (9.4)
	I have some problems with performing my usual activities	54 (65.1)	59 (63.4)	113 (64.2)	46 (63.9)	49 (62.8)	95 (63.3)	40 (67.8)	38 (59.4)	78 (63.4)	31 (57.4)	40 (63.5)	71 (60.7)
	I am unable to perform my usual activities	22 (26.5)	28 (30.1)	20 (28.4)	19 (26.4)	21 (26.9)	40 (26.7)	16 (27.1)	18 (28.1)	34 (27.6)	19 (35.2)	16 (25.4)	35 (29.9)
	Total	83 (100)	93 (100)	176 (100)	72 (100)	78 (100)	150 (100)	59 (100)	64 (100)	123 (100)	54 (100)	63 (100)	117 (100)
Pain /discomfort	I have no pain or discomfort	11 (13.3)	9 (9.8)	20 (11.4)	9 (12.5)	10 (13.2)	19 (12.8)	6 (10.3)	3 (4.8)	9 (7.5)	8 (14.8)	4 (6.6)	12 (10.4)
	I have moderate pain or discomfort	59 (71.1)	72 (78.3)	131 (74.9)	55 (76.4)	55 (72.4)	110 (74.3)	44 (75.9)	54 (87.1)	98 (81.7)	34 (63.0)	53 (86.9)	87 (75.7)
	I have extreme pain or discomfort	13 (15.7)	11 (12.0)	24 (13.7)	8 (11.1)	11 (14.5)	19 (12.8)	8 (13.8)	5 (8.1)	13 (10.8)	12 (22.2)	4 (6.6)	16 (13.9)
	Total	83 (100)	92 (100)	175 (100)	72 (100)	76 (100)	148 (100)	58 (100)	62 (100)	120 (100)	54 (100)	61 (100)	35 (29.9)
Anxiety / depression	I am not anxious or depressed	34 (42.0)	29 (31.9)	63 (36.6)	31 (43.1)	23 (29.9)	54 (36.2)	23 (40.4)	18 (29.0)	41 (34.5)	19 (34.5)	23 (37.7)	42 (36.2)
	I am moderately anxious or depressed	42 (51.9)	55 (60.4)	97(56.4)	37 (51.4)	52 (67.5)	89 (59.7)	31 (54.4)	41 (66.1)	72 (60.5)	29 (52.7)	34 (55.7)	63 (54.3)
	I am extremely anxious or depressed	5 (6.2)	7 (7.7)	12 (7.0)	4 (5.6)	2 (2.6)	6 (4.0)	3 (5.3)	3 (4.8)	6 (5.0)	7 (12.7)	4 (6.6)	11 (9.5)
	Total	81 (100)	91 (100)	172 (100)	72 (100)	77 (100)	149 (100)	57 (100)	62 (100)	119 (100)	55 (100)	61 (100)	116 (100)

Table 6 There were no meaningful or significant associations between the PEI responses to the questions and the two groups A (Intervention) and B (Control) and in the total sample at baseline, week 2, week 4, or week 6 respectively.

Question	Response n (%)	Baseline				Week 2				Week 4				Week 6			
		Group A (Intervention)	Group B (Control)	Total	*P* value	Group A (Intervention)	Group B (Control)	Total	*P* value	Group A (Intervention)	Group B (Control)	Total	*P* value	Group A (Intervention)	Group B (Control)	Total	*P* value
Able to cope with life	Much better	8 (10.0)	8 (9.0)	16 (9.5)	0.301	4 (5.8)	9 (12.7)	13 (9.3)	0.693	1 (1.9)	1 (1.8)	2 (1.8)	0.781	2 (3.8)	6 (10.3)	8 (7.3)	0.607
	Better	32 (40.0)	28 (31.5)	60 (35.5)		22 (31.9)	16 (22.5)	38 (27.1)		19 (35.8)	19 (33.3)	38 (34.5)		17 (32.7)	15 (25.9)	32 (29.1)	
	Same or less	40 (50.0)	53 (59.6)	93 (55.0)		43 (62.3)	46 (64.8)	89 (63.6)		33 (62.3)	37 (64.9)	70 (63.6)		33 (63.5)	37 (63.8)	70 (63.6)	
	Total	80 (100)	89 (100)	169 (100) +2 (1.1) Not Applicable		69 (100)	71 (100)	140 (100) + 2 (1.4) Not Applicable		53 (100)	57 (100)	110 (100) +5 (4.3) Not Applicable		52 (100)	58 (100)	110 (100) +3 (2.7) Not Applicable	
Able to understand your illness	Much better	8 (10.8)	14 (15.9)	22 (13.6)	0.662	4 (6.3)	9 (13.0)	13 (13.8)	0.481	2 (3.8)	4 (7.1)	6 (5.5)	0.676	4 (8.0)	6 (10.3)	10 (9.3)	0.346
	Better	30 (40.5)	31 (35.2)	61 (37.7)		22 (34.4)	20 (29.0)	42 (31.6)		19 (35.8)	19 (33.9)	38 (34.9)		11 (22.0)	17 (29.3)	28 (25.9)	
	Same or less	36 (48.6)	43 (48.9)	79 (48.8)		38 (59.4)	40 (58.0)	78 (58.6)		32 (60.4)	33 (58.9)	65 (59.6)		35 (70.0)	35 (60.3)	70 964.8)	
	Total	74 (100)	88 (100)	162 (100) +5 (2.7) Not Applicable		64 (100)	69 (100)	133 (100) +8 (5.7) Not Applicable		53 (100)	56 (100)	109 (100) +7 (6.0) Not Applicable		50 (100)	58 (100)	109 (100) +4 (3.6) Not Applicable	
Able to cope with your illness	Much better	6 (7.8)	9 (10.0)	15 (9.0)	0.835	2 (3.0)	7 (10.1)	9 (6.6)	0.989	1 (1.9)	3 (5.1)	4 (3.6)	0.995	3 (5.9)	5 (8.5)	8 (7.3)	0.884
	Better	30 (39.0)	33 (36.7)	63 (37.7)		26 (38.8)	17 (24.6)	43 (31.6)		16 (30.2)	14 (23.7)	30 (26.8)		13 (25.5)	13 (22.0)	26 (23.6)	
	Same or less	41 (53.2)	48 (53.3)	89 (53.3)		39 (58.2)	45 (65.2)	84 (61.8)		36 (67.9)	42 (71.2)	78 (69.6)		35 (68.6)	41 (69.5)	76 (69.1)	
	Total	77 (100)	90 (100)	167 (100) +3 (1.6) Not Applicable		67 (100)	69 (100)	136 (100) +6 (4.2) Not Applicable		53 (100)	59 (100)	112 (100) +4 (3.4) Not Applicable		51 (100)	59 (100)	110 (100) +3 (2.7) Not Applicable	
Able to keep yourself healthy	Much Better	5 (7.1)	6 (7.1)	11 (7.1)	0.721	3 (4.8)	9 (14.1)	12 (9.4)	0.939	2 (3.8)	3 (5.6)	5 (4.7)	0.948	2 (4.1)	5 (8.9)	7 (6.7)	0.446
	Better	23 (32.9)	25 (29.4)	48 (31.0)		21 (33.3)	10 (15.6)	31 (24.4)		12 (23.1)	11 (20.4)	23 (21.7)		10 (20.4)	11 (19.6)	21 (20)	
	Same or less	42 (60.0)	54 (63.5)	96 (61.9)		39 (61.9)	45 (70.3)	84 (66.1)		38 (73.1)	40 (74.1)	78 (73.6)		37 (75.5)	40 (71.4)	77 (73.3)	
	Total	70 (100)	85 (100)	155 (100) +9 (5.5) Not Applicable		63 (100)	64 (100)	127 (100) +13 (9.3) Not Applicable		52 (100)	54 (100)	106 (100) +9 (7.8) Not Applicable		49 (100)	56 (100)	105 (100) +7 (6.3) Not Applicable	
Confident about your health	Much More	2 (2.7)	3 (3.4)	5 (3.1)	0.687	3 (4.5)	5 (7.0)	8 (5.8)	0.507	1 (2.0)	1 (1.7)	2 (1.8)	0.445	2 (4.0)	3 (5.2)	5 (4.6)	0.319
	More	19 (25.7)	24 (27.6)	43 (26.7)		12 (18.2)	14 (19.7)	26 (19.0)		9 (17.6)	7 (11.9)	16 (14.5)		4 (8.0)	9 (15.5)	13 (12.0)	
	Same or less	53 (71.6)	60 (69.0)	113 (70.2)		51 (77.3)	52 (73.2)	103 (75.2)		41 (80.4)	51 (86.4)	92 (83.6)		44 (88.0)	46 (79.3)	90 (83.3)	
	Total	74 (100)	87 (100)	161 (100) +7 (4.2) Not Applicable		66 (100)	71 (100)	137 (100) +6 (4.2) Not Applicable		51 (100)	59 (100)	110 (100) +5 (4.3) Not Applicable		50 (100)	58 (100)	108 (100) +5 (4.4) Not Applicable	
Able to help yourself	Much More	7 (9.6)	8 (9.2)	15 (9.4)	0.365	3 (4.5)	5 (6.9)	8 (5.8)	0.305	4 (7.0)	0 (-)	4 (3.6)	0.088	3 (6.3)	3 (5.2)	6 (5.7)	0.625
	More	24 (32.9)	21 (24.1)	58 (66.7)		20 (30.3)	11 (15.3)	31 (22.5)		8 (15.1)	8 (14.0)	16 (14.5)		9 (18.8)	9 (15.5)	18 (17.0)	
	Same or less	42 (57.5)	58 (66.7)	100 (62.5)		43 (65.2)	56 (77.8)	99 (71.7)		41 (77.4)	49 (86.0)	90 (81.8)		36 (75.0)	46 (79.3)	82 (77.4)	
	Total	73 (100)	87 (100)	160 (100) +8 (4.8) Not Applicable		66 (100)	72 (100)	138 (100) +4 (2.8) Not Applicable		53 (100)	57 (100)	110 (100) +5 (4.3) Not Applicable		48 (100)	58 (100)	106 (100) +6 (5.4) Not Applicable	

Appendix 1
SPARC

We would like to know a bit more about you and your concerns. Please fill in the questionnaire overleaf (with help from a relative or carer if needed) and return it with the study questionnaire booklet. There are no “right” or “wrong” answers. If you are unsure of a question, please leave it blank.

THANK YOU.

SPARC*

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	☐	☐
b. Community nurse	☐	☐
c. Hospital nurse	☐	☐
d. Religious advisor	☐	☐
e. Social worker	☐	☐
f. Family	☐	☐
g. Other people (please state)		

PHYSICAL SYMPTOMS

Please circle one answer per line

In the past month have you been distressed or bothered by	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
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

*Sheffield Profile for Assessment and Referral to Care

RELIGIOUS AND SPIRITUAL ISSUES		Please circle one answer per line			
		Not at all	A little bit	Quite a bit	Very much
In the past month have you been distressed or bothered by					
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					
In the past month have you been distressed or bothered by					
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					
In the past month have you been distressed or bothered by					
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

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?	☐	☐
44.	Would you like to talk to another professional about your condition or treatment?	☐	☐
45.	**Would you like any more information about the following?**		
a.	Your condition	☐	☐
b.	Your care	☐	☐
c.	Your treatment	☐	☐
d.	Other types of support	☐	☐
e.	Financial issues	☐	☐
f.	Other (please state)		

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

This form was completed by:
Name [Please print]

Patient / Carer / Professional*

*circle as appropriate

Date

FOR OFFICE USE ONLY

Thank you for completing this form.

Please return in the stamped addressed envelope [free post] to:

Mr Nisar Ahmed/Dr Bill Noble

Trent Palliative Care Centre

FREEPOST SF 1605

Sheffield

S11 8TE

Appendix 2 Questionnaire Booklet

Academic Unit of Supportive Care

Sykes House
Little Common Lane
Sheffield
S11 9NE
Tel: 0114 262 0174 ext 28

Dr Bill Noble
Macmillan Senior
Lecturer in Palliative Medicine
email: m.winslow@sheffield.ac.uk
email: n.ahmed@sheffield.ac.uk

Questionnaire

Short Title: A Feasibility Study of SPARC: a holistic needs assessment questionnaire.

Thank you for agreeing to help us with our research. Please complete the study questionnaire booklet. Further questionnaires will be sent to you after two weeks, four weeks and six weeks.

Could you please -

1. Complete the questionnaires for yourself, or you can complete them with the help of a family member, friend or carer.
2. Return the questionnaires in the enclosed pre-paid (freepost) envelope.

Thank you for your help

Appendix 2 Questionnaire Booklet

Measure Yourself Concerns and Wellbeing (MYCAW)

First form

Full name..... Date of birth .....

Date first completed .....

Please write down one or two concerns or problems that bother you most.

Concern or problem 1

Concern or problem 2

Please turn over

Appendix 2 Questionnaire Booklet

Please circle a number to show how severe each concern or problem is now:

This should be YOUR opinion, no-one else's!

Concern or problem 1:

0	**1**	**2**	**3**	**4**	**5**	**6**
Not bothering me at all						bothers me greatly

Concern or problem 2:

0	**1**	**2**	**3**	**4**	**5**	**6**
Not bothering me at all						bothers me greatly

Wellbeing:

How would you rate your general feeling of wellbeing now? (How do you feel in yourself?)

0	**1**	**2**	**3**	**4**	**5**	**6**
As good as it could be						As bad as it could be

Appendix 2 Questionnaire Booklet

Health Questionnaire *English version for the UK (validated for Ireland)*

By placing a tick in one box in each group below, please indicate which statements best describe your own health state today.

Mobility

I have no problems in walking about	❑
I have some problems in walking about	❑
I am confined to bed	❑

Self-Care

I have no problems with self-care	❑
I have some problems washing or dressing myself	❑
I am unable to wash or dress myself	❑

Usual Activities (*e.g. work, study, housework, family or leisure activities)*

I have no problems with performing my usual activities	❑
I have some problems with performing my usual activities	❑
I am unable to perform my usual activities	❑

Pain/Discomfort

I have no pain or discomfort	❑
I have moderate pain or discomfort	❑
I have extreme pain or discomfort	❑

Anxiety/Depression

I am not anxious or depressed	❑
I am moderately anxious or depressed	❑
I am extremely anxious or depressed	❑

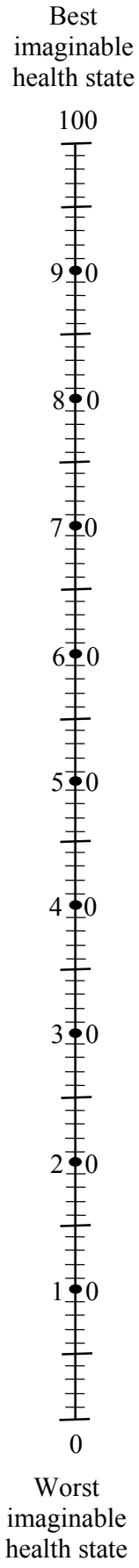
Please turn over

Appendix 2 Questionnaire Booklet

To help people say how good or bad a health state is, we have drawn a scale (rather like a thermometer) on which the best state you can imagine is marked 100 and the worst state you can imagine is marked 0.

We would like you to indicate on this scale how good or bad your own health is today, in your opinion. Please do this by drawing a line from the box below to whichever point on the scale indicates how good or bad your health state is today.

Your own health state today



Appendix 2 Questionnaire Booklet

The Patient Enablement Instrument

Thinking about the last time you saw a doctor or nurse from palliative care, do you feel you are:

	Much better	Better	Same or less	Not applicable
able to cope with life?				
able to understand your illness?				
able to cope with your illness?				
able to keep yourself healthy?				

	Much more	More	Same or less	Not applicable
confident about your health?				
able to help yourself?				

Please turn over

Appendix 2 Questionnaire Booklet

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Sheffield
S11 8TE