## Transforming Care After Treatment

# NHS Lanarkshire's Lung Cancer Project Evaluation

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Final Version
1st August 2017

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# Executive Summary

**Background:** The NHS Lanarkshire Lung Cancer Project is part of the Transforming Care after Treatment programme, a partnership between the Scottish Government, Macmillan Cancer Support, NHS Scotland and local authorities. It aims to explore new ways of working to redesign care after treatment for cancer. Lung cancer is the most common cancer within Lanarkshire. More people are being diagnosed and living with lung cancer but it continues to have a poor prognosis. It is therefore essential that all patient needs, not just medical are appropriately addressed.

This is an evaluation of a two year project aiming to influence changes in follow up care for lung cancer patients through the testing of digital health technology. The statistics in this report are the results of a self-evaluation carried out by local project staff in collaboration with Edinburgh Napier University TCAT Evaluation Team. The views expressed in this report do not necessarily represent those of Edinburgh Napier University or Macmillan Cancer Support.

**Methodology:** The Sheffield Profile of Referral and Assessment of Care (SPARC) was selected to support patients to identify their needs. The SPARC contains 45 items which are scored by the patient as 0 - not at all, 1 - a little bit, 2 - quite a bit, and 3 - very much depending on level of need. This was developed onto an online platform, Docobo-WEB by telehealth providers Docobo, allowing patients' to access the assessment on any day between 6am and 11pm from a mobile phone, tablet, laptop or personal computer. Patients were offered six monthly SPARC assessments to identify unmet need and review from a lung cancer clinical nurse specialist with the provision of a personalised care plan and access to self management information.

To support the evaluation of the project patients were asked to complete a Functional Assessment of Cancer Therapy – Lung (FACT-L), Memorial Symptoms Assessment Scale (MSAS) and Supportive Care Needs Survey Long-Form 59 (SCNS) prior to their first and after their third and sixth SPARC questionnaire. A patient experience questionnaire was also provided on completion of their sixth assessment.

**Results:** 275 patients were eligible and invited to participate in the project of which 21% (n = 58) agreed. 248 eSPARC questionnaires were completed identifying 3396 concerns. Only

47% of patients completing a full six assessments and the number of concerns appeared to plateau after the third assessment leading to the suggestion that six monthly assessments are not required by most patients.

Patients were offered a telephone or face to face consultation. The majority of patients opted for a telephone consultation (88%). This appeared to be the most time effective method for consultation taking only on average 20 minutes compared to an average of 48 minutes for a face to face consultation.

71% of participants completed a patient experience questionnaire. Overall patient satisfaction in the project was high with 90% rating the service as excellent and 10% rating it as good. Data analysis for 26 patients' who had completed 3 FACT-L, MSAS and SCNS questionnaires was provided by Edinburgh Napier University. Across these questionnaires a statistically significant reduction in symptom burden, psychological distress and care needs was demonstrated with a statistically significant improvement in quality of life.

**Recommendations:** This e-health model of care is acceptable to patients, time efficient and clinically effective; however, it was tested on a relatively small number of patients. Further testing is therefore recommended on the wider cancer population to understand the true impact of this model of working.

An application has been made for a year's TCAT Phase three funding to support the NHS Lanarkshire electronic-Cancer Nursing (e-CaN) project. This will see the project continue with lung cancer patients and extend to head and neck, urology and breast cancer patients (n = 2361). In line with the findings of the project patients will be offered an electronic SPARC questionnaire around the time of diagnosis and following treatment a telephone consultation from a cancer nurse specialist and the provision of a personalised care plan. NHS Lanarkshire will support a test in change by providing a health care support worker to be trained to undertake this role under the supervision of the cancer nurse specialist.

# Section1:  Introduction

## 1.1 Introduction

This report outlines the evaluation of NHS Lanarkshire's (NHSL) two year lung cancer project that aims to influence changes in follow up for patients with lung cancer through the testing of digital health technology.

It is one of eleven phase one Transforming Care After Treatment (TCAT) projects within Scotland and is part of the wider TCAT programme.  The TCAT programme was launched in June 2013 with five years funding from Macmillan Cancer Support.  Through partnership working between the Scottish Government, Macmillan Cancer Support, NHS Scotland and local authorities it aims to influence the redesign of care following active treatment for cancer (Scottish Government 2016a).

Lung cancer is the most common cancer within Lanarkshire.  In light of an aging population, developments in diagnostics and advances in treatment options, it is anticipated that the incidence of lung cancer will rise in coming years (Aung & Clark 2011).  Lung cancer continues to have one of the lowest cancer survival rates in Scotland due to nearly half of people being diagnosed in the later stages, with only a third of people surviving more than a year after diagnosis (Cancer Research UK 2016).  Follow up care is therefore concentrated in the first two years following treatment and it is essential that all needs, not just medical, are addressed appropriately.  Currently in NHSL lung cancer patients are offered a standard follow up appointment 6 weeks post treatment.  They then have routine quarterly, biannual or annual medical follow up for up to 5 years.

Although patients attend for routine follow up, a report from Macmillan Cancer Support suggests that a third of all cancer patients have unmet needs that continue to be a concern for over half of these patients six months post treatment (Rowe et al 2014).  The Scottish Cancer Patient Experience Survey found that only 26% of cancer patients in Lanarkshire have been provided with a personalised care plan and only 41% of patients felt supported by their health and social care teams after treatment (Scottish Government 2016b).  This indicates that the traditional medical model of follow up does not sufficiently identify all of the patients' needs and that gaps in care still exist.

To bridge this gap and improve patient outcomes the Scottish Government set out in its Beating Cancer:  Ambition and Action paper (2016c), that following treatment all patients should have a holistic care needs assessment, personalised care plan and treatment summary. This is in alignment with the components of the TCAT programme (Box 1) with at least one component to be explored in each TCAT project (Cruickshank et al 2016).

- Holistic care needs assessment
- End of treatment summaries
- Cancer care review
- Health and well-being events
- Risk stratified follow-up care

(Box 1 – TCAT components)

The changes occurring within cancer care are set in the wider context of an evolving health care system.  The Scottish Government shared their vision for the development and delivery of e-Health within NHS Scotland in their e-Health Strategy (2015).   Similarities exist in their vision and that of the TCAT programme.  Both aim to support patients to self manage their condition, live healthier lives at home rather than hospital and promote joint working and information sharing between health and social care partnerships.  Therefore it seems advantageous to consider a transformational project that embraced the aims of both of these visions.

## 1.2 Background & Aims

The South Lanarkshire Lung Cancer project was launched on 1st March 2016 and evaluated until the 31st March 2017.  The team consisted of two staff members; a project manager and lung cancer clinical nurse specialist (LCNS) who were in post from November 2016 until August 2017.  The aim of the project was to test the use of electronic patient reported outcomes measures (PROM), a form of holistic care needs assessment, to support patients following the completion of treatment.

The PROM selected for the project was the Sheffield Profile of Assessment and Referral of Care (SPARC) (Appendix I).  It was selected following multiple feasibility studies within NHS Lanarkshire exploring the use of PROM’s in the delivery of supportive care to cancer patients (Maguire et al 2013a, Maguire et al 2013b, Maguire et al 2015a, Maguire et al

2015b, Kotronoulas et 2017a, Kotronoulas et 2017b, Kotronoulas et 2017c, Kotronoulas et 2017d, Kotronoulas et 2017e, Kotronoulas et 2017f, Maguire et al 2017). The SPARC tool was deemed to be the preferred PROM by both lung cancer patients and LCNS's. It consists of forty-five items over eight domains including:

- Communication and information issues
- Physical symptoms
- Psychological issues
- Religious and spiritual issues
- Independence and activity
- Family and social issues
- Treatment issues
- Personal issues

A free text box is also available for patients to raise any other concerns they might have. Each item is scored by the patient as 0 - not at all, 1 - a little bit, 2 - quite a bit, and 3 - very much. The SPARC does not focus on the overall score but on each concern individually as scored by the patient (Leppert et al 2011).

Permission was obtained from Dr Sam Ahmedzai, owner of the SPARC tool, for it to be transferred onto an online platform. The initial three months of the project focused on working with telehealth providers Docobo while the SPARC tool was built onto their DOCOBO-WEB platform and to test the final product. A scoping exercise was undertaken to find services in the local community that could support patients following completion of treatment. Once identified, meetings were arranged to discuss the services they offered and how they could be accessed, to foster good relationships and build on partnership working. A self management document was then written to correlate with each concern on the SPARC tool. This provided simple advice for patients on steps they could take to manage their concerns and signposting to professionals or services that could help them. This was developed on a Microsoft Word document and built into the DOCOBO-WEB platform for patients to access online while completing their assessment.

The project manager developed a Patient Information Leaflet (PiL) (Appendix II) with the support of the NHSL Patient Information & Experience Manager and Information Governance Manager. A graphic of a mobile phone was developed by a graphic designer to indicate and promote the technology required for the purpose of the project. The final draft of the leaflet was produced in conjunction with Medical Illustration and used the same format as other NHSL PiLs.

# Section 2: Method

## 2.1 Project Design

The aim of the project was to recruit 100 people to test the use of digital health technology in the delivery of supportive care to patients following completion of treatment for lung cancer. An electronic SPARC (eSPARC) questionnaire was offered monthly for six months post treatment. Patients were eligible for participation if they had a lung cancer diagnosis, lived in South Lanarkshire and completed surgery, radical radiotherapy, palliative radiotherapy or chemotherapy. As the aim of the project was to test digital health technology and eligible patients had to be computer literate or be able to nominate a person on their behalf to complete the eSPARC online. For the purpose of the project we focused on active treatment pathways. Therefore patients receiving best supportive care were not eligible for participation.

Three further PROM's were selected to support the project evaluation, these being the:

- Functional Assessment of Cancer Therapy – Lung (FACT-L) (Appendix III)
- Memorial Symptoms Assessment Scale (MSAS) (Appendix IV)
- Supportive Care Needs Survey Long-Form 59 (SCNS) (Appendix V)

The participants were asked to complete these PROM's prior to their first and following their third and sixth eSPARC questionnaire. Caldicott approval was granted to share the PROM's data with the Edinburgh Napier University's research team for analysis. A patient experience questionnaire (Appendix VI), approved by NHSL Clinical effectiveness team, was also provided following their final eSPARC to gather feedback about the project.

Another aim of the project was to pilot the use of the electronic Treatment Summary (TSUM) developed by NHS Forth Valley. Initially the NHSL Applications Manager agreed to support the pilot of the TSUM. However a minimal Service Level Agreement from NHS Forth Valley to provide support to NHSL in the event of a complete system failure could not be established. Therefore the use of this electronic TSUM could not be supported in NHSL and the pilot could not proceed. These issues were escalated through the TCAT steering group and a national solution to access and support the use of this technology is currently being considered.

## 2.2 Recruitment

The project team met with the acute sector LCNS team, chemotherapy day unit nursing team at Hairmyres Hospital and radiotherapy nurses at the Lanarkshire Beatson. An update of the project was given with a supply of PiLs. Each team were asked to support recruitment to the project by discussing it with patients who were reaching the end of treatment with their details being passed to the project manager to make contact with them.

Initially agreement was sought from the LCNS's and the radiotherapy nurses to support recruitment. However the LCNS's felt that it was often difficult to raise the project with the patient. They have a limited time to spend with patients and provide a great deal of information that can often be emotionally sensitive and distressing. Therefore it was not always deemed appropriate to discuss the project. The radiotherapy team advised that they had discussed the project with patients but they had declined the offer. No details were provided on numbers of patients offered the project or reasons for declining. The chemotherapy day unit nursing team identified patients reaching the end of their treatment and invited the project manager to attend the day unit to speak to them about the project.

To ensure equality the decision was taken for the project team to attend the lung multidisciplinary team (MDT) meeting at Hairmyres Hospital to identify newly diagnosed lung cancer patients living in South Lanarkshire. Patients were then tracked by the project manager. Once the patient had completed treatment a letter and PiL were sent inviting them onto the project. This was followed up with a telephone call the following week to provide further information and answer any questions. The patient was then invited to attend Kilbryde Hospice (where the project team were based) or Monklands Hospital (where patients attended for oncology outpatient appointments) to meet with the project team to sign the consent form (Apendix VII), complete the baseline PROM's and be shown how to access Docobo.

It is estimated that between 1st January 2016 and 31st December 2016 487 patients were diagnosed with lung cancer in Lanarkshire with only 142 patients living in South Lanarkshire. By May 2016 it was realised that the numbers of lung cancer patients in South Lanarkshire was low and meeting the target of 100 patients would be unlikely. Following a request from the project manager the cancer tracker team provided information on patients' diagnosed from March 2015 onwards and the decision was taken to invite those suitable retrospectively. In August 2016 a further decision was taken to roll the project out to include lung cancer patients in North Lanarkshire.

The recruitment process has since evolved and consent is now obtained by telephone. A copy of the consent form and baseline PROM's are then sent to the patient by post. Once returned the patient selects the day they wish to complete the eSPARC questionnaire and are registered onto the Docobo system by the project manager.

## 2.3 Intervention

On their chosen day the patient received an email containing a link taking them to the Docobo website (DOCOBO-WEB) to access the eSPARC questionnaire. This was available between 6am and 11pm. To remind the patient that their eSPARC questionnaire was available a text message was sent via NHS.net to encourage them to check their emails.

Once completed the details became visible on DOCOBO-WEB's clinicians' page allowing the concerns to be reviewed by the LCNS. The patient was given the option of a face-to-face or telephone consultation to discuss their concerns. The focus of the consultation was to assess the concerns scored 2 – quite a bit and 3 – very much. For concerns scored as 1 – a little bit patients were directed to the self management document. A plan of care to manage each concern was then agreed between the patient and LCNS, including a combination of self management information, signposting and onward referral.

This information was used to populate a care plan (Appendix VIII) that is shared with the patient via email or post depending on their preference. The project team sought advice from the lead GP in South Lanarkshire regarding how best to share the care plan with the patients' practice. As the use of emails varies between GP practices it was decided that a paper copy should be sent by post. A paper copy of the care plan was also scanned onto the clinical portal. To ensure that this was easily identified the project manager arranged for a national code specifically for TCAT to be allocated to the care plans. Over the course of the year this has since evolved. Now using Win Voice technology the care plan is uploaded directly onto clinical portal and transferred electronically to the GP practice.

# Section 3: Results

## 3.1 Recruitment

Four hundred and thirty four patients were identified as having a lung cancer diagnosis with 63% (N=275) eligible for participation. Of those invited 21% (N=58) registered for the project. Reasons for declining participation included not requiring additional support at this time (41%), due to the project being electronic (21%) and focusing on other health concerns at this time (7%). Of the two hundred and seventy five patients invited to participate a third of these patients have since died highlighting the vulnerability and rapid decline of this patient group.

Statistical analysis of the data was carried out by Edinburgh Napier University. It was found that patients who were slightly younger (mean age =68.11) were more likely to accept the invitation than those who declined (mean age=71.31). There was a statistically significant difference (p= 0.033) between accepting/declining the project based on treatment with patients undergoing palliative radiotherapy more likely to decline the service and patients undergoing surgery were more likely to accept the service.

## 3.2 Participant Characteristics

Participant characteristics are summarised in Table 1. These are reflective of lung cancer trends seen in the UK with more women being diagnosed with lung cancer than men (Cancer Research UK 2016), the majority being over the age of 65 (National Cancer Registration and Analysis Service 2017) and diagnosed with non-small cell lung cancer (Cancer Research UK 2016). A range of Scottish Index of Multiple Deprivation groups were involved in the project, with 65% of participants retired and 43% living with two or more co-morbidities.

Surgical patients were statistically more likely to participate in the project, accounting for over half of participants (52%), compared to those receiving chemotherapy, radical radiotherapy and palliative radiotherapy.

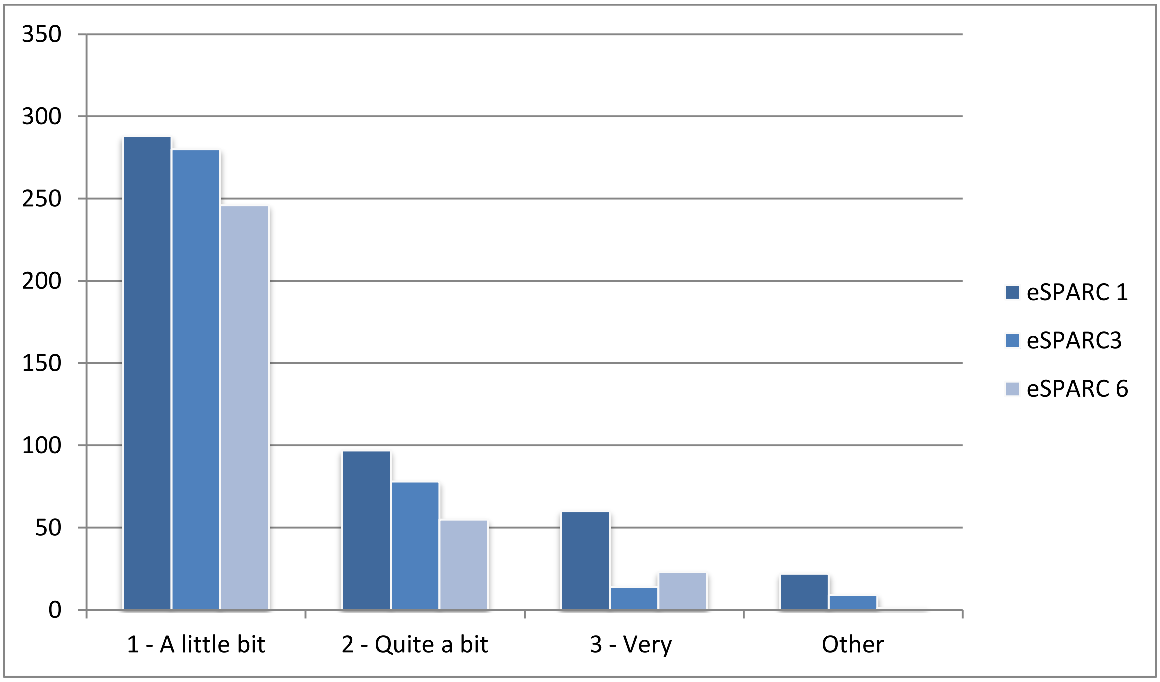
| | **Number** | **Percentage** |
|---|---|---|
| **Gender** | | |
| Female | 31 | 53% |
| Male | 27 | 47% |
| | | |
| **Age** | | |
| 40 – 49 years | 2 | 3% |
| 50 – 59 years | 11 | 19% |
| 60 – 69 years | 19 | 33% |
| 70 – 79 years | 22 | 38% |
| 80+ years | 4 | 7% |
| | | |
| **SIMD** | | |
| 1 (most deprived) | 13 | 22% |
| 2 | 15 | 26% |
| 3 | 14 | 24% |
| 4 | 8 | 14% |
| 5 (least deprived) | 8 | 14% |
| | | |
| **Economic Activity** | | |
| Employed | 7 | 12% |
| Self Employed | 1 | 2% |
| Unemployed | 4 | 7% |
| Retired | 38 | 65% |
| Looking after home/family | 1 | 2% |
| Long term sick or disabled | 7 | 12% |
| | | |
| **Diagnosis** | | |
| Non small cell lung cancer | 53 | 91% |
| Small cell lung cancer | 3 | 5% |
| Mesothelioma | 1 | 2% |
| Neuroendocrine | 1 | 2% |
| | | |
| **Primary Treatment** | | |
| Biological Therapies | 1 | 2% |
| **Chemoradiation** | 4 | 7% |
| Chemotherapy | 13 | 22% |
| Radiotherapy | 10 | 17% |
| Surgery | 30 | 52% |
| | | |
| **Co-morbidities** | | |
| 1 | 18 | 31% |
| 2 | 11 | 19% |
| 3+ | 25 | 43% |

(Table 1 - Participant Characteristics)

## 3.3 eSPARC Questionnaire

The 58 patients who participated in the project completed a total of 248 eSPARC assessments with 47% completing a full 6 eSPARC assessments. Reasons for not completing the project included patients feeling their needs had been met so further assessments were not needed, other health problems had arisen, changes in personal circumstance, 10 patients were part way through the project when the evaluation data was submitted and 9 patients died before completing the project.

The median length of time to complete the first eSPARC questionnaire was 13 minutes decreasing with each assessment to 10 by the sixth assessment. From the 248 completed assessments 3396 concerns were identified. The average number of concerns reduced from 18 to 12 between the first and sixth assessment. A plateau of 12 concerns was reached by the third assessment which might suggest that this is the optimum number of assessments to provide. Data analysis of the 28 patient who completed a full 6 assessments shows a 30% reduction in concerns with the number of high concerns falling by 62% between the first and sixth assessment (Table 2).



(Table 2 –Number of Concerns N = 28)

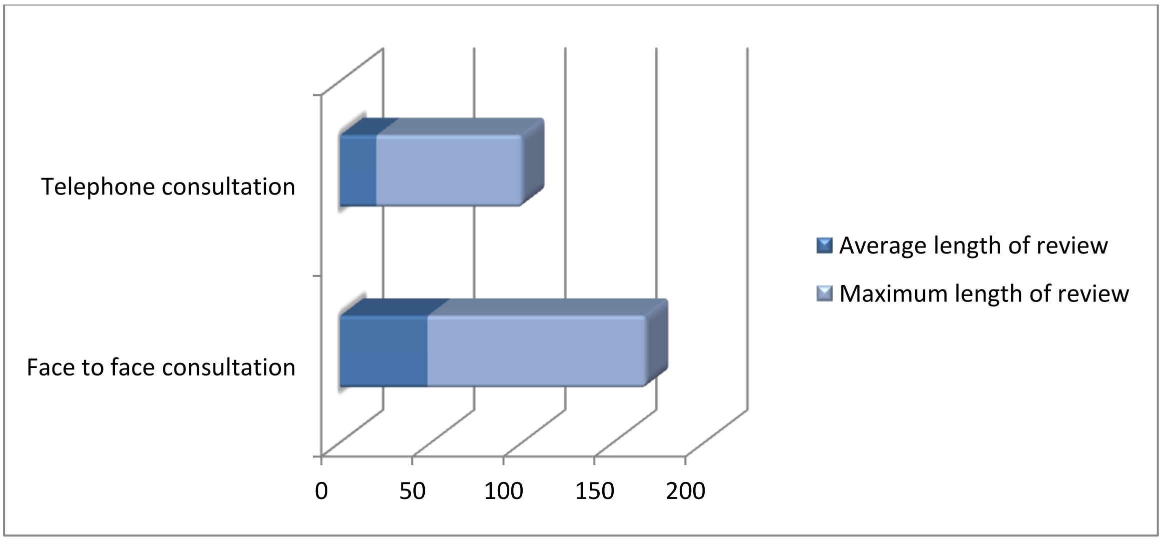
There was an increase of 39% in high concerns between the third and sixth assessment with 5 out of the 28 patients having high concerns at their sixth assessment. Two of these patients had a chest infection, one patient had long standing health problems and their high concerns had reduced at this point, one patient had symptoms caused by disease progression and another had side effects of treatment following recommencement for disease progression. Notably 43% of this patient group had 3 or more co morbidities. Therefore changes in level and severity of concern might not be as a consequence of their cancer or its treatment but rather the impact of other co morbidities. That being said the top concerns are reflective of those experienced by lung cancer patients and remain similar over the 6 time points as displayed in table 3.

| eSPARC 1 | eSPARC 2 | eSPARC 3 | eSPARC 4 | eSPARC 5 | eSPARC 6 |
|---|---|---|---|---|---|
| Shortness of breath (N=22) | Feeling tired (N=23) | Feeling tired (N=25) | Shortness of breath (N=22) | Shortness of breath (N=20) | Shortness of breath (N=24) |
| Feeling tired (N=20) | Shortness of breath (N=22) | Shortness of breath (N=23) | Feeling tired (N=22) | Feeling tired (N=20) | Feeling tired (N=19) |
| Feeling sleepy during the day (N=20 | Problems sleeping at night (N=19) | Feeling weak (N=19) | Feeling weak (N=19) | Pain (N=15) | Pain (N=15) |
| Cough (N=19) | Feeling weak (N=19) | Feeling that everything is an effort (N=19) | Feeling that everything is an effort (N=18) | Feeling weak (N=15) | Feeling sleepy during the day (N=15) |

(Table 3 - Top concerns)

## 3.4 Nurse Consultation

233 nurse consultations were carried out. A consultation was offered if the patient had concerns scored 2 – quite a bit, 3 – very much or had other concerns. Patients who only had concerns scored 1 – a little bit were directed to the self management information to support them to independently manage their concerns. If the low concerns persisted or new concerns developed a nurse consultation was offered. A face to face or telephone consultation was offered. The majority of nurse consultations were carried out by telephone (88%). Face to face reviews accounted for 6% of reviews with no review required 6% of the time.



(Table 4 - Telephone Vs Face to Face Consultation)

Overall the average length of a nurse consultation was 22 minutes. However there was a significant difference between the average length of time for a face to face consultation compared to a telephone consultation (48 Vs 20 minutes). Similarly to completing the assessment the average length of time for nurse consultation reduces from 31 minutes to 17 minutes by the sixth assessment (Table 4).

## 3.5 Care Planning

Self management information was given to manage 2771 (82%) concerns. This included the provision of the self management document, specific information written and links to further information on the personalised care plan. For patients who preferred their care plan to be posted further information was ordered or printed for them. No action was required for 152 concerns. The reasons for this were that the concerns had resolved prior to the assessment or that it was due to a cancer or long-term condition related symptom for which management had been optimised.

There were 343 signposting and 123 onward referrals made to local services, with the top five services displayed in table 5. Kilbryde Hospice features as the main service to signpost to. They offered a range of services on a drop in basis including a community choir, relaxation and gentle exercise which helped to meet the main concerns of breathlessness and fatigue (Table 3). The project was initially rolled out in South Lanarkshire where the hospice is based. It also hosted the project team and was where they initially met with patients to obtain consent. Therefore project staff and patients were familiar with the facility which might explain the higher number of signposting to this service over other local support services.

| Signposting | Onward referral |
|---|---|
| Kilbryde hospice (34) | Macmillan Benefits Advice Service (12) |
| Local Pharmacist (27) | Kilbryde Hospice (9) |
| GP (26) | South Lanarkshire Leisure Active Health (7) |
| The Haven (22) | Lung Cancer CNS (7) |
| The Maggie's Centre (20) | Occupational Therapist (6) |
| Get Walking Lanarkshire (10) | South Lanarkshire leisure Weigh to Go (4) |

(Table 5 – Signposting and onward referrals)

Interestingly the highest number of referrals was made to the Macmillan Benefits Team however 'more information about financial issues' was not one of the top concerns. It was selected by 7 patients with 42% of referrals made due to financial issues being identified through the assessment process during the nurse consultation (Table 6).

| Signposting | Onward Referral |
|---|---|
| Shortness of breath (N=39) | Shortness of breath (N=16) |
| Feeling tired (N=27) | Problems sleeping at night (N=9) |
| Dry mouth (N=23) | Feeling tired (N=9) |
| Problems sleeping at night (N=21) | Pain (N=7) |
| Feeling weak (N=21) | More information about financial issues (N=7) |
| Cough (N=21) | Losing your independence (N=7) |
| Worrying about the effect that your illness is having on your family or other people (N=20) | Feeling weak (N=7) |
| Feeling that everything is an effort (N=15) | Do you need any help with your personal affairs (N=6) |

(Table 6 – Concerns for signposting and onward referral)

Referral back to the acute sector LCNS also featured as a top referral. Great care was taken to ensure the project team did not work in isolation but in partnership with the acute sector LCNS team. On four occasions this allowed the prompt management of treatment related side effects. On three occasions a change in symptoms was noticed from the eSPARC questionnaire. This led to the seamless coordination between the project nurse, acute sector LCNS and the GP to arrange investigation and clinic review for suspected disease progression.

Although data was not collected, anecdotally the acute sector LCNS team have reported a reduction in telephone calls to their service following the launch of the project. This has created capacity to enable the development of new nurse led immunotherapy clinics to coincide with the approval of new immunotherapy treatments to be used in practice.

Of the 28 patients who completed 6 eSPARC questionnaires, the number of signposting and onward referrals reduced by 49% and 94% respectively, between the first and sixth assessment. This correlates with the reduction in concerns seen by the sixth eSPARC questionnaire adding weight to the argument that six assessments are not required as care needs are identified and managed before this time point.

## 3.6 Patient Experience

41 patients (71%) completed the patient experience questionnaire (Box 1). Overall the feedback for the service was positive with 90% of patients rating it as excellent and the other 10% rating it as good:

*“I had someone to advise me which stopped me worrying” (Patient no. 7)*

*“I really appreciated the helpful and friendly help, support and advice. The team were easy to speak to and very friendly” (Patient no.33)*

98% of patients agreed that the eSPARC questionnaire was easy to schedule and access at a time that was convenient for them. Patient’s verbalised that they valued having the flexibility to complete the assessment on a day of their choosing between 6am – 11pm:

*“I liked the idea that you had a whole day to do it. It meant you could go back and forward to it and didn't have to do it all in one go” (Patient no.13)*

*“I was allowed the whole day to complete my assessment” (Patient no. 51)*

One patient agreed that it was easy to schedule but would have preferred a longer time frame to complete the questionnaire:

*“Given just a 12 hour period to complete” (Patient no. 47)*

One patient disagreed that the assessment was easy to schedule due to other health problems and clinic appointments. Throughout the questionnaire they explained that they had to withdraw from the project due to other heath concerns however they felt that it could have potentially helped them:

*“It became very difficult to schedule assessments due to other appointments...The service was good...Wish I had been able to complete the programme - I feel it might have helped me.” (Patient no. 19)*

Q1 The written instructions on how to access the SPARC assessment were clear and easy to understand
Q2 It was easy to schedule in my assessment at a time that was convenient for me
Q3 The SPARC assessment allowed me to raise all the concerns regarding the impact of my cancer and treatment on my quality of life
Q4 The self management information was clear and easy to understand
Q5 I used the self management information to manage my concerns
Q6 The self management information supported me to access local services
Q7 The project team were able to support me and signpost me to relevant services
Q8 Overall how would you rate the service
Q9 Have you contacted your GP, NHS 24, or attended A&E in the last 6 months?
Q10 Do you have any further comments, questions or concerns?

(Box 2 – Patient Experience Question Schedule)

The SPARC questionnaire is validated and regarded to be effective at identifying patient’s concerns (Ahmed et al 2015). Providing it in electronic format did not appear to impact on its effectiveness. Nearly all patients (98%) agreed that the SPARC assessment and nurse consultation gave them the opportunity to discuss any concerns regarding their cancer and effects of treatment:

*“It was great to have a 1 to 1 consultation after the assessment. This enabled me to discuss any concerns I may have had” (Patient no.13)*

*“I was able to discuss the affect cancer had on me and on my family including the 'domino' affect which ensued. I was always listened to and given advice.” (Patient 53)*

The self management document was available on DOCOBO-WEB to view anytime and emailed to the patient along with each care plan. Patients did not appear to be deterred by it being in electronic format with 98% agreeing that it was clear and easy to understand. 90% of patients reported that they used the self management information to manage their concerns and 85% to access local services. Patients appeared to find the value in having information that they could refer to as and when they needed it.

*"It was good to have the self management information as you could always go back and check it when necessary. I was able to access additional support" (Patient no. 53)*

*"I found it very useful. I used this and will keep for future use" (Patient no. 31)*

Not all patients required signposting or onward referral to local services. However 85% of patients agreed that the project helped them to access the appropriate services:

*"Was a great help - Social Services helped with extra banisters inside and out" (Patient No.7)*

*"The Memory Group was very useful. I enjoyed the group and it has helped me manage better in this area" (Patient no.31)*

*"Totally agree. The team helped me obtain resources and aids to help me" (Patient no.56)*

The psychological impact of cancer and its treatment can be life changing (Macmillan 2013). Encouragingly patients who participated in the project appeared to value the emotional support it provided them with:

*"The service has provided good practical help and emotional back up" (Patient no.2)*

*"I had someone to advise me which stopped me worrying. I stay alone and I don't worry when I have a telephone number to phone and get advice which keeps me healthy" (Patient no.7)*

*"Although I have had no major concerns/problems the nurse always contacted me by phone to discuss my responses and make sure that I had all the help I needed. Just having a quick chat with a concerned person really boosted my mood if I had been a little down." (Patient 20)*

Taking part in the project also helped patients to understand their cancer and what to expect from the future, both in terms of recovery and follow up:

*"Information and help gave to me was very helpful. The after care when you have had cancer is nil. Nothing is explained about how you might feel or any effects you might have" (Patient no. 11)*

*"Doing this project has helped me to understand about my lung cancer." (Patient no. 24)*

This feedback suggest that from the patients perspective the process of undertaking an eSPARC questionnaire followed up by a consultation with a LCNS is an acceptable model of care to help them raise their concerns and access support to manage them.

## 3.7 Patient reported Outcome Measures

Edinburgh Napier University provided data analysis of the FACT-L, MSAS and SCNS. The following data focuses on the 26 patients who completed all 6 eSPARC questionnaires. The FACT-L, MSAS and SCNS were completed before the 1st assessment and after the 3rd and 6th assessment.

The FACT-L is a validated tool that measures quality of life. It contains 38 items, scored with a 5 point Likert Scale, covering 5 domains; these being physical well-being (PWB), social/family well-being (SWB), emotional well-being (EWB), functional well-being (FWB) and a lung cancer subscale (LCS). A Trial Outcome Index (TOI) can also be calculated by adding the PWB, FWB and LCS scores. The TOI score is considered to be more sensitive to change and commonly used as a quality of life measure in clinical trials. (Webster et al 2003) An increase in score indicates an improvement in quality of life.

Between the first and third time point a statistically significant improvement (Table 7) was achieved in the PWB (P=0.007), EWB (P=0.01), TOI (P=0.019), FACT-G (P=0.021) and FACT-L (P=0.021) domains. This was reflected in the patient reported response to the statement "I am content with my quality of life right now". An 11% increase was seen in patients reporting to 'very much' being content with their quality of life between their first and sixth assessment.

| **Outcome** | **Time Point 1 (Before first assessment)** | **Time Point 2 (After 3rd Assessment)** | **Time Point 3 (After 6th assessment)** | **P value (Before 1st assessment vs After 6th Assessment)** |
|---|---|---|---|---|
| **PWB (physical)** | 21.42 | 21.92 | 23.88 | 0.007 |
| **SWB (social)** | 21.04 | 20.31 | 21.15 | 0.905 |
| **EWB (emotional)** | 18.42 | 19.04 | 20.15 | 0.01 |
| **FWB (functional)** | 15.27 | 14.85 | 16.42 | 0.235 |
| **LCS (lung cancer subscale)** | 18.35 | 17.88 | 19.65 | 0.105 |
| **TOI (trial outcome index)** | 55.04 | 54.65 | 59.96 | 0.019 |
| **FACT-G** | 76.15 | 76.12 | 81.62 | 0.021 |
| **FACT-L** | 94.5 | 94 | 101.27 | 0.021 |

(Table7 - Mean FACT-L score n=26)

This indicates that the quality of life of these 26 patients improved after the project intervention of six monthly eSPARC questionnaires, a nurse consultation and provision of personalised care plan.

The MSAS is a validated tool which, using Likert Scales, measures the severity, frequency and distress of 32 symptoms (Chang et al 2000). From these scores four subscale scores are produced, these being the Physical Subscale (PHYS), Psychological Subscale (PSYCH), Global Distress Index (GDI) and Total MSAS score (MSAS). The PHYS looks at the physical symptom burden experienced by the patient and the PSYCH looks at the emotional burden (Measurement Instrument Database for the Social Sciences 2017). The MSAS and GDI looks at the overall distress however changes to the GDI score appears to be more sensitive to changes in overall quality of life (Portenoy et al 1994).

| **Outcome** | **Time Point 1 (Before first assessment)** | **Time Point 2 (After 3rd Assessment)** | **Time Point 3 (After 6th assessment)** | **P value (Before 1st assessment vs After 6th Assessment)** |
|---|---|---|---|---|
| **GDI** | 1.07 | 0.89 | 0.70 | 0.006 |
| **Physical sub scale (PHYS)** | 1.12 | 0.99 | 0.77 | 0.001 |
| **Psychological sub scale (PSYCH)** | 1.19 | 0.97 | 0.86 | 0.009 |
| **MSAS** | 1.12 | 0.91 | 0.78 | <0.000 |

(Table 8 - Mean MSAS score n=26)

A reduction in the score of these subscales highlights a reduction in physical symptom burden, psychological distress and improvement in overall quality of life. Between the first and third time point a statistically significant reduction across all subscales was achieved (Table 8). This indicates an increase in overall quality of life following participation in the project.

The SCNS consists of 59 items covering 5 domains, these being psychological needs, health system and information needs, physical and daily living needs, patient care and support needs and sexuality needs. Again a Likert scale model is used for patients to score their level of need. For scores 1 and 2 it is considered that the patient has no need and for scores of 3 to 5 it is considered the patient has unmet need (McElduff et al 2004).

| **Outcome** | **Time Point 1**<br>**(Before first assessment)** | **Time Point 2**<br>**(After 3rd Assessment)** | **Time Point 3**<br>**(After 6th assessment)** | **P value (Before 1st assessment vs After 6th Assessment)** |
|---|---|---|---|---|
| **Psychological** | 49.88 | 41.38 | 36.31 | 0.000 |
| **Health system and information needs** | 36.85 | 28.62 | 27.96 | 0.004 |
| **Physical and daily living** | 16.62 | 14.35 | 13.27 | 0.003 |
| **Patient care and support needs** | 15.04 | 12.88 | 12.54 | 0.051 |
| **Sexuality** | 4.65 | 3.88 | 3.88 | 0.079 |
| **Non specific** | 8.31 | 6.23 | 6.19 | 0.010 |

(Table 9 - Mean SCNS score n=26)

A statistically significantly improvement was seen across all domains with the exception of, patient care and sexuality between the first and third time point (Table 9). Again this suggests that project intervention was successful in identifying and managing unmet needs. Interestingly the most significant improvements were seen earlier between time point 1 and 2. This suggests that three assessments might be the optimum number of assessments required to meet the majority of patients needs.

The domain of patient care and support needs relates to patients experience within hospital. As the project supported patients in their own home through the use of technology it would be unlikely that the project intervention would influence this score. Only 9% of patients identified “The effects of your condition on your sexual life” as a concern on their eSPARC assessment which might explain the lack of improvement seen in this domain.

From the responses to individual SCNS questions there was a 26% and 34% reduction in patients reporting “Being treated like a person and not just another case” and “Being informed about things you can do to help yourself get well” as unmet needs. The provision of electronic assessments and telephone consultation to produce a personalised care plan appears to be effective models to deliver patient focused care and empower the patient to self manage their condition.

# Section 4: Discussion

## 4.1 Recruitment

This model of care was tested on a small number of patients and had an uptake of 21%, which might be considered low. That being said other factors need to be taken into account when considering this uptake rate.

The project was only offered to lung cancer patients and is not reflective of the general cancer population. The vulnerability of this group of patients could have impacted on project participation. Lung cancer patients carry a poor prognosis with only a third of patients surviving a year after diagnosis (Cancer Research UK 2017). This correlates with the finding of the project as a third of diagnosed lung cancer patients were excluded as they were for best supportive care and a third of invited patients have since died. Consequently it is recommended that this model of working is tested on other cancer types to explore the uptake rate within a general cancer population.

It is recommended that to improve quality of life all patients should have their needs assessed and be provided with an individual care plan following treatment for cancer (Scottish Government 2016c). However, it has also been suggested that only a third of patients will have unmet needs after treatment (Rowe et al 2014). Therefore, although offered to all, it is recognised that not all patients will opt to complete an assessment. Forty-one percent of patients invited to participate in the project stated that they did not have any needs and did not require an assessment at this time. Due to challenges with recruitment the project team invited patients in retrospect and not always close to the point of completing treatment. Therefore it is possible that the timing of offering the assessment has influenced the uptake rate.

## 4.2 Timing and Frequency

From an organisational perspective tracking patients to determine when they finished treatment was labour intensive and somewhat inefficient. The National Institute for Clinical excellence (2004) advise that a holistic care needs assessment should be offered at multiple points on the patient’s cancer journey not only after treatment but starting from the point of diagnosis. Identifying patients from the MDT provides patient information in real time. Not only is it a more time efficient way for staff to work but also ensures that all patients are offered an assessment timeously and at the point of diagnosis. Given the benefits to both the patient and the organisation it is proposed that an eSPARC should be offered at the point of diagnosis rather than only after treatment and patients should be identified from the MDT.

Project participants were offered monthly questionnaires for 6 months. The findings from the evaluation suggest that this number of assessments is not required. The number of concerns plateau at 12 after 8 weeks following the third eSPARC questionnaire. The level of concern and need for signposting and onward referral also reduced at this time point. This was confirmed by the analysis of the SCNS which showed the greatest statistically significant reduction in care needs and improvement in quality of life by the third time point.

Consequently optimum benefit may be derived by offering the minimum of an eSPARC near the point of diagnosis and around 8 weeks following treatment. Not all patients will require additional assessments; however this should be based on the individual need of the patient. A follow up consultation should be offered 8 weeks after the provision of the care plan to review the patients' progress and establish if further assessment is needed.

## 4.3 Technology Enabled Care

Albeit holistic care needs assessment and care planning were the TCAT components being explored in this project, but the main focus was on the use of technology as a way to deliver this care. This is in alignment with the Scottish Government's e-Health Strategy which aims to empower patients to self manage their condition and live longer at home rather than hospital. The evaluation of this project has highlighted the benefits to both the patient and the organisation in adopting an e-Health model of care to support lung cancer patients following treatment.

Returning to hospital for a clinic appointment can be a stressful experience for patients, relatives and carers. Some can be faced with the stress and worry of arranging and paying for transport or finding a parking space. Others might be faced with the challenge of negotiating time off of work to attend clinic (Beaver et al 2009). This model of care reduces that burden. It offers patients the flexibility of highlighting their unmet needs or concerns in the comfort of their own home or while at work, on a day and time that is convenient to them. Given the choice the majority of patients opted to have their consultation by telephone and all patients rated the service as excellent (90%) or good (10%). Feedback highlights that patients found the technology easy to use, only taking on average 13 minutes to complete the questionnaire online. They also engaged with the electronic self management information with 85% of patients agreeing that it helped them to engage with local services.

From an organisational perspective there was also a clear benefit on resources. The telephone consultation took half of the time of a face to face appointment. Although more work is needed to explore additional factors which might attribute to this finding, such as complexity of need, it indicates a more efficient way of working allowing more patients to be supported. The use of Winscribe Voice technology has negated the use of consumable materials and ensured that information regarding the patients concerns and plan of care is shared in real time with key members of their care teams. If rolled out this model has the potential to be at the very least cost neutral if not cost effective. A health economic report would help to establish the true cost effectiveness of the project and strengthen this theory.

Twenty-one percent of patients declined to participate in the project due to it being an electronic assessment. One of the limitations of the project is that the aim was to test technology rather than the use of holistic care needs assessment and care planning. It was not a randomised controlled trial and did not compare the uptake of electronic assessment against paper assessment. As such it is unknown how many of the patients who declined an electronic assessment would have opted to complete a SPARC had a paper version been offered. For this reason it is recommended that patients who decline an eSPARC should be offered a paper version to ensure they are given the opportunity to identify any unmet needs. That being said patients should also be enabled to develop their IT literacy to empower them to access care and support electronically if that is their wish. This can be facilitated and achieved through partnership working with local services, such as the Macmillan Cancer Information Support Service.

## 4.4 Clinical Effectiveness and Quality

Many barriers exist in the implementation of digital technology in healthcare. One such barrier is the perception that using technology in place of face to face contact would diminish the relationships between the patient and care provider, in turn reducing the quality of care received by the patient (Ross et al 2016). Contrary to this the patient feedback regarding the project and analysis of the FACT-L, MSAS and SCNS appears to suggest otherwise.

Patient feedback appears overwhelmingly positive with an emerging theme of reassurance offered by the delivery of electronic assessment, telephone consultation and care planning. More importantly the analysis of FACT-L, MSAS and SCNS shows a reduction in physical and emotional symptom burden, a reduction in care needs and an overall improvement in quality of life proving the clinical effectiveness and quality of this model of care. Again these results are reflective of a small number of lung cancer patients and further testing in the wider cancer population is warranted.

# Section 5: Transformational Change for the Future

## 5.1 Sharing the Learning

The learning from the project has been shared through oral presentation to the lung cancer managed clinical network and cancer medicine outcomes programme; through poster presentation at the European Oncology Nurses Society (EONS) 10 conference (Appendix IX) and the NHS Scotland conference (Appendix X); participation in the National Lung Cancer Nurses Forum and workshop; attendance at the Lanarkshire Technology Enabled Care Group (TEC) and an article on the interim results has been accepted for publication in the peer reviewed Journal of Cancer Nursing Practice.

However the most notable engagement has been locally with the NHSL's cancer specific clinical nurse specialists. Interest in this model of working has led to the project being rolled out to head and neck and urology patients. Since this work started in May 2017 1 head and neck patient and 10 urology patients have registered onto the project although the data generated does not form part of this evaluation. The breast team have since expressed an interest and this momentum has culminated in the development of NHSL's electronic-Cancer Nursing (e-CaN) Project and forms the basis of the TACT Phase 3 proposal.

## 5.2 Phase Three – NHS Lanarkshire e-CaN Project

An application for TCAT Phase three funding has been submitted to further develop this model of working. The phase three project will be titled the NHSL's e-CaN project (Table 10) and it will run from 1st September 2017 until 31st August 2018.

It is proposed that the project will be offered to all lung, urology, head and neck and breast patients within NHSL at the point of diagnosis. For the year 2017/2018 it is estimated that 2361 patients will be offered an eSPARC and a minimum of a 20% uptake is anticipated. In light of phase one learning patients will be offered 2 eSPARC's rather than 6; one around the time of diagnosis and one around 8 weeks after treatment. A follow up consultation will be provided 8 weeks following provision of a care plan and further assessment will be provided if required. Patients will continue to be invited by letter with a follow up telephone call. However to allow timely invitation to the project close to the point of diagnosis patients will be identified from MDT lists.

| Design | PROM | Evaluation |
|---|---|---|
| **Inclusion criteria**<br>• Lung Cancer (N = 620)<br>• Head & Neck (N = 185)<br>• Urology (N = 865)<br>• Breast (N = 691)<br>**Recruitment**<br>• Newly diagnosed patients identified through MDT<br>• All newly diagnosed patients offered online SPARC (N = 2361)<br>• Patients who decline due to it being electronic offered paper SPARC<br>• Estimated uptake 20% (N = 472)<br>**Schedule**<br>• Electronic SPARC following diagnosis and 2 – 6 months after completion of primary treatment<br>• Telephone consultation and provision of care plan<br>• Follow up review after 8 weeks | **Sheffield Profile for Assessment and Referral for Care** (SPARC)<br>• 9 domains<br>- Communication and Information,<br>- Physical symptoms,<br>- Psychological issues<br>- Religious and spiritual issues<br>- Independence and activity,<br>- Family and social issues,<br>- Treatment issues,<br>- Personal issues<br>- Other concerns.<br>• 45 items<br>• Access electronically via Docobo Web | **Evaluation**<br>• 3 PROM's completed before first and after last SPARC<br>- Tumour specific FACT<br>- Memorial Symptom Assessment Scale<br>- Supportive Care Needs Survey<br>• Patient Experience Survey<br>• Evaluation supported by Edinburgh Napier University |

(Table 10 - e-CaN Project Design)

As the majority of patients requested telephone consultation this will now become standard practice for the project. The process of consultation and provision of personalised care plan will remain the same. However NHS Lanarkshire has shown commitment to support the e-CaN project and will use an internal vacancy to provide the project with a health care support worker. As a test of change the health care support worker will be trained by the project CNS to review the e-SPARC and populate the care plan. If successfully implemented it is a vision for the future that the health care support worker would undertake this role rather than a CNS. Outcomes will continue to be measured through the FACT, MSAS and SCNS questionnaires provided at the first and last eSPARC.

To ensure patients have a voice in this work patient experience questionnaires will be provided after the last eSPARC. The e-CaN project contributes to the wider Living with and Beyond Cancer Network bringing together health, social care and third sector professionals and patient representatives to ensure a joined up approach to the development of cancer service and foster joint working.

# Section 6: Conclusion

More people will be living longer with the effects of cancer and its treatment as the number of people living with cancer is set to rise. In response to this, the Scottish Government (2016c) challenged health, social care, and third sector staff to develop new “sustainable and innovative” ways of working to meet this demand and better support patients. Granted further testing in the general cancer population is required but the findings from this evaluation suggest that this model of working does just that. It appears to be time efficient and clinically effective, reducing both physical and psychological symptom burden, care needs and improving quality of life and should be considered as an effective approach to support those affected by cancer.

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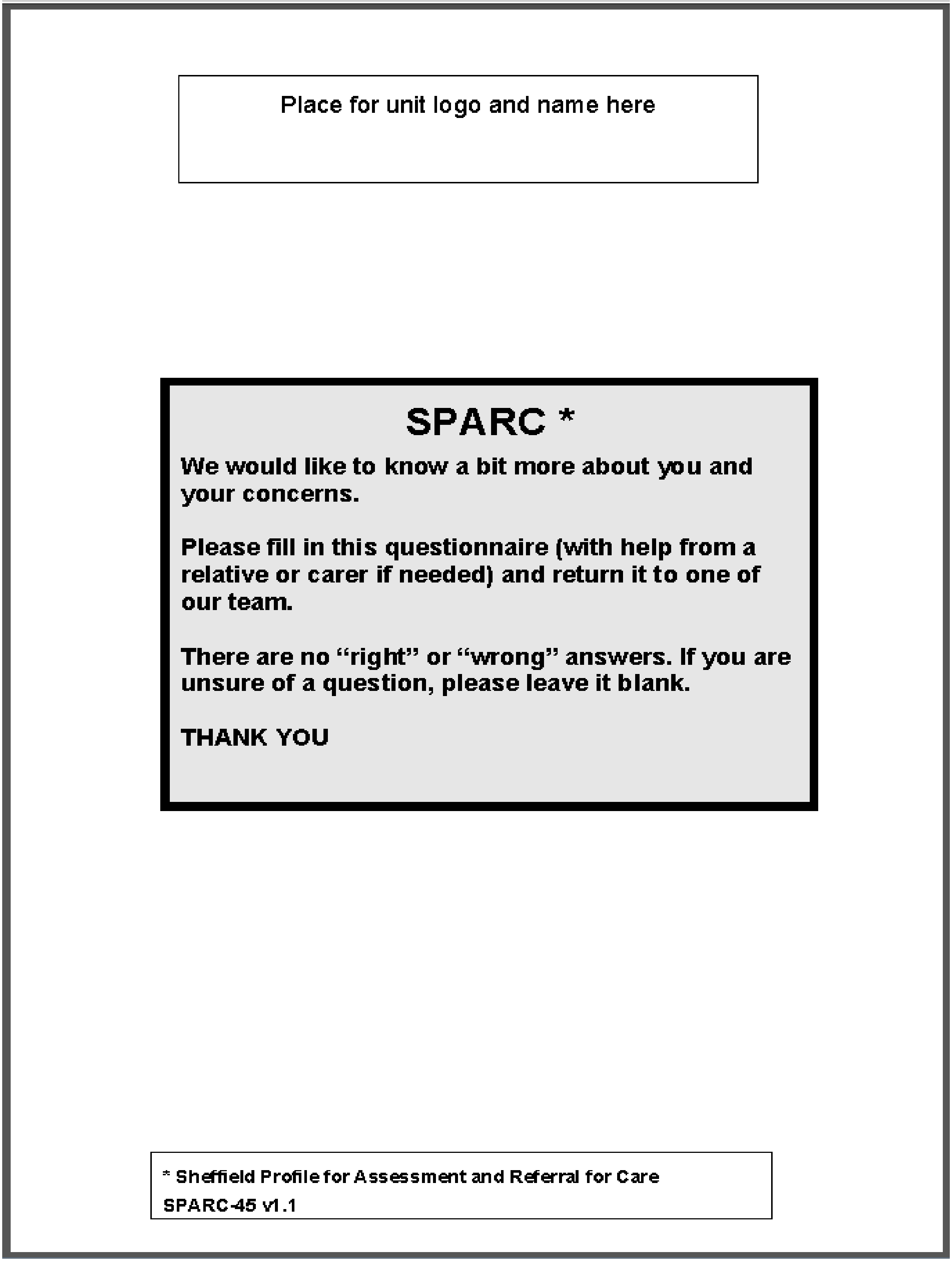
# Appendix I



Place for unit logo and name here

## SPARC *

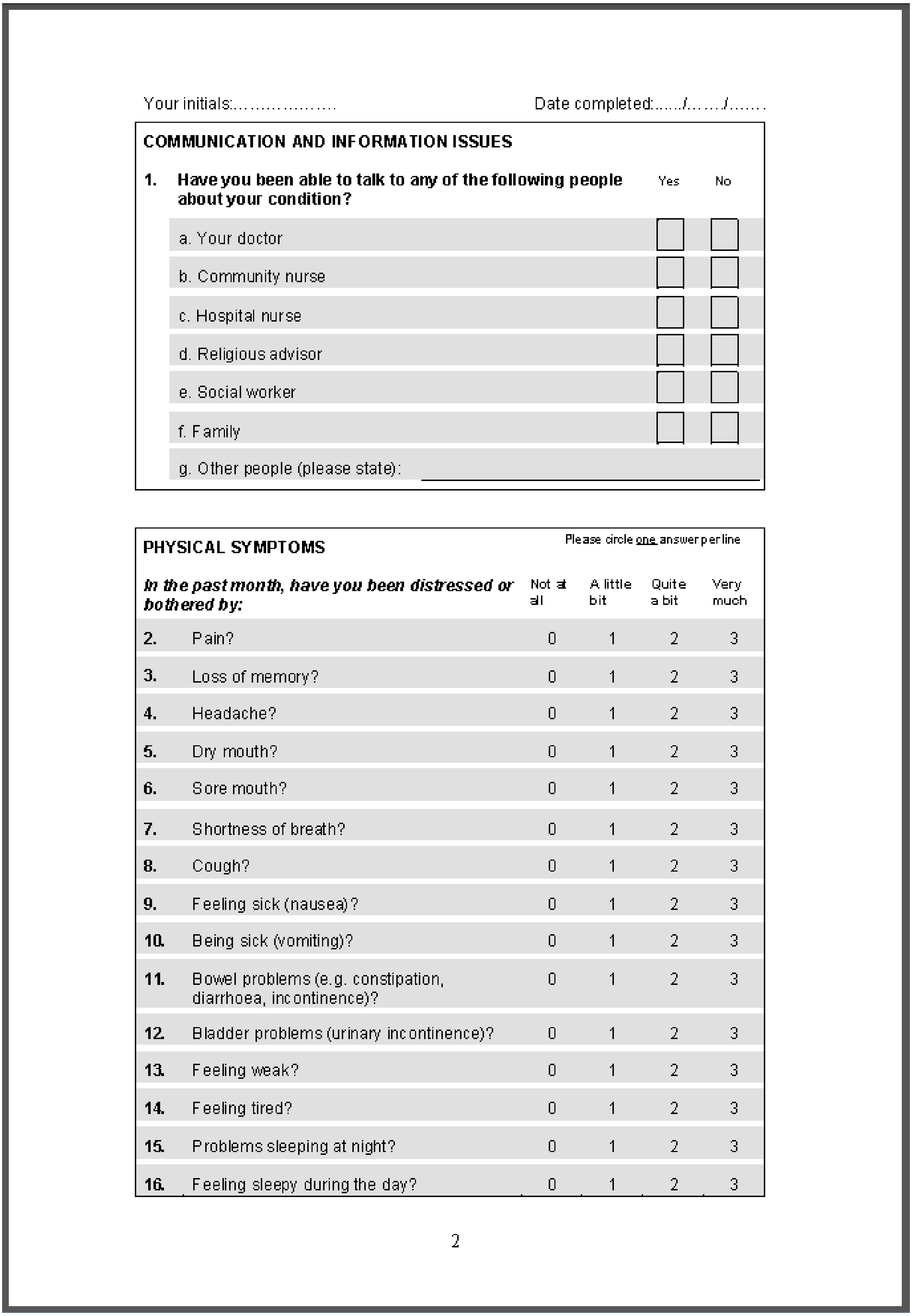
We would like to know a bit more about you and your concerns.

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**

* Sheffield Profile for Assessment and Referral for Care
SPARC-45 v1.1



Your initials:………………  Date completed:……/……./…….

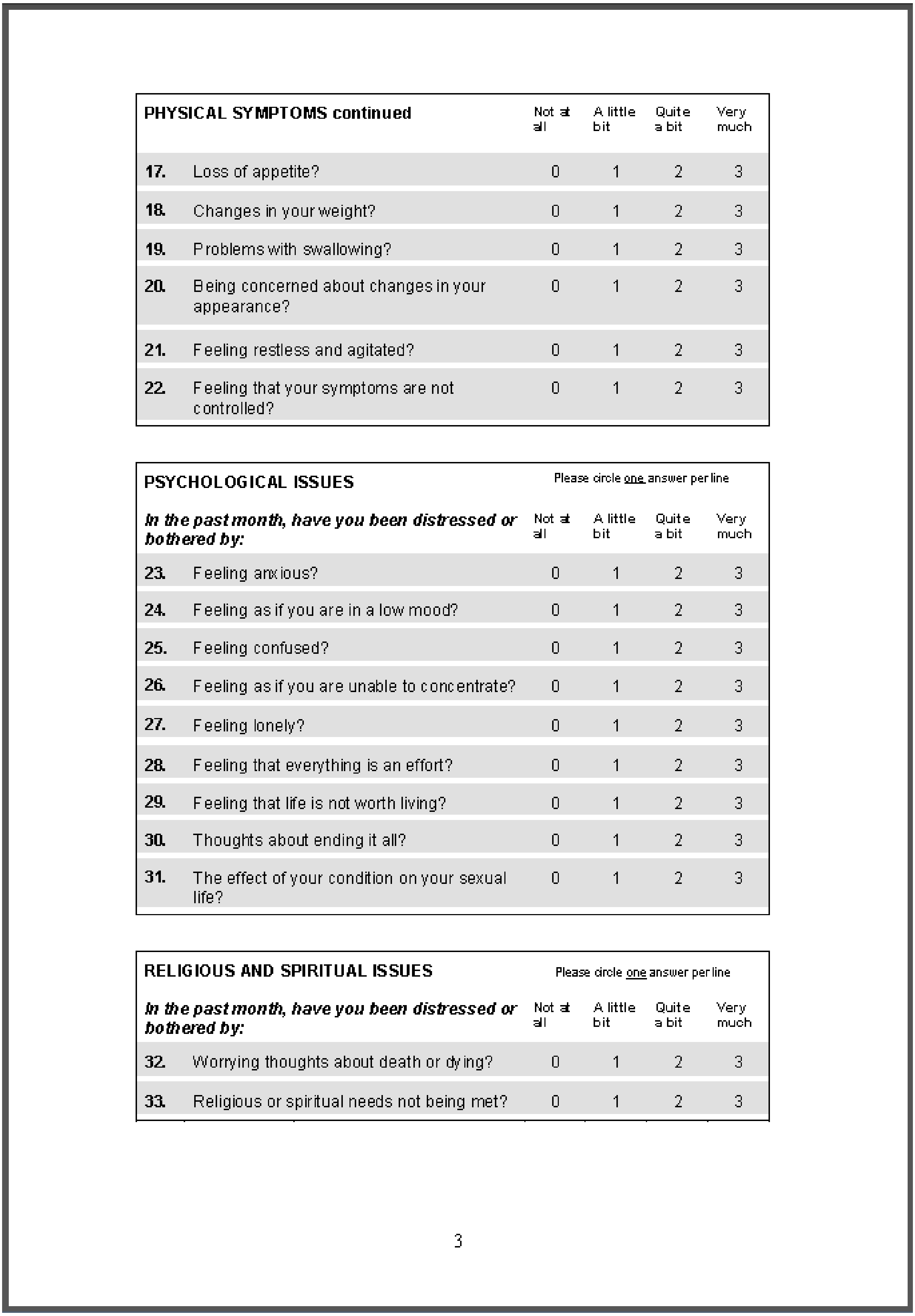
**COMMUNICATION AND INFORMATION ISSUES**

| | | |
|---|---|---|
| **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 (e.g. constipation, diarrhoea, 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 |



| **PHYSICAL SYMPTOMS continued** | Not at all | A little bit | Quite a bit | Very much |
|---|---|---|---|---|
| **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**

Please circle one answer per line

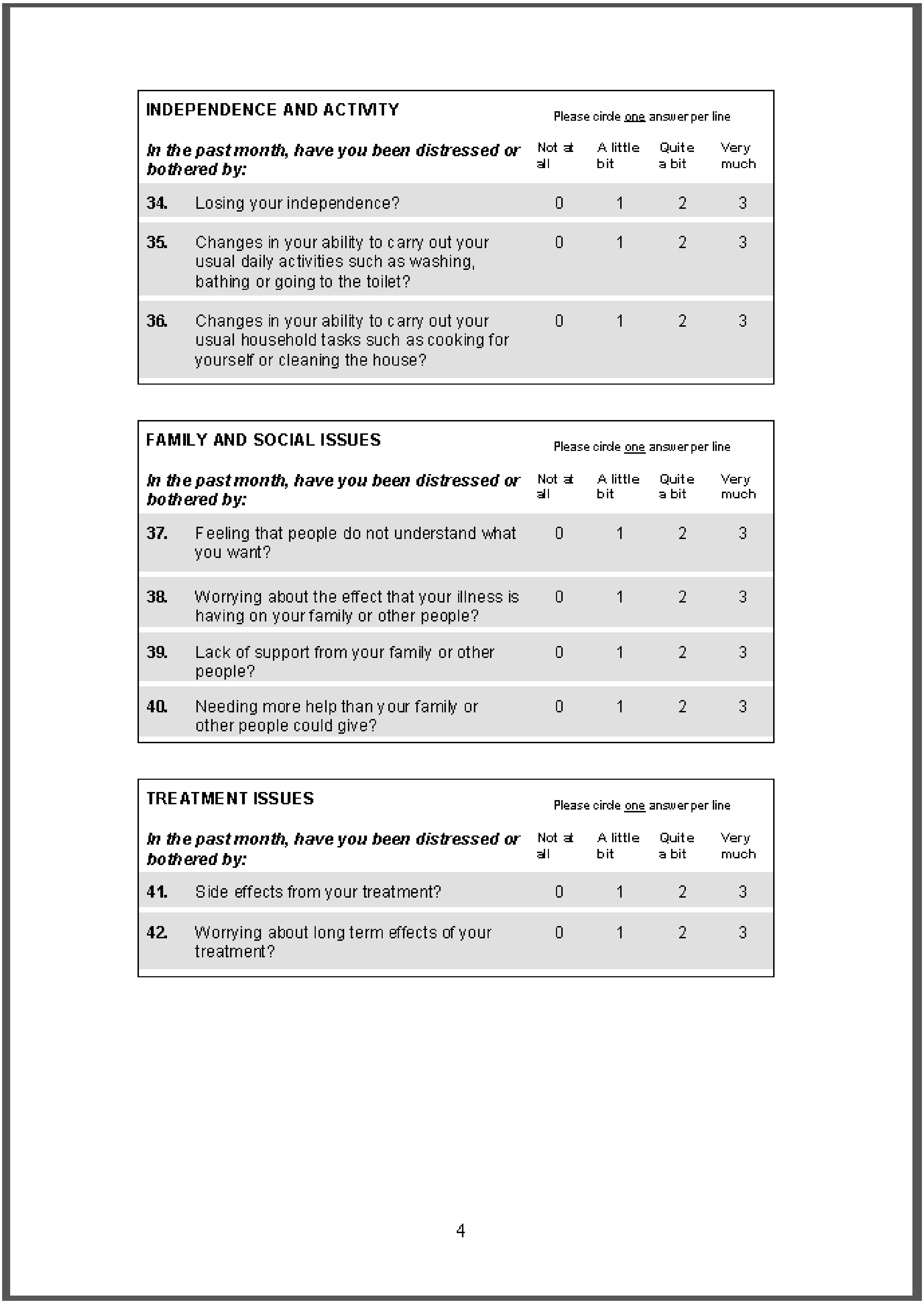
| ***In the past month, have you been distressed or bothered by:*** | Not at all | A little bit | Quite a bit | Very much |
|---|---|---|---|---|
| **23.** Feeling anxious? | 0 | 1 | 2 | 3 |
| **24.** Feeling as if you are in a low mood? | 0 | 1 | 2 | 3 |
| **25.** Feeling confused? | 0 | 1 | 2 | 3 |
| **26.** Feeling as if you are 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 |

**RELIGIOUS AND SPIRITUAL ISSUES**

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 |
|---|---|---|---|---|
| **32.** Worrying thoughts about death or dying? | 0 | 1 | 2 | 3 |
| **33.** Religious or spiritual needs not being met? | 0 | 1 | 2 | 3 |

3



### INDEPENDENCE AND ACTIVITY

Please circle <u>one</u> 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 |
|---|---|---|---|---|---|
| **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

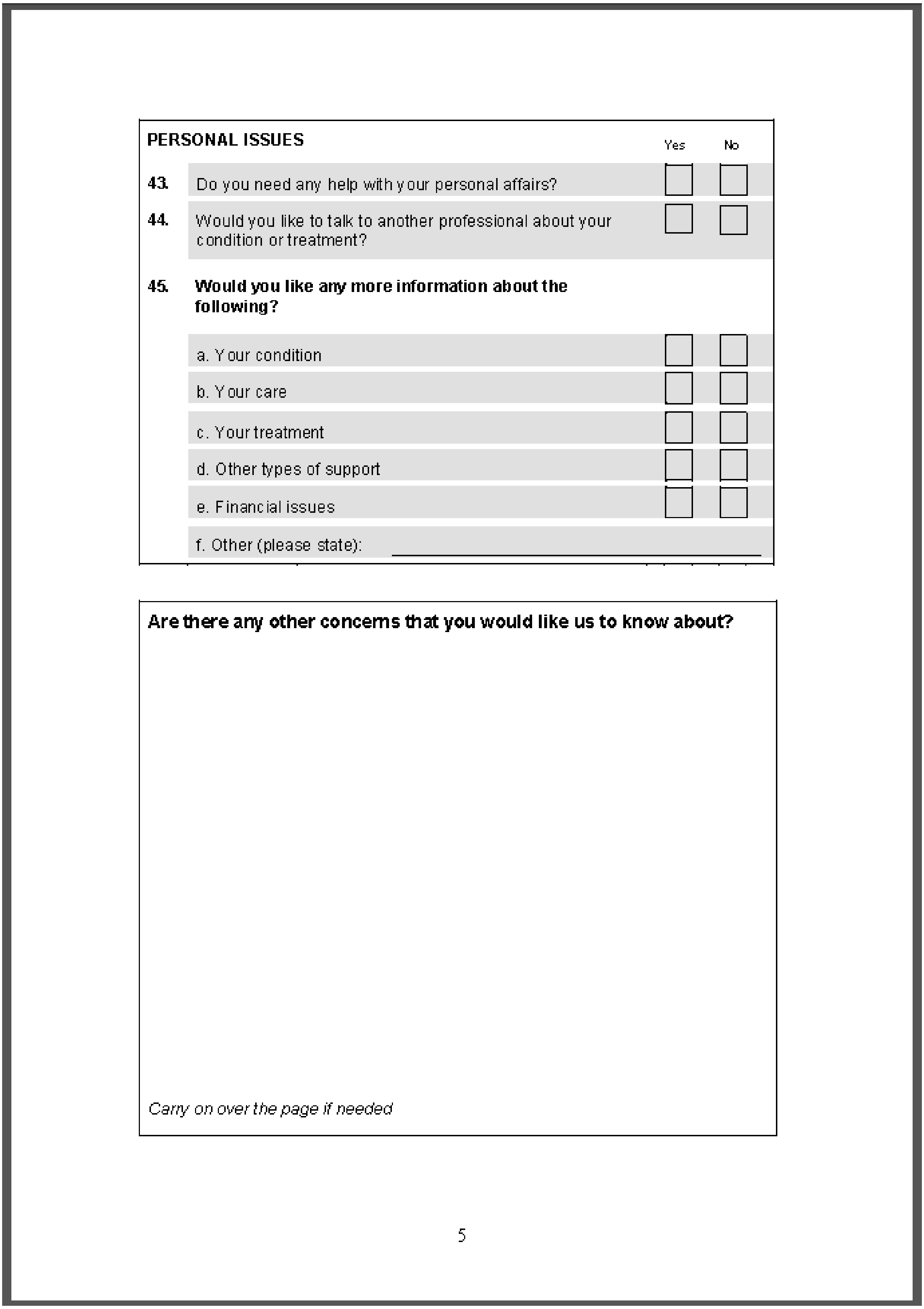
Please circle <u>one</u> answer per line

| ***In the past month, have you been distressed or bothered by:*** | | Not at all | A little bit | Quite a bit | Very much |
|---|---|---|---|---|---|
| **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

Please circle <u>one</u> 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 |
|---|---|---|---|---|---|
| **41.** | Side effects from your treatment? | 0 | 1 | 2 | 3 |
| **42.** | Worrying about long term effects of your treatment? | 0 | 1 | 2 | 3 |



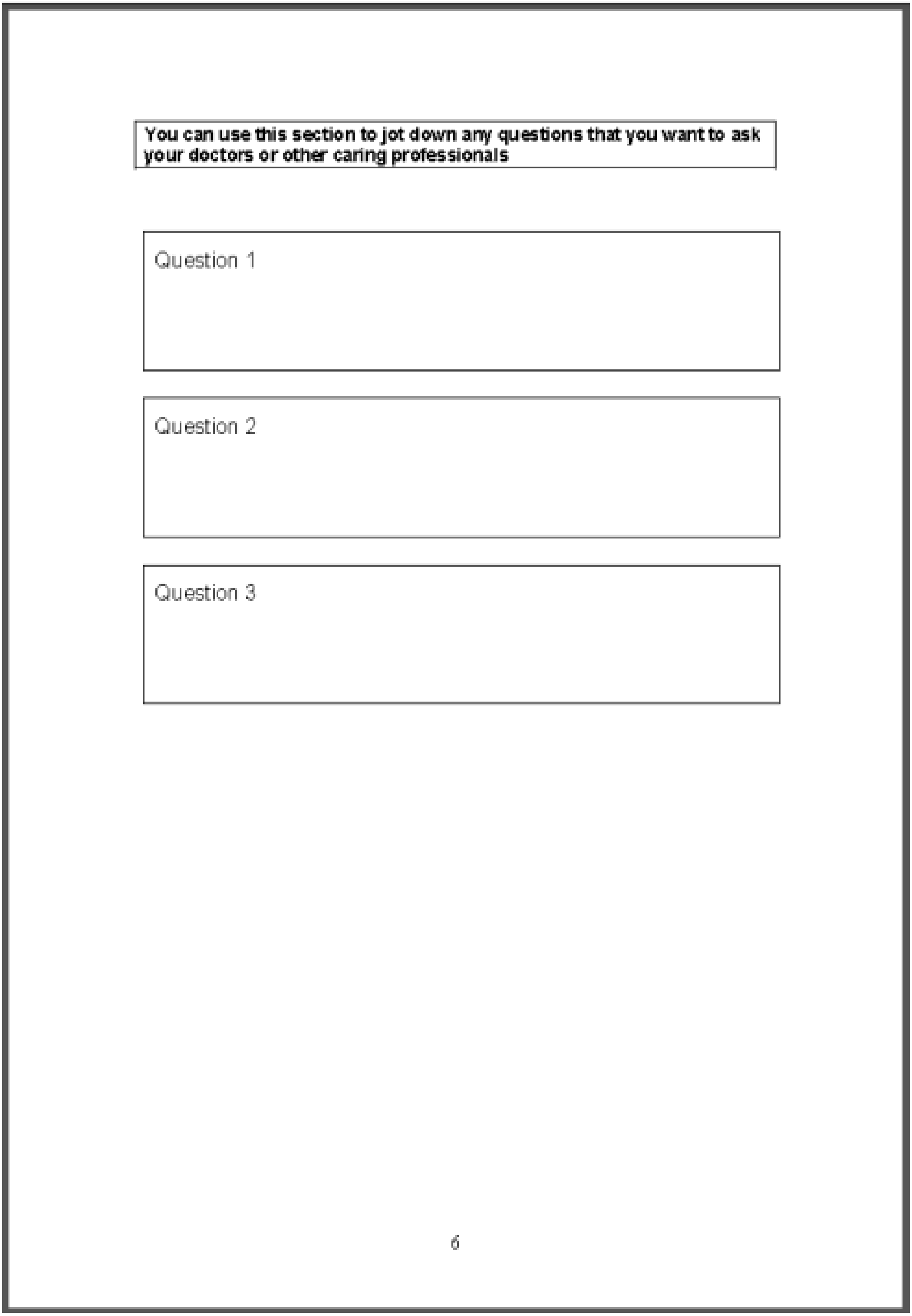
**PERSONAL ISSUES**

| | | 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 that you would like us to know about?**

*Carry on over the page if needed*

5



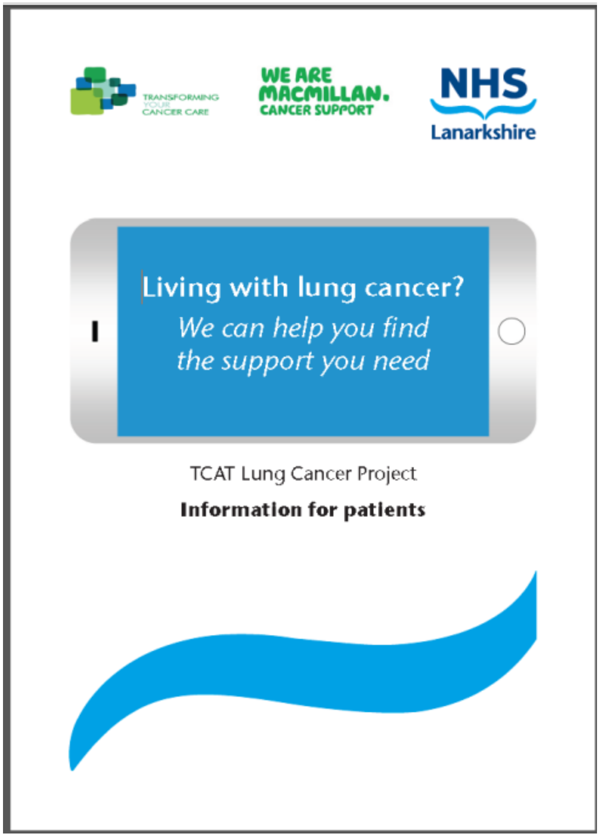
**You can use this section to jot down any questions that you want to ask your doctors or other caring professionals**

| |
|---|
| Question 1 |

| |
|---|
| Question 2 |

| |
|---|
| Question 3 |

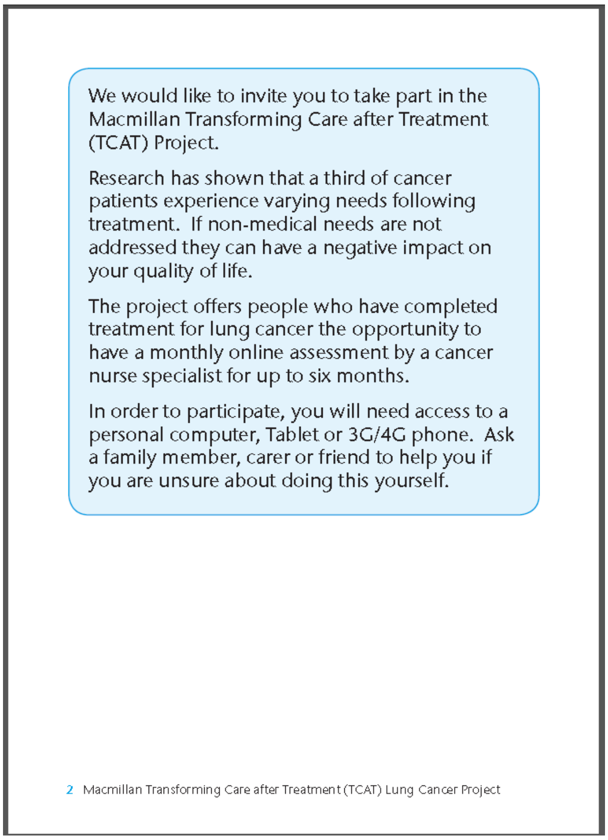
# Appendix II


Living with lung cancer?

*We can help you find the support you need*

TCAT Lung Cancer Project

**Information for patients**

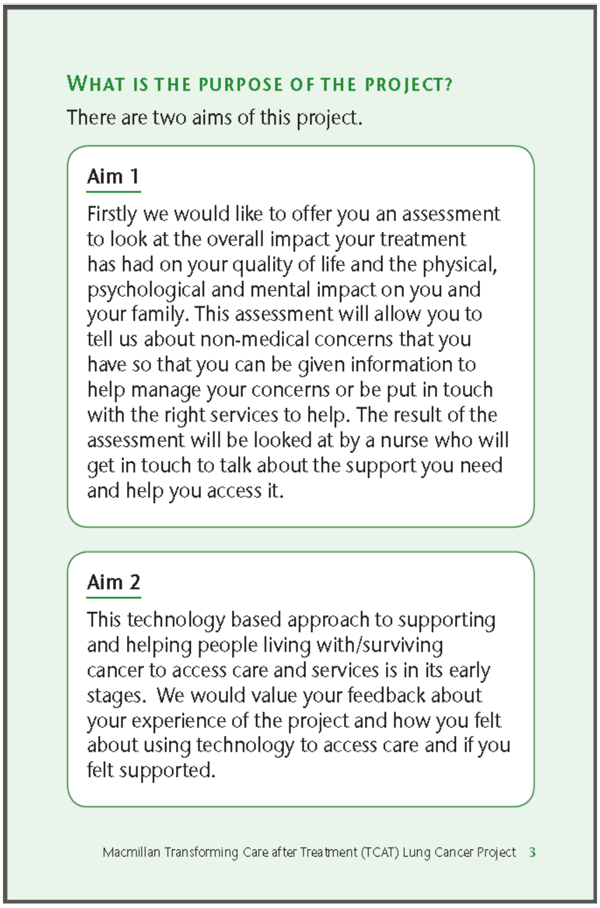

We would like to invite you to take part in the Macmillan Transforming Care after Treatment (TCAT) Project.

Research has shown that a third of cancer patients experience varying needs following treatment. If non-medical needs are not addressed they can have a negative impact on your quality of life.

The project offers people who have completed treatment for lung cancer the opportunity to have a monthly online assessment by a cancer nurse specialist for up to six months.

In order to participate, you will need access to a personal computer, Tablet or 3G/4G phone. Ask a family member, carer or friend to help you if you are unsure about doing this yourself.

2 Macmillan Transforming Care after Treatment (TCAT) Lung Cancer Project


## WHAT IS THE PURPOSE OF THE PROJECT?

There are two aims of this project.

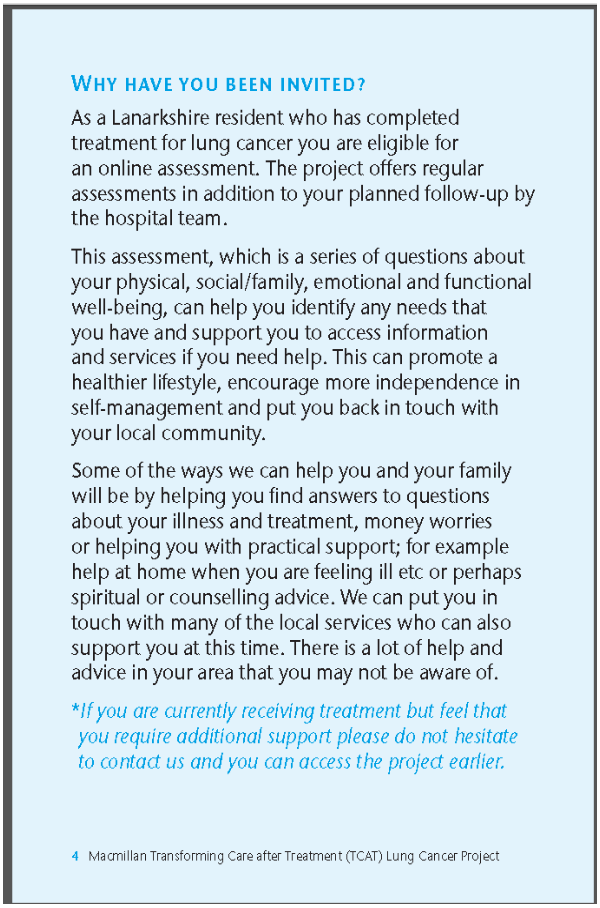
### Aim 1

Firstly we would like to offer you an assessment to look at the overall impact your treatment has had on your quality of life and the physical, psychological and mental impact on you and your family. This assessment will allow you to tell us about non-medical concerns that you have so that you can be given information to help manage your concerns or be put in touch with the right services to help. The result of the assessment will be looked at by a nurse who will get in touch to talk about the support you need and help you access it.

### Aim 2

This technology based approach to supporting and helping people living with/surviving cancer to access care and services is in its early stages. We would value your feedback about your experience of the project and how you felt about using technology to access care and if you felt supported.

Macmillan Transforming Care after Treatment (TCAT) Lung Cancer Project 3


## WHY HAVE YOU BEEN INVITED?

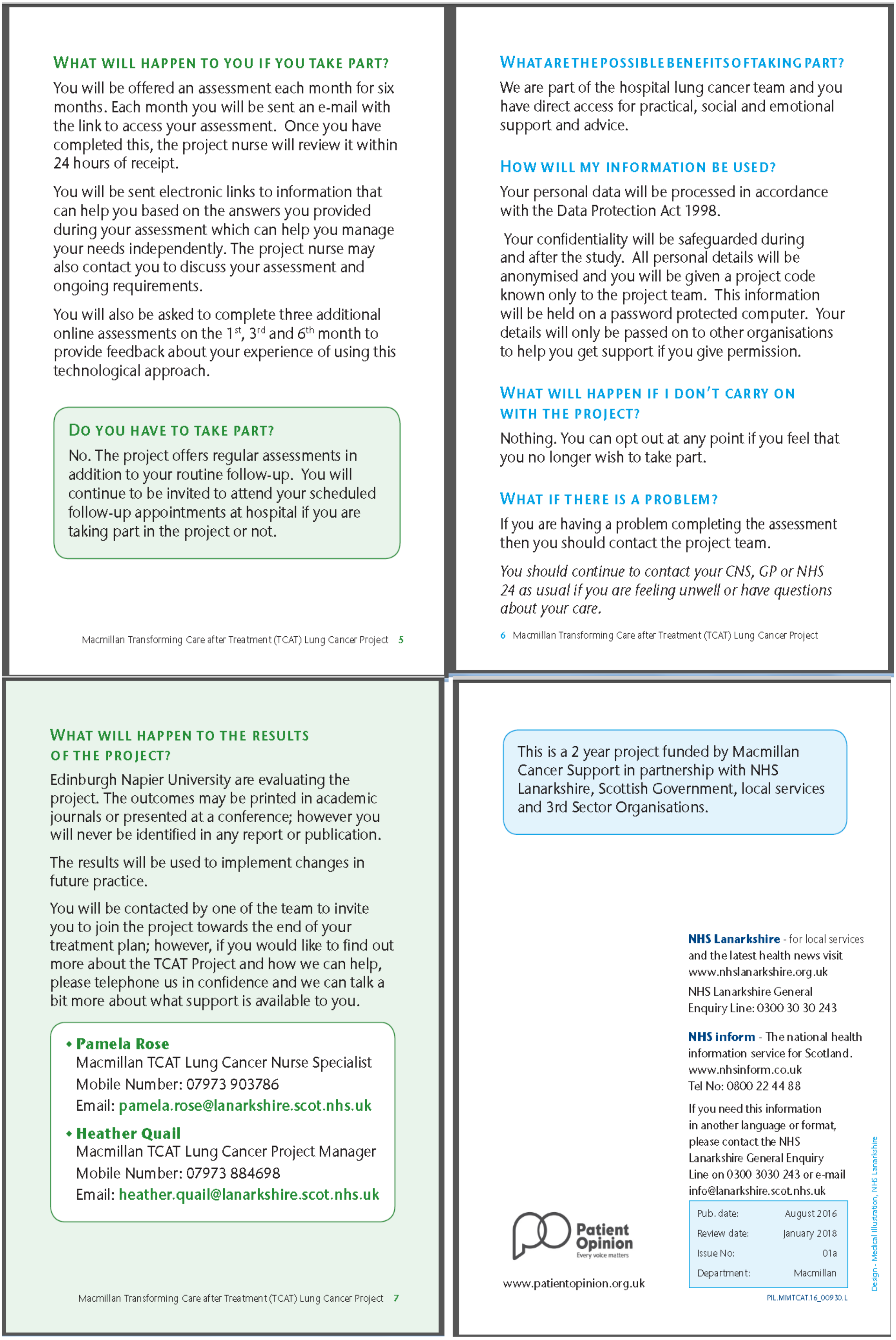
As a Lanarkshire resident who has completed treatment for lung cancer you are eligible for an online assessment. The project offers regular assessments in addition to your planned follow-up by the hospital team.

This assessment, which is a series of questions about your physical, social/family, emotional and functional well-being, can help you identify any needs that you have and support you to access information and services if you need help. This can promote a healthier lifestyle, encourage more independence in self-management and put you back in touch with your local community.

Some of the ways we can help you and your family will be by helping you find answers to questions about your illness and treatment, money worries or helping you with practical support; for example help at home when you are feeling ill etc or perhaps spiritual or counselling advice. We can put you in touch with many of the local services who can also support you at this time. There is a lot of help and advice in your area that you may not be aware of.

**If you are currently receiving treatment but feel that you require additional support please do not hesitate to contact us and you can access the project earlier.*

4 Macmillan Transforming Care after Treatment (TCAT) Lung Cancer Project



### WHAT WILL HAPPEN TO YOU IF YOU TAKE PART?

You will be offered an assessment each month for six months. Each month you will be sent an e-mail with the link to access your assessment. Once you have completed this, the project nurse will review it within 24 hours of receipt.

You will be sent electronic links to information that can help you based on the answers you provided during your assessment which can help you manage your needs independently. The project nurse may also contact you to discuss your assessment and ongoing requirements.

You will also be asked to complete three additional online assessments on the 1st, 3rd and 6th month to provide feedback about your experience of using this technological approach.

### DO YOU HAVE TO TAKE PART?

No. The project offers regular assessments in addition to your routine follow-up. You will continue to be invited to attend your scheduled follow-up appointments at hospital if you are taking part in the project or not.

Macmillan Transforming Care after Treatment (TCAT) Lung Cancer Project 5

### WHAT ARE THE POSSIBLE BENEFITS OF TAKING PART?

We are part of the hospital lung cancer team and you have direct access for practical, social and emotional support and advice.

### HOW WILL MY INFORMATION BE USED?

Your personal data will be processed in accordance with the Data Protection Act 1998.

Your confidentiality will be safeguarded during and after the study. All personal details will be anonymised and you will be given a project code known only to the project team. This information will be held on a password protected computer. Your details will only be passed on to other organisations to help you get support if you give permission.

### WHAT WILL HAPPEN IF I DON'T CARRY ON WITH THE PROJECT?

Nothing. You can opt out at any point if you feel that you no longer wish to take part.

### WHAT IF THERE IS A PROBLEM?

If you are having a problem completing the assessment then you should contact the project team.

*You should continue to contact your CNS, GP or NHS 24 as usual if you are feeling unwell or have questions about your care.*

6 Macmillan Transforming Care after Treatment (TCAT) Lung Cancer Project

### WHAT WILL HAPPEN TO THE RESULTS OF THE PROJECT?

Edinburgh Napier University are evaluating the project. The outcomes may be printed in academic journals or presented at a conference; however you will never be identified in any report or publication.

The results will be used to implement changes in future practice.

You will be contacted by one of the team to invite you to join the project towards the end of your treatment plan; however, if you would like to find out more about the TCAT Project and how we can help, please telephone us in confidence and we can talk a bit more about what support is available to you.

- **Pamela Rose**
  Macmillan TCAT Lung Cancer Nurse Specialist
  Mobile Number: 07973 903786
  Email: **pamela.rose@lanarkshire.scot.nhs.uk**
- **Heather Quail**
  Macmillan TCAT Lung Cancer Project Manager
  Mobile Number: 07973 884698
  Email: **heather.quail@lanarkshire.scot.nhs.uk**

Macmillan Transforming Care after Treatment (TCAT) Lung Cancer Project 7

This is a 2 year project funded by Macmillan Cancer Support in partnership with NHS Lanarkshire, Scottish Government, local services and 3rd Sector Organisations.

**NHS Lanarkshire** - for local services and the latest health news visit www.nhslanarkshire.org.uk

NHS Lanarkshire General Enquiry Line: 0300 30 30 243

**NHS inform** - The national health information service for Scotland.
www.nhsinform.co.uk
Tel No: 0800 22 44 88

If you need this information in another language or format, please contact the NHS Lanarkshire General Enquiry Line on 0300 3030 243 or e-mail info@lanarkshire.scot.nhs.uk

| | |
|---|---|
| Pub. date: | August 2016 |
| Review date: | January 2018 |
| Issue No: | 01a |
| Department: | Macmillan |

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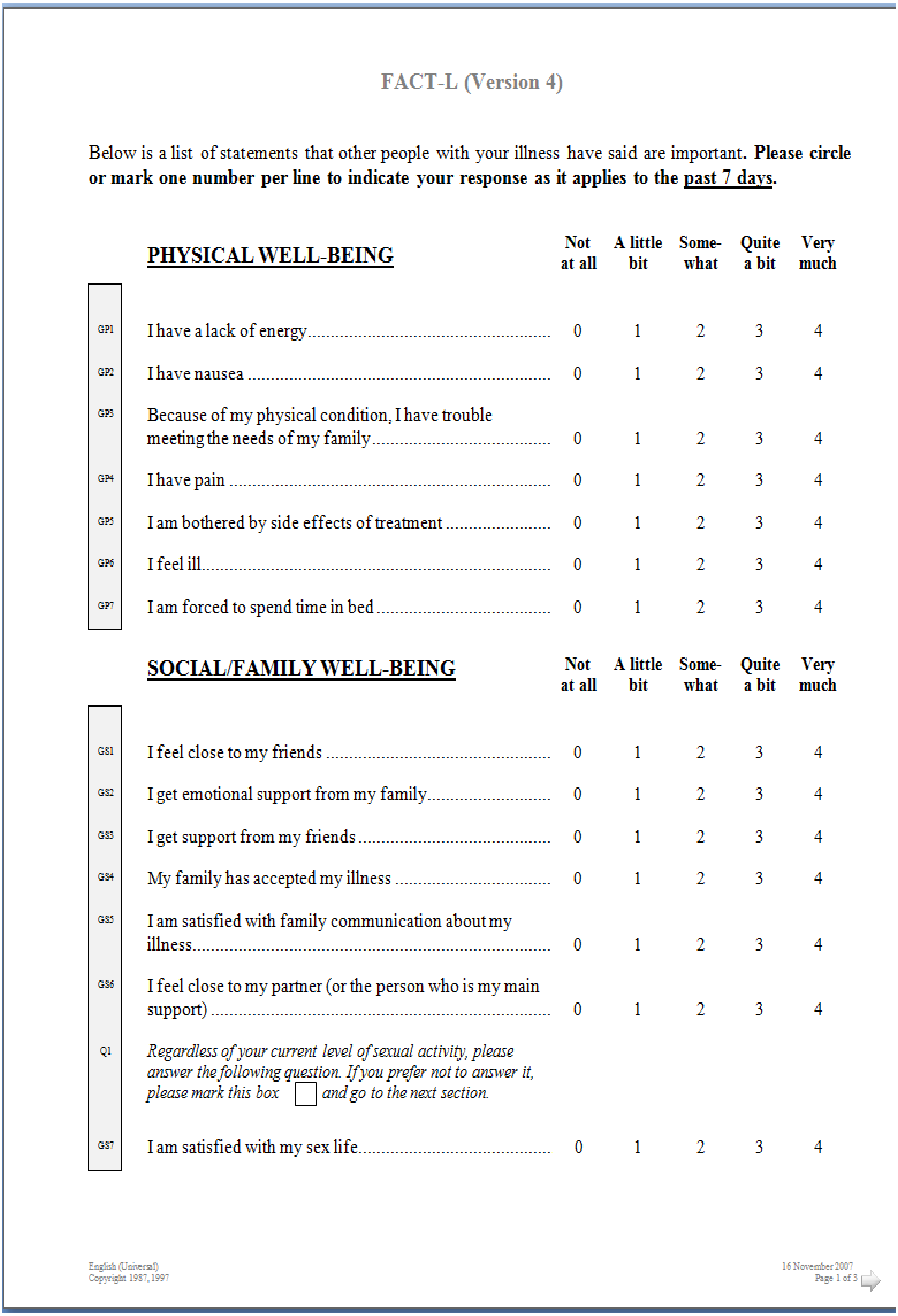
Design - Medical Illustration, NHS Lanarkshire

Patient Opinion
Every voice matters

www.patientopinion.org.uk

# Appendix III



## FACT-L (Version 4)

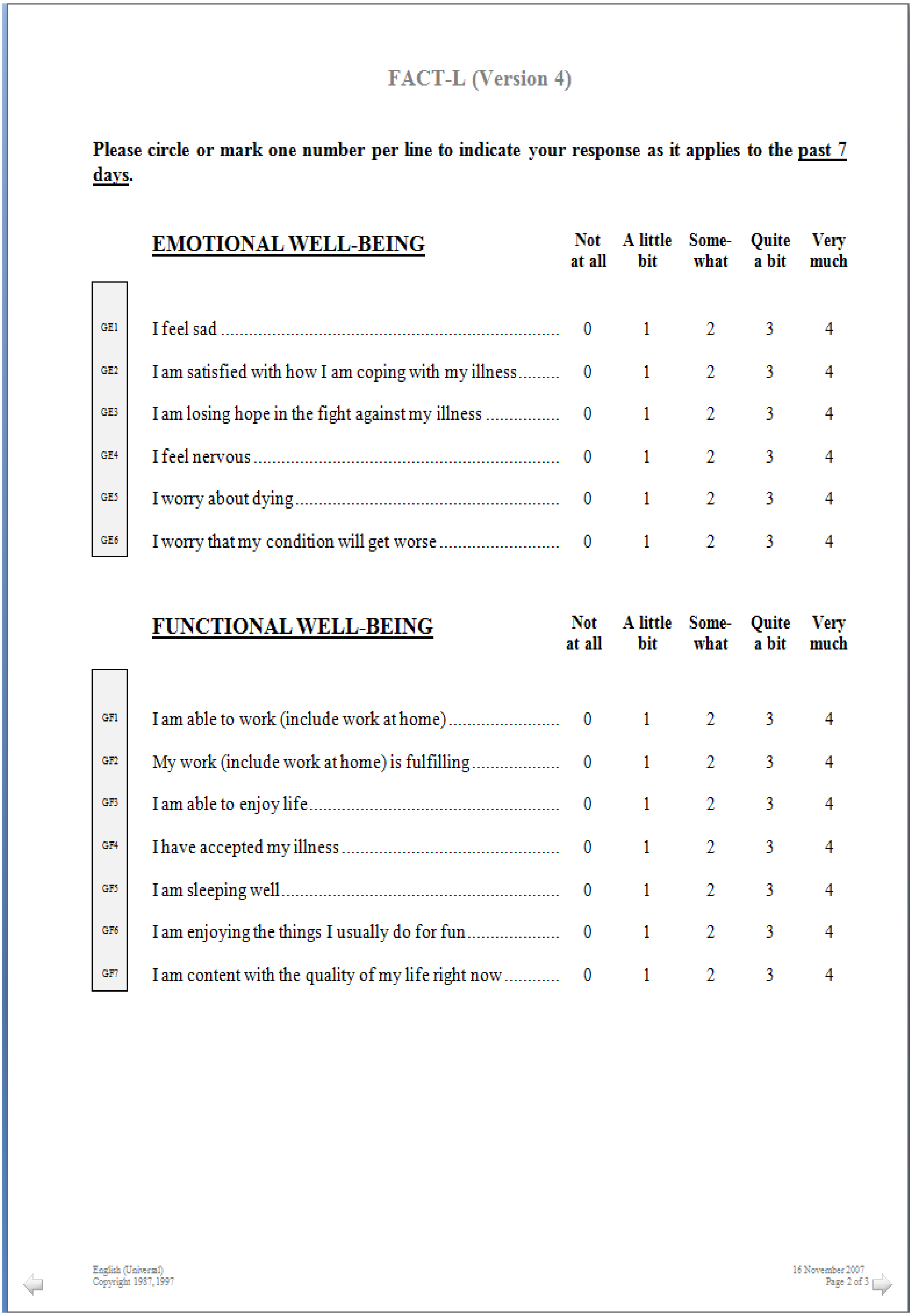
Below is a list of statements that other people with your illness have said are important. **Please circle or mark one number per line to indicate your response as it applies to the past 7 days.**

| | **PHYSICAL WELL-BEING** | **Not at all** | **A little bit** | **Some-what** | **Quite a bit** | **Very much** |
|---|---|---|---|---|---|---|
| GP1 | I have a lack of energy | 0 | 1 | 2 | 3 | 4 |
| GP2 | I have nausea | 0 | 1 | 2 | 3 | 4 |
| GP3 | Because of my physical condition, I have trouble meeting the needs of my family | 0 | 1 | 2 | 3 | 4 |
| GP4 | I have pain | 0 | 1 | 2 | 3 | 4 |
| GP5 | I am bothered by side effects of treatment | 0 | 1 | 2 | 3 | 4 |
| GP6 | I feel ill | 0 | 1 | 2 | 3 | 4 |
| GP7 | I am forced to spend time in bed | 0 | 1 | 2 | 3 | 4 |

| | **SOCIAL/FAMILY WELL-BEING** | **Not at all** | **A little bit** | **Some-what** | **Quite a bit** | **Very much** |
|---|---|---|---|---|---|---|
| GS1 | I feel close to my friends | 0 | 1 | 2 | 3 | 4 |
| GS2 | I get emotional support from my family | 0 | 1 | 2 | 3 | 4 |
| GS3 | I get support from my friends | 0 | 1 | 2 | 3 | 4 |
| GS4 | My family has accepted my illness | 0 | 1 | 2 | 3 | 4 |
| GS5 | I am satisfied with family communication about my illness | 0 | 1 | 2 | 3 | 4 |
| GS6 | I feel close to my partner (or the person who is my main support) | 0 | 1 | 2 | 3 | 4 |
| Q1 | *Regardless of your current level of sexual activity, please answer the following question. If you prefer not to answer it, please mark this box* ☐ *and go to the next section.* | | | | | |
| GS7 | I am satisfied with my sex life | 0 | 1 | 2 | 3 | 4 |

English (Universal)

16 November 2007
Page 1 of 3



## FACT-L (Version 4)

**Please circle or mark one number per line to indicate your response as it applies to the past 7 days.**

|  | **EMOTIONAL WELL-BEING** | **Not at all** | **A little bit** | **Some-what** | **Quite a bit** | **Very much** |
|---|---|---|---|---|---|---|
| GE1 | I feel sad | 0 | 1 | 2 | 3 | 4 |
| GE2 | I am satisfied with how I am coping with my illness | 0 | 1 | 2 | 3 | 4 |
| GE3 | I am losing hope in the fight against my illness | 0 | 1 | 2 | 3 | 4 |
| GE4 | I feel nervous | 0 | 1 | 2 | 3 | 4 |
| GE5 | I worry about dying | 0 | 1 | 2 | 3 | 4 |
| GE6 | I worry that my condition will get worse | 0 | 1 | 2 | 3 | 4 |

|  | **FUNCTIONAL WELL-BEING** | **Not at all** | **A little bit** | **Some-what** | **Quite a bit** | **Very much** |
|---|---|---|---|---|---|---|
| GF1 | I am able to work (include work at home) | 0 | 1 | 2 | 3 | 4 |
| GF2 | My work (include work at home) is fulfilling | 0 | 1 | 2 | 3 | 4 |
| GF3 | I am able to enjoy life | 0 | 1 | 2 | 3 | 4 |
| GF4 | I have accepted my illness | 0 | 1 | 2 | 3 | 4 |
| GF5 | I am sleeping well | 0 | 1 | 2 | 3 | 4 |
| GF6 | I am enjoying the things I usually do for fun | 0 | 1 | 2 | 3 | 4 |
| GF7 | I am content with the quality of my life right now | 0 | 1 | 2 | 3 | 4 |

English (Universal)
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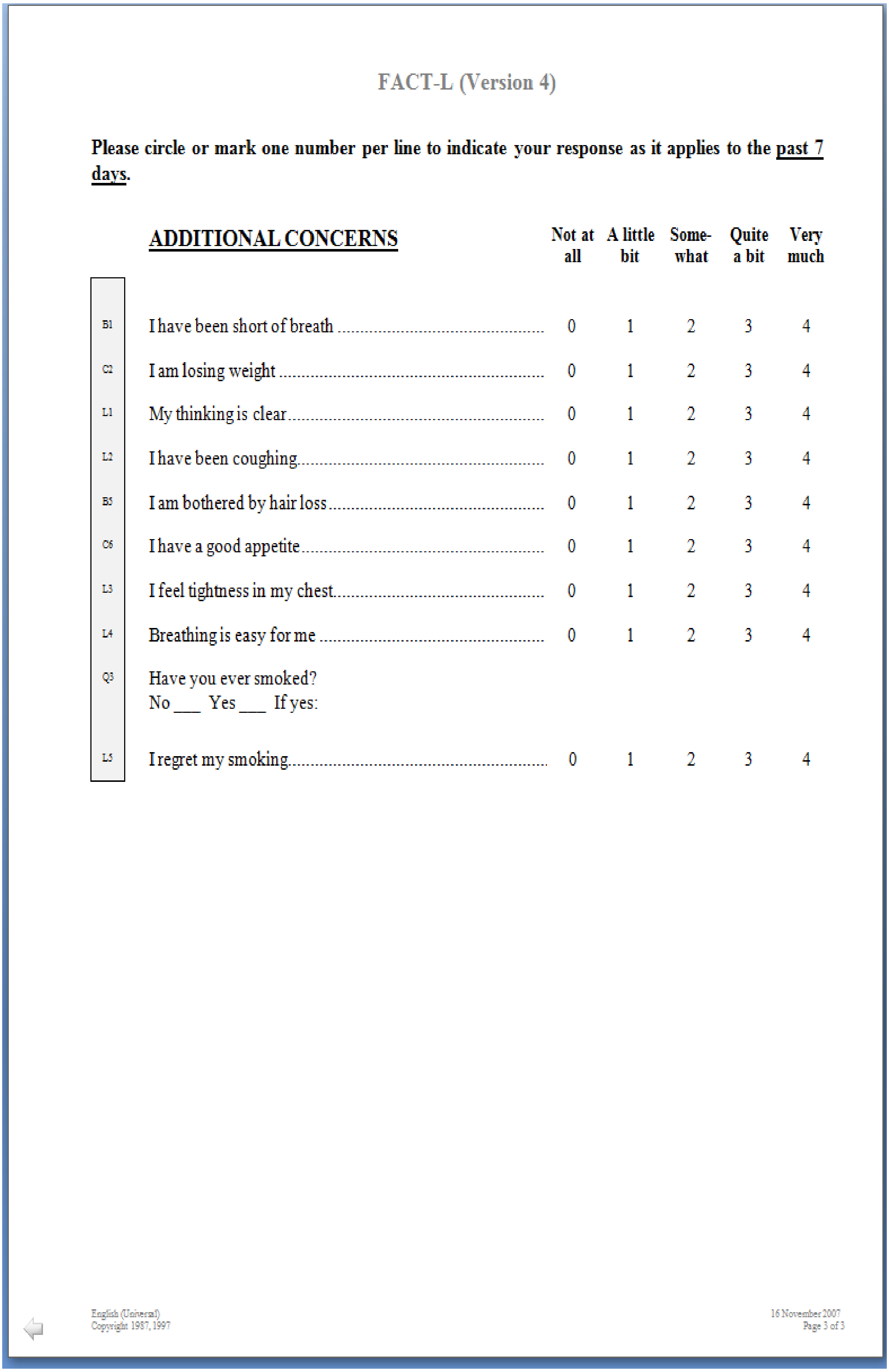
16 November 2007
Page 2 of 3



## FACT-L (Version 4)

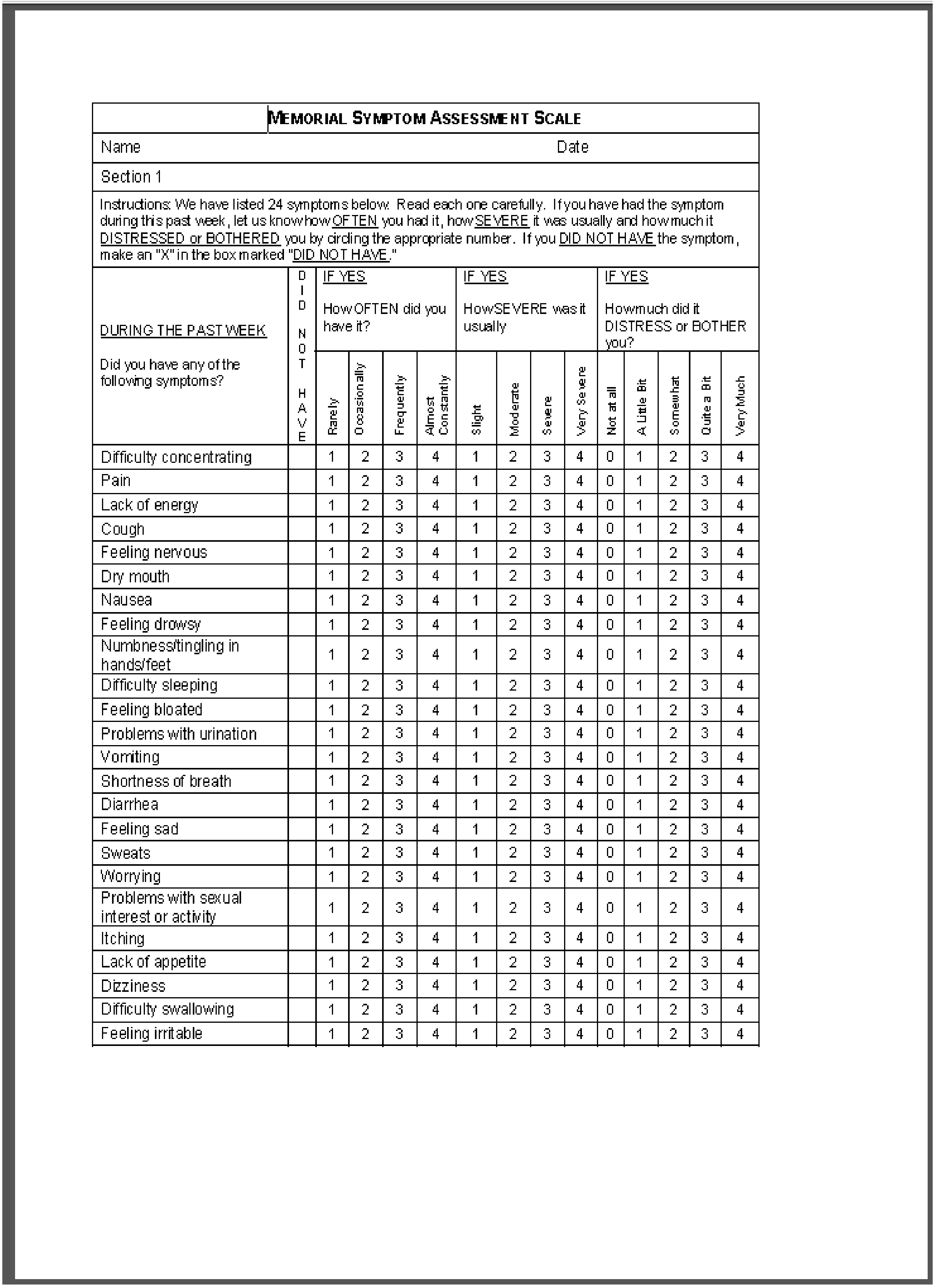
**Please circle or mark one number per line to indicate your response as it applies to the past 7 days.**

| | **ADDITIONAL CONCERNS** | **Not at all** | **A little bit** | **Some-what** | **Quite a bit** | **Very much** |
|---|---|---|---|---|---|---|
| B1 | I have been short of breath | 0 | 1 | 2 | 3 | 4 |
| C2 | I am losing weight | 0 | 1 | 2 | 3 | 4 |
| L1 | My thinking is clear | 0 | 1 | 2 | 3 | 4 |
| L2 | I have been coughing | 0 | 1 | 2 | 3 | 4 |
| B5 | I am bothered by hair loss | 0 | 1 | 2 | 3 | 4 |
| C6 | I have a good appetite | 0 | 1 | 2 | 3 | 4 |
| L3 | I feel tightness in my chest | 0 | 1 | 2 | 3 | 4 |
| L4 | Breathing is easy for me | 0 | 1 | 2 | 3 | 4 |
| Q3 | Have you ever smoked?<br>No ___ Yes ___ If yes: | | | | | |
| L5 | I regret my smoking | 0 | 1 | 2 | 3 | 4 |

English (Universal)

16 November 2007
Page 3 of 3

# Appendix IV



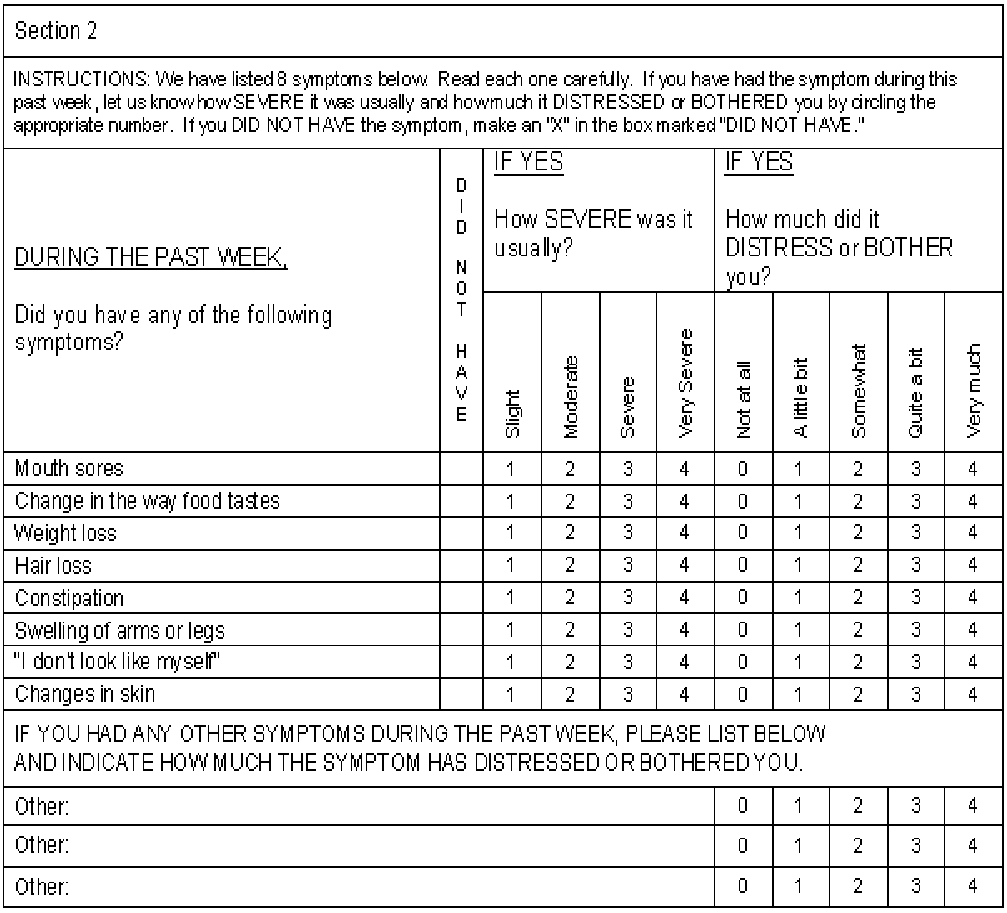
**MEMORIAL SYMPTOM ASSESSMENT SCALE**

Name Date

Section 1

Instructions: We have listed 24 symptoms below. Read each one carefully. If you have had the symptom during this past week, let us know how OFTEN you had it, how SEVERE it was usually and how much it DISTRESSED or BOTHERED you by circling the appropriate number. If you DID NOT HAVE the symptom, make an "X" in the box marked "DID NOT HAVE."

| DURING THE PAST WEEK<br>Did you have any of the following symptoms? | DID NOT HAVE | IF YES<br>How OFTEN did you have it? | | | | IF YES<br>How SEVERE was it usually | | | | IF YES<br>How much did it DISTRESS or BOTHER you? | | | | |
|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|
| | | Rarely | Occasionally | Frequently | Almost Constantly | Slight | Moderate | Severe | Very Severe | Not at all | A Little Bit | Somewhat | Quite a Bit | Very Much |
| Difficulty concentrating | | 1 | 2 | 3 | 4 | 1 | 2 | 3 | 4 | 0 | 1 | 2 | 3 | 4 |
| Pain | | 1 | 2 | 3 | 4 | 1 | 2 | 3 | 4 | 0 | 1 | 2 | 3 | 4 |
| Lack of energy | | 1 | 2 | 3 | 4 | 1 | 2 | 3 | 4 | 0 | 1 | 2 | 3 | 4 |
| Cough | | 1 | 2 | 3 | 4 | 1 | 2 | 3 | 4 | 0 | 1 | 2 | 3 | 4 |
| Feeling nervous | | 1 | 2 | 3 | 4 | 1 | 2 | 3 | 4 | 0 | 1 | 2 | 3 | 4 |
| Dry mouth | | 1 | 2 | 3 | 4 | 1 | 2 | 3 | 4 | 0 | 1 | 2 | 3 | 4 |
| Nausea | | 1 | 2 | 3 | 4 | 1 | 2 | 3 | 4 | 0 | 1 | 2 | 3 | 4 |
| Feeling drowsy | | 1 | 2 | 3 | 4 | 1 | 2 | 3 | 4 | 0 | 1 | 2 | 3 | 4 |
| Numbness/tingling in hands/feet | | 1 | 2 | 3 | 4 | 1 | 2 | 3 | 4 | 0 | 1 | 2 | 3 | 4 |
| Difficulty sleeping | | 1 | 2 | 3 | 4 | 1 | 2 | 3 | 4 | 0 | 1 | 2 | 3 | 4 |
| Feeling bloated | | 1 | 2 | 3 | 4 | 1 | 2 | 3 | 4 | 0 | 1 | 2 | 3 | 4 |
| Problems with urination | | 1 | 2 | 3 | 4 | 1 | 2 | 3 | 4 | 0 | 1 | 2 | 3 | 4 |
| Vomiting | | 1 | 2 | 3 | 4 | 1 | 2 | 3 | 4 | 0 | 1 | 2 | 3 | 4 |
| Shortness of breath | | 1 | 2 | 3 | 4 | 1 | 2 | 3 | 4 | 0 | 1 | 2 | 3 | 4 |
| Diarrhea | | 1 | 2 | 3 | 4 | 1 | 2 | 3 | 4 | 0 | 1 | 2 | 3 | 4 |
| Feeling sad | | 1 | 2 | 3 | 4 | 1 | 2 | 3 | 4 | 0 | 1 | 2 | 3 | 4 |
| Sweats | | 1 | 2 | 3 | 4 | 1 | 2 | 3 | 4 | 0 | 1 | 2 | 3 | 4 |
| Worrying | | 1 | 2 | 3 | 4 | 1 | 2 | 3 | 4 | 0 | 1 | 2 | 3 | 4 |
| Problems with sexual interest or activity | | 1 | 2 | 3 | 4 | 1 | 2 | 3 | 4 | 0 | 1 | 2 | 3 | 4 |
| Itching | | 1 | 2 | 3 | 4 | 1 | 2 | 3 | 4 | 0 | 1 | 2 | 3 | 4 |
| Lack of appetite | | 1 | 2 | 3 | 4 | 1 | 2 | 3 | 4 | 0 | 1 | 2 | 3 | 4 |
| Dizziness | | 1 | 2 | 3 | 4 | 1 | 2 | 3 | 4 | 0 | 1 | 2 | 3 | 4 |
| Difficulty swallowing | | 1 | 2 | 3 | 4 | 1 | 2 | 3 | 4 | 0 | 1 | 2 | 3 | 4 |
| Feeling irritable | | 1 | 2 | 3 | 4 | 1 | 2 | 3 | 4 | 0 | 1 | 2 | 3 | 4 |



Section 2

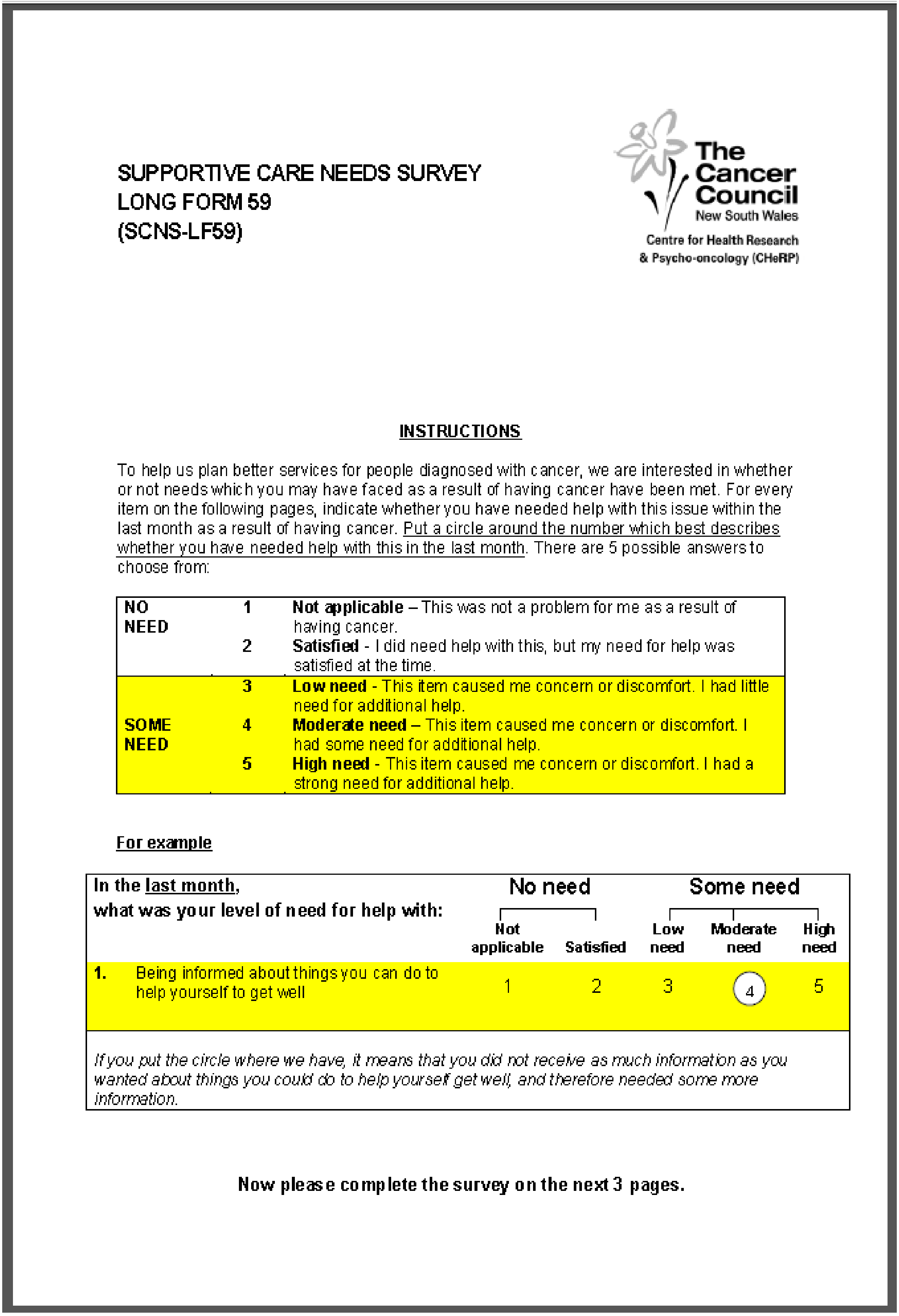
INSTRUCTIONS: We have listed 8 symptoms below. Read each one carefully. If you have had the symptom during this past week, let us know how SEVERE it was usually and how much it DISTRESSED or BOTHERED you by circling the appropriate number. If you DID NOT HAVE the symptom, make an "X" in the box marked "DID NOT HAVE."

| <u>DURING THE PAST WEEK,</u><br>Did you have any of the following symptoms? | DID NOT HAVE | <u>IF YES</u><br>How SEVERE was it usually? | | | | <u>IF YES</u><br>How much did it DISTRESS or BOTHER you? | | | | |
|---|---|---|---|---|---|---|---|---|---|---|
| | | Slight | Moderate | Severe | Very Severe | Not at all | A little bit | Somewhat | Quite a bit | Very much |
| Mouth sores | | 1 | 2 | 3 | 4 | 0 | 1 | 2 | 3 | 4 |
| Change in the way food tastes | | 1 | 2 | 3 | 4 | 0 | 1 | 2 | 3 | 4 |
| Weight loss | | 1 | 2 | 3 | 4 | 0 | 1 | 2 | 3 | 4 |
| Hair loss | | 1 | 2 | 3 | 4 | 0 | 1 | 2 | 3 | 4 |
| Constipation | | 1 | 2 | 3 | 4 | 0 | 1 | 2 | 3 | 4 |
| Swelling of arms or legs | | 1 | 2 | 3 | 4 | 0 | 1 | 2 | 3 | 4 |
| "I don't look like myself" | | 1 | 2 | 3 | 4 | 0 | 1 | 2 | 3 | 4 |
| Changes in skin | | 1 | 2 | 3 | 4 | 0 | 1 | 2 | 3 | 4 |

IF YOU HAD ANY OTHER SYMPTOMS DURING THE PAST WEEK, PLEASE LIST BELOW AND INDICATE HOW MUCH THE SYMPTOM HAS DISTRESSED OR BOTHERED YOU.

| | | | | | |
|---|---|---|---|---|---|
| Other: | 0 | 1 | 2 | 3 | 4 |
| Other: | 0 | 1 | 2 | 3 | 4 |
| Other: | 0 | 1 | 2 | 3 | 4 |

# Appendix V



SUPPORTIVE CARE NEEDS SURVEY
LONG FORM 59
(SCNS-LF59)

The Cancer Council
New South Wales
Centre for Health Research
& Psycho-oncology (CHeRP)

## INSTRUCTIONS

To help us plan better services for people diagnosed with cancer, we are interested in whether or not needs which you may have faced as a result of having cancer have been met. For every item on the following pages, indicate whether you have needed help with this issue within the last month as a result of having cancer. Put a circle around the number which best describes whether you have needed help with this in the last month. There are 5 possible answers to choose from:

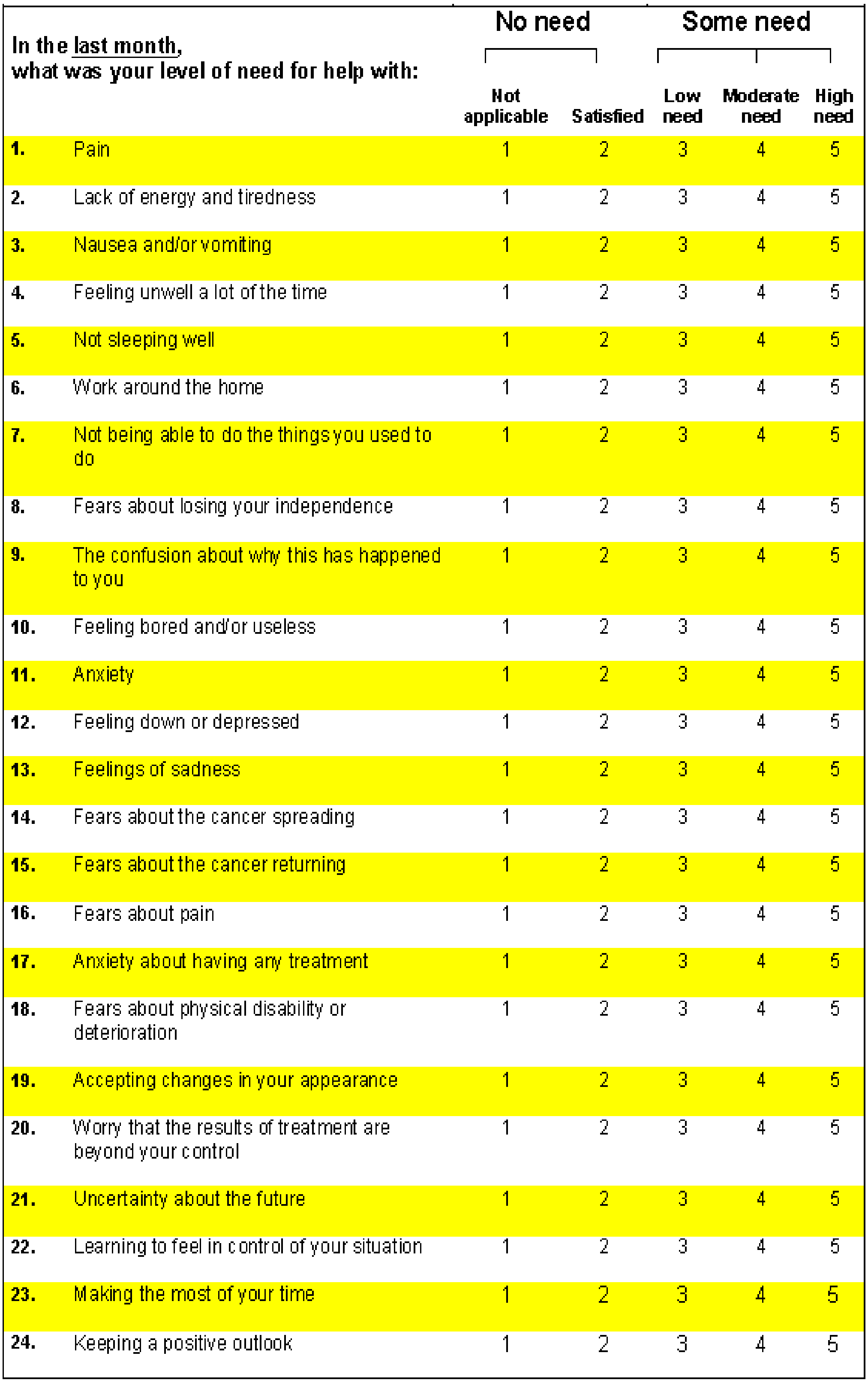
| | | |
|---|---|---|
| **NO NEED** | 1 | **Not applicable** – This was not a problem for me as a result of having cancer. |
| | 2 | **Satisfied** - I did need help with this, but my need for help was satisfied at the time. |
| **SOME NEED** | 3 | **Low need** - This item caused me concern or discomfort. I had little need for additional help. |
| | 4 | **Moderate need** – This item caused me concern or discomfort. I had some need for additional help. |
| | 5 | **High need** - This item caused me concern or discomfort. I had a strong need for additional help. |

**For example**

| **In the last month, what was your level of need for help with:** | No need<br>**Not applicable** | <br>**Satisfied** | Some need<br>**Low need** | <br>**Moderate need** | <br>**High need** |
|---|---|---|---|---|---|
| **1.** Being informed about things you can do to help yourself to get well | 1 | 2 | 3 | [✓ 4] | 5 |

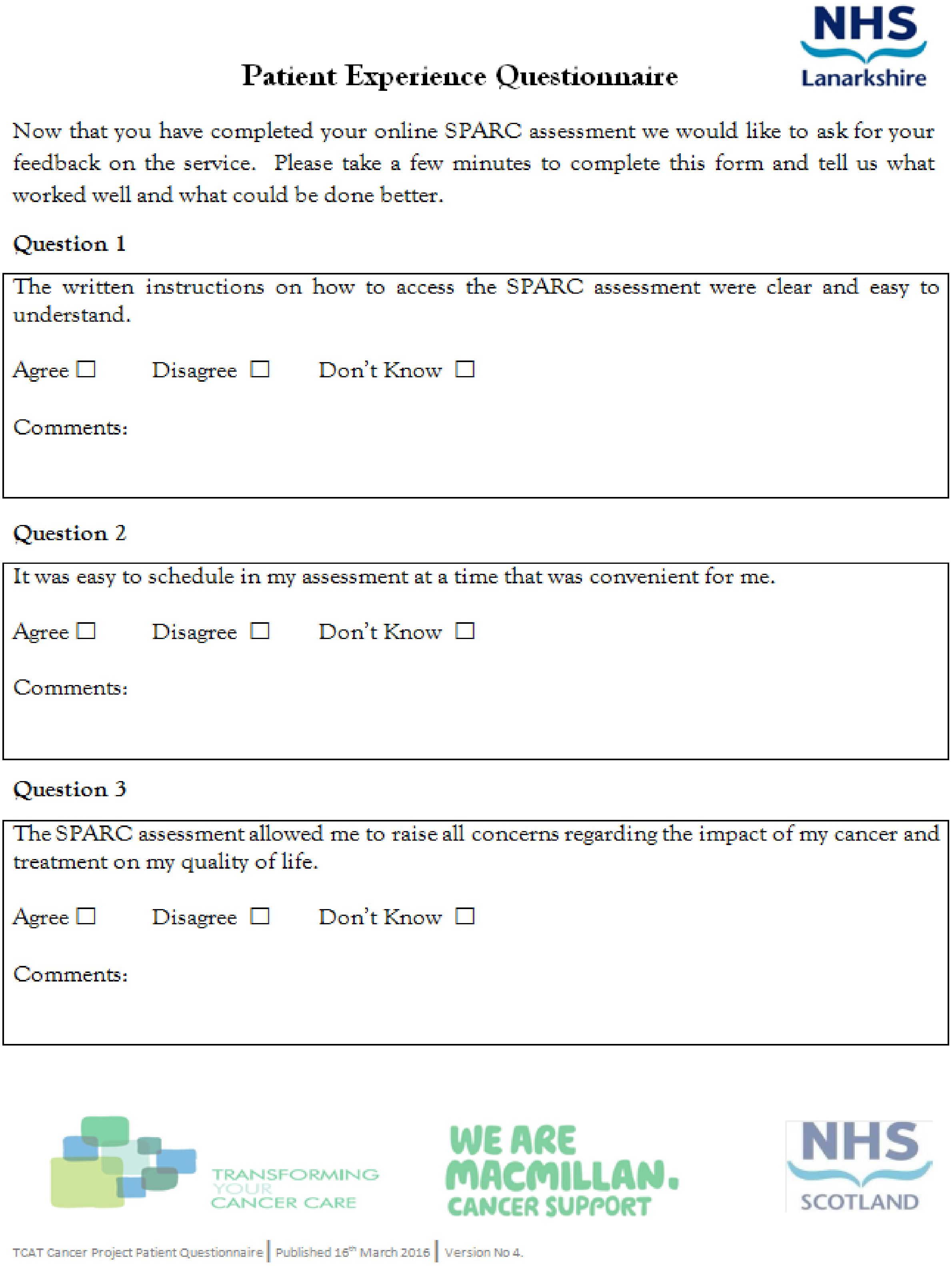
*If you put the circle where we have, it means that you did not receive as much information as you wanted about things you could do to help yourself get well, and therefore needed some more information.*

**Now please complete the survey on the next 3 pages.**



| **In the last month, what was your level of need for help with:** | | **No need** | | **Some need** | | |
|---|---|---|---|---|---|---|
| | | **Not applicable** | **Satisfied** | **Low need** | **Moderate need** | **High need** |
| **1.** | Pain | 1 | 2 | 3 | 4 | 5 |
| **2.** | Lack of energy and tiredness | 1 | 2 | 3 | 4 | 5 |
| **3.** | Nausea and/or vomiting | 1 | 2 | 3 | 4 | 5 |
| **4.** | Feeling unwell a lot of the time | 1 | 2 | 3 | 4 | 5 |
| **5.** | Not sleeping well | 1 | 2 | 3 | 4 | 5 |
| **6.** | Work around the home | 1 | 2 | 3 | 4 | 5 |
| **7.** | Not being able to do the things you used to do | 1 | 2 | 3 | 4 | 5 |
| **8.** | Fears about losing your independence | 1 | 2 | 3 | 4 | 5 |
| **9.** | The confusion about why this has happened to you | 1 | 2 | 3 | 4 | 5 |
| **10.** | Feeling bored and/or useless | 1 | 2 | 3 | 4 | 5 |
| **11.** | Anxiety | 1 | 2 | 3 | 4 | 5 |
| **12.** | Feeling down or depressed | 1 | 2 | 3 | 4 | 5 |
| **13.** | Feelings of sadness | 1 | 2 | 3 | 4 | 5 |
| **14.** | Fears about the cancer spreading | 1 | 2 | 3 | 4 | 5 |
| **15.** | Fears about the cancer returning | 1 | 2 | 3 | 4 | 5 |
| **16.** | Fears about pain | 1 | 2 | 3 | 4 | 5 |
| **17.** | Anxiety about having any treatment | 1 | 2 | 3 | 4 | 5 |
| **18.** | Fears about physical disability or deterioration | 1 | 2 | 3 | 4 | 5 |
| **19.** | Accepting changes in your appearance | 1 | 2 | 3 | 4 | 5 |
| **20.** | Worry that the results of treatment are beyond your control | 1 | 2 | 3 | 4 | 5 |
| **21.** | Uncertainty about the future | 1 | 2 | 3 | 4 | 5 |
| **22.** | Learning to feel in control of your situation | 1 | 2 | 3 | 4 | 5 |
| **23.** | Making the most of your time | 1 | 2 | 3 | 4 | 5 |
| **24.** | Keeping a positive outlook | 1 | 2 | 3 | 4 | 5 |

# Appendix VI



## Patient Experience Questionnaire

NHS Lanarkshire

Now that you have completed your online SPARC assessment we would like to ask for your feedback on the service. Please take a few minutes to complete this form and tell us what worked well and what could be done better.

**Question 1**

The written instructions on how to access the SPARC assessment were clear and easy to understand.

Agree ☐ Disagree ☐ Don't Know ☐

Comments:

**Question 2**

It was easy to schedule in my assessment at a time that was convenient for me.

Agree ☐ Disagree ☐ Don't Know ☐

Comments:

**Question 3**

The SPARC assessment allowed me to raise all concerns regarding the impact of my cancer and treatment on my quality of life.

Agree ☐ Disagree ☐ Don't Know ☐

Comments:

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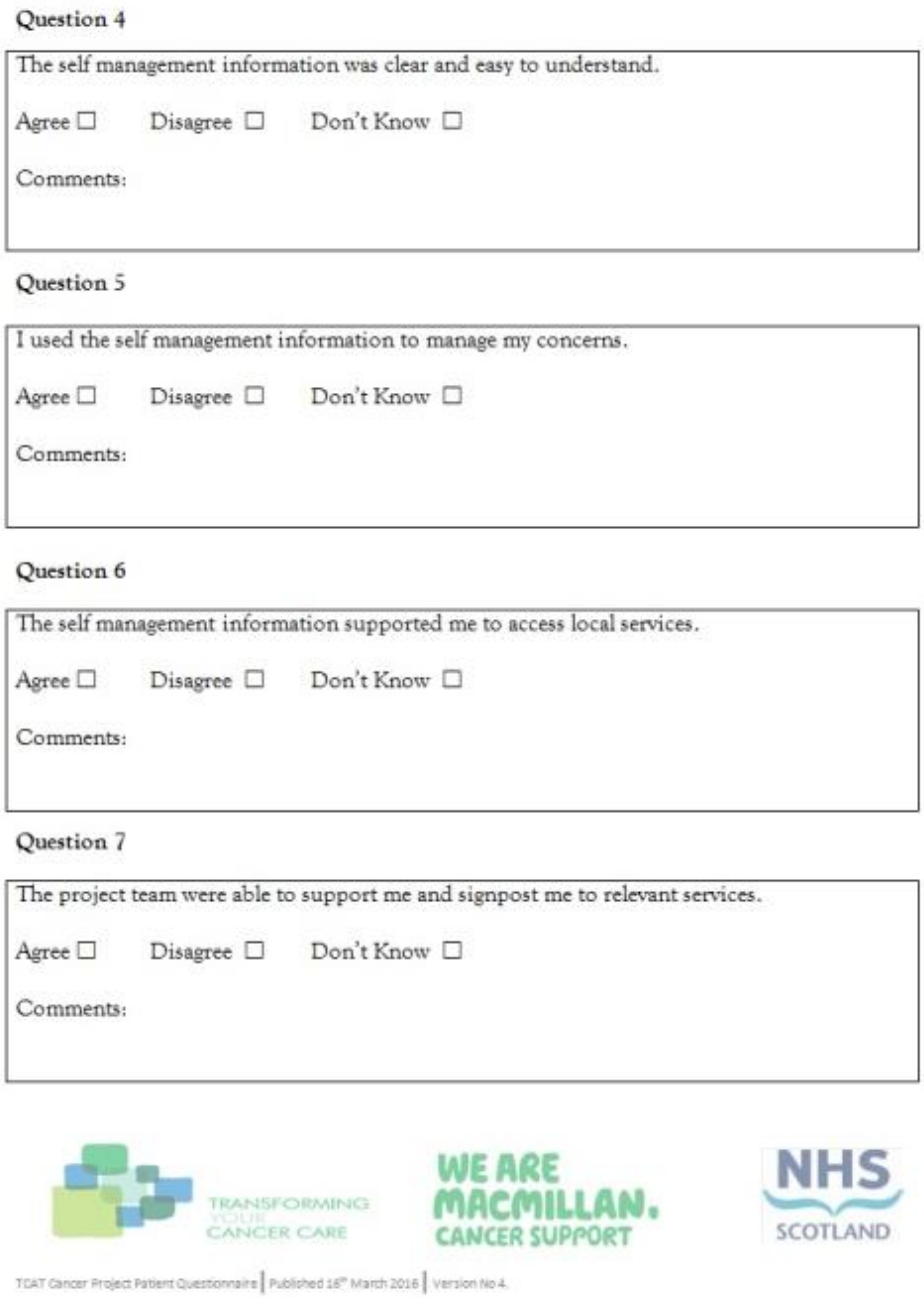
NHS SCOTLAND

TCAT Cancer Project Patient Questionnaire | Published 16th March 2016 | Version No 4.



**Question 4**

| |
|---|
| The self management information was clear and easy to understand.<br>Agree ☐ Disagree ☐ Don't Know ☐<br>Comments: |

**Question 5**

| |
|---|
| I used the self management information to manage my concerns.<br>Agree ☐ Disagree ☐ Don't Know ☐<br>Comments: |

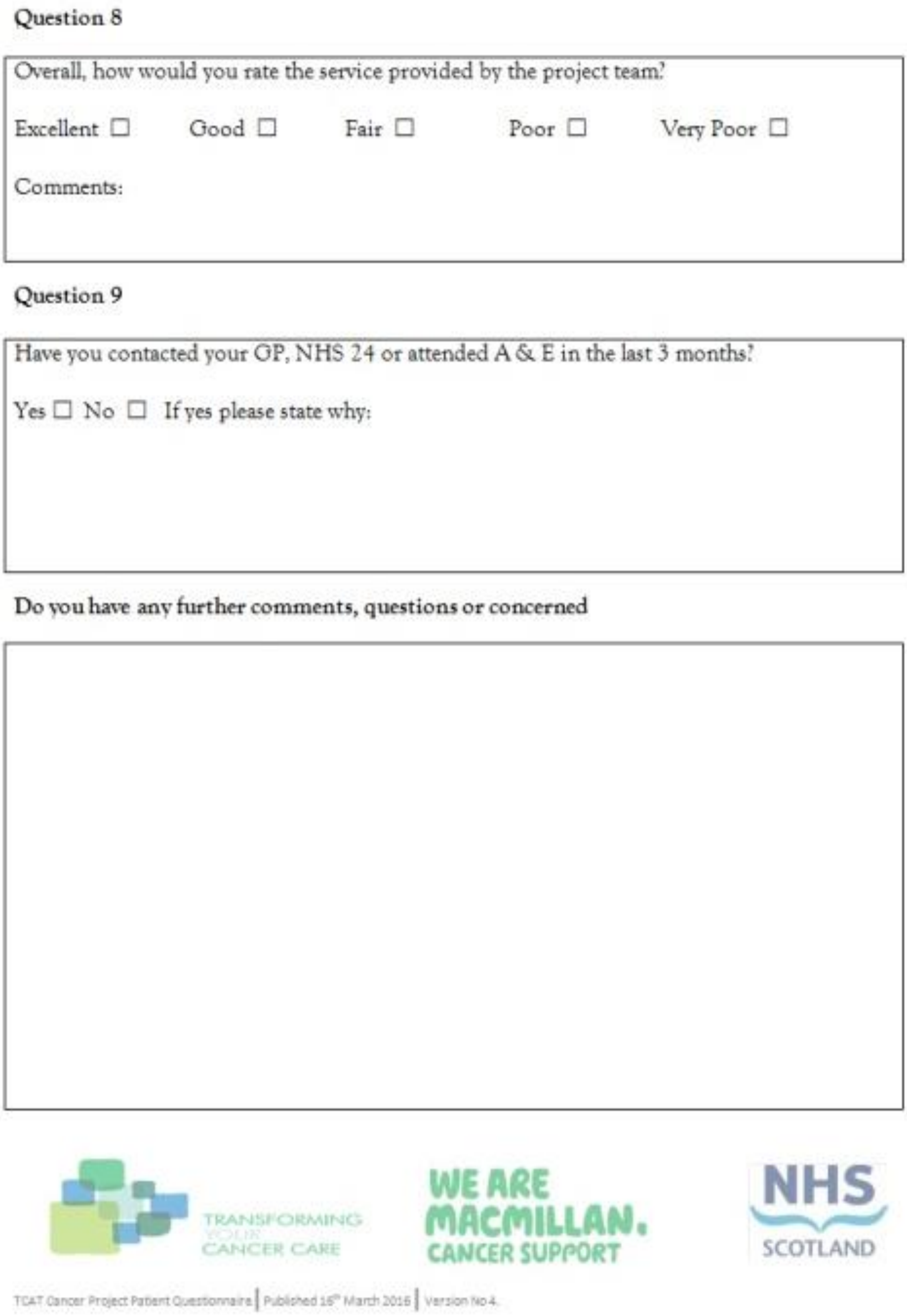
**Question 6**

| |
|---|
| The self management information supported me to access local services.<br>Agree ☐ Disagree ☐ Don't Know ☐<br>Comments: |

**Question 7**

| |
|---|
| The project team were able to support me and signpost me to relevant services.<br>Agree ☐ Disagree ☐ Don't Know ☐<br>Comments: |

TCAT Cancer Project Patient Questionnaire | Published 16th March 2016 | Version No 4.



**Question 8**

Overall, how would you rate the service provided by the project team?

Excellent ☐ Good ☐ Fair ☐ Poor ☐ Very Poor ☐

Comments:

**Question 9**

Have you contacted your GP, NHS 24 or attended A & E in the last 3 months?

Yes ☐ No ☐ If yes please state why:

**Do you have any further comments, questions or concerned**

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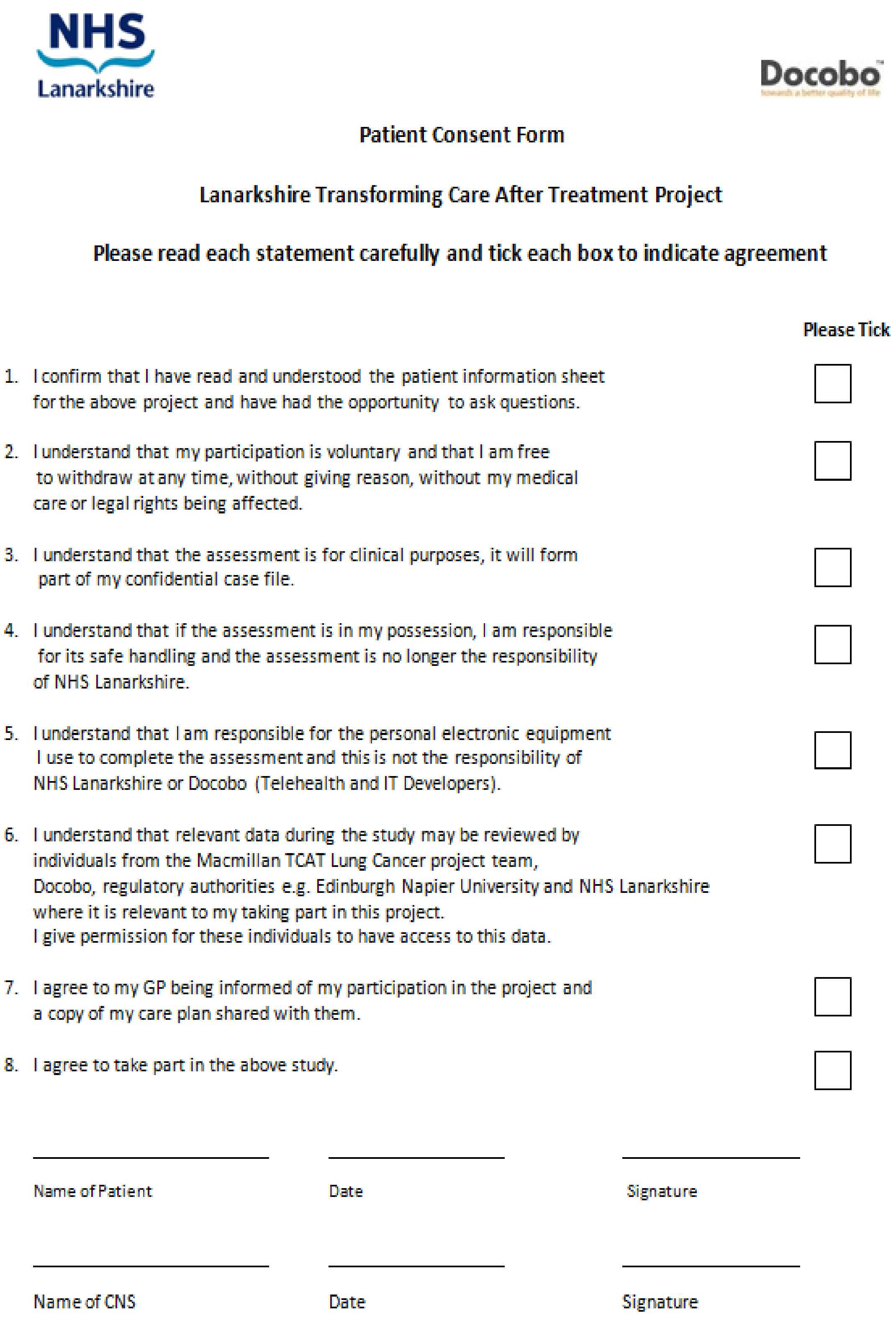
TCAT Cancer Project Patient Questionnaire | Published 16th March 2016 | Version No 4.

# Appendix VII



NHS Lanarkshire

Docobo

## Patient Consent Form

## Lanarkshire Transforming Care After Treatment Project

**Please read each statement carefully and tick each box to indicate agreement**

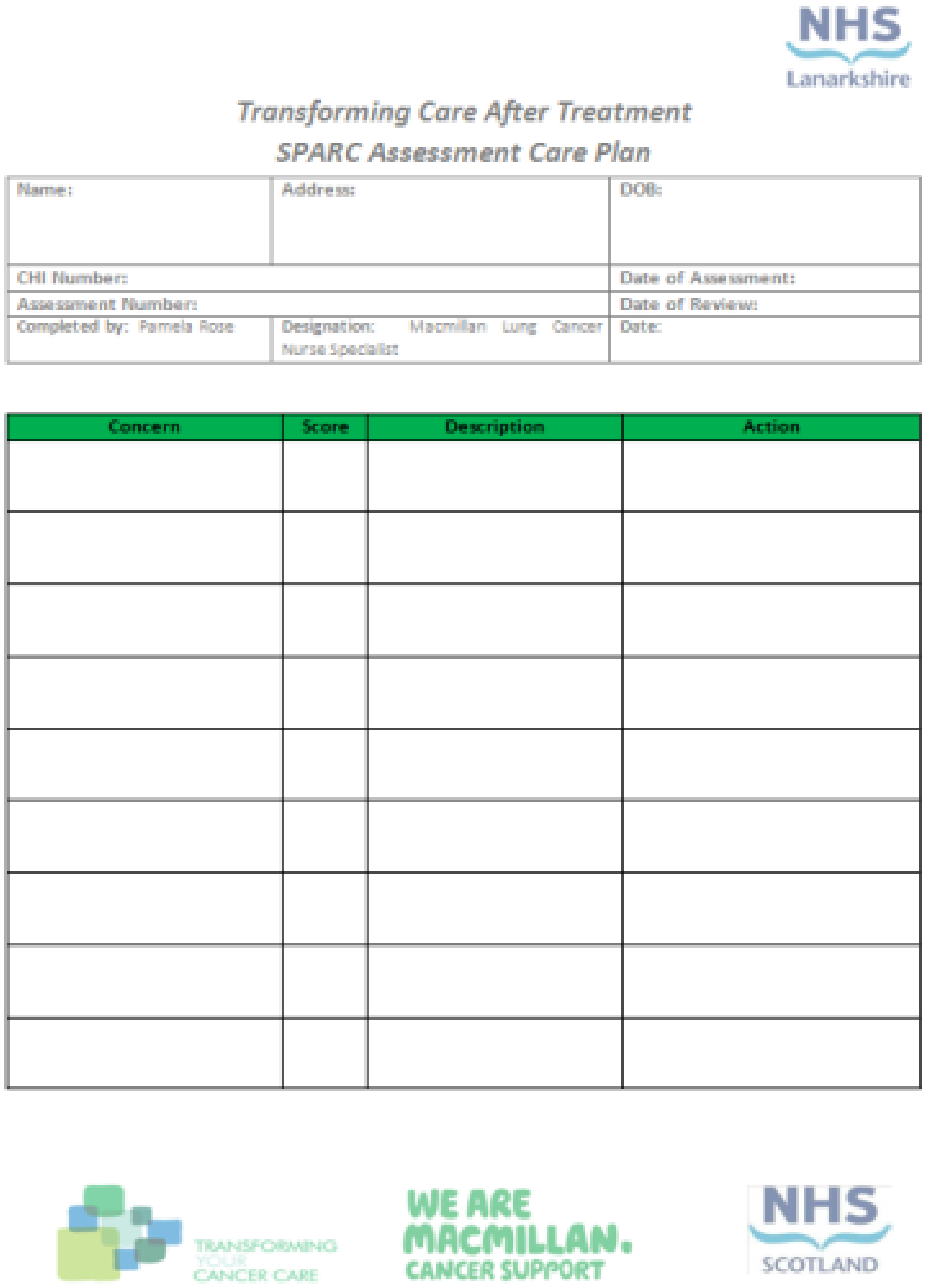
**Please Tick**

1. I confirm that I have read and understood the patient information sheet for the above project and have had the opportunity to ask questions. ☐
2. I understand that my participation is voluntary and that I am free to withdraw at any time, without giving reason, without my medical care or legal rights being affected. ☐
3. I understand that the assessment is for clinical purposes, it will form part of my confidential case file. ☐
4. I understand that if the assessment is in my possession, I am responsible for its safe handling and the assessment is no longer the responsibility of NHS Lanarkshire. ☐
5. I understand that I am responsible for the personal electronic equipment I use to complete the assessment and this is not the responsibility of NHS Lanarkshire or Docobo (Telehealth and IT Developers). ☐
6. I understand that relevant data during the study may be reviewed by individuals from the Macmillan TCAT Lung Cancer project team, Docobo, regulatory authorities e.g. Edinburgh Napier University and NHS Lanarkshire where it is relevant to my taking part in this project. I give permission for these individuals to have access to this data. ☐
7. I agree to my GP being informed of my participation in the project and a copy of my care plan shared with them. ☐
8. I agree to take part in the above study. ☐

Name of Patient ____________ Date ____________ Signature ____________

Name of CNS ____________ Date ____________ Signature ____________

# Appendix VIII



NHS
Lanarkshire

## Transforming Care After Treatment

## SPARC Assessment Care Plan

| | | |
|---|---|---|
| Name: | Address: | DOB: |
| CHI Number: | | Date of Assessment: |
| Assessment Number: | | Date of Review: |
| Completed by: Pamela Rose | Designation: Macmillan Lung Cancer Nurse Specialist | Date: |

| Concern | Score | Description | Action |
|---|---|---|---|
| | | | |
| | | | |
| | | | |
| | | | |
| | | | |
| | | | |
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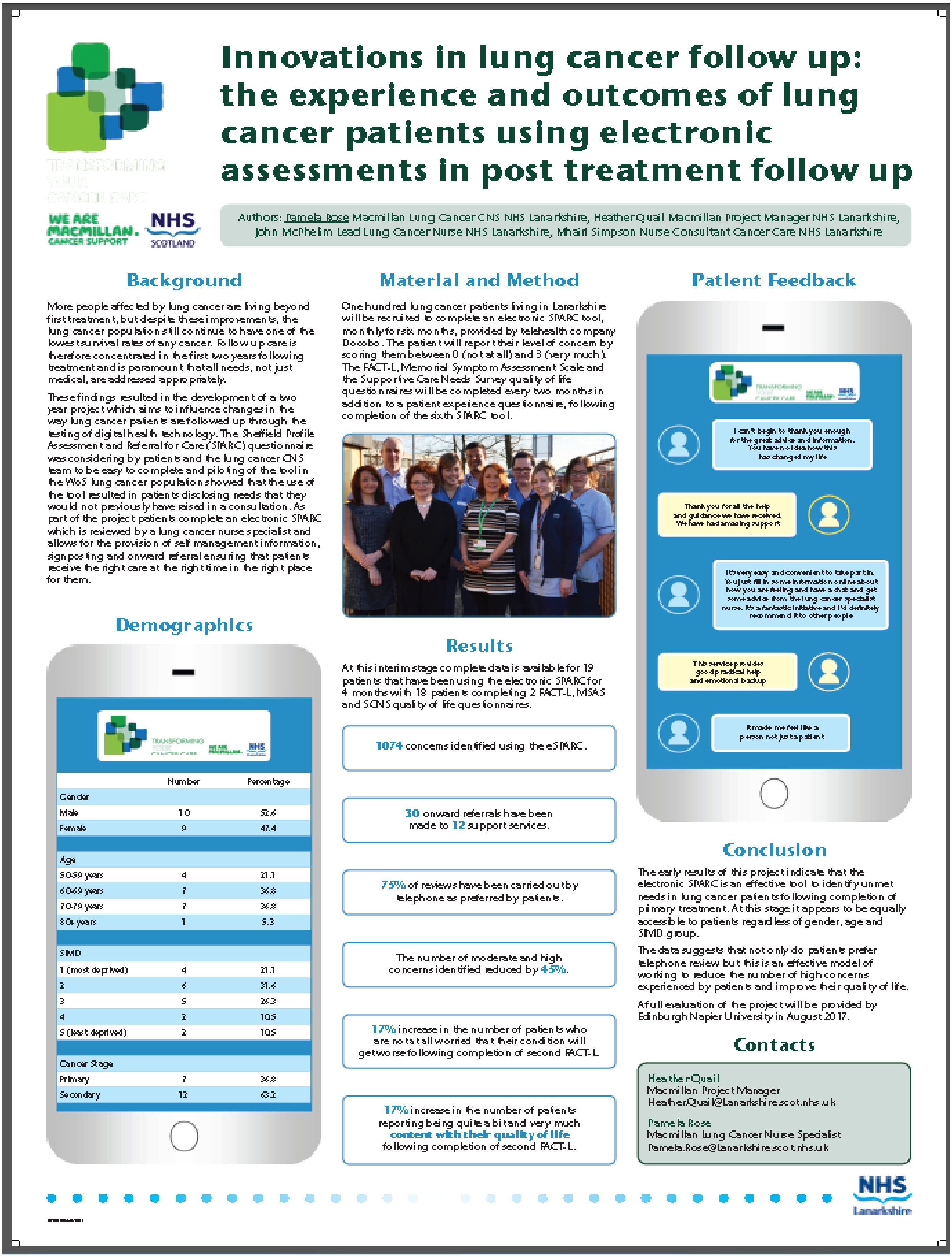
# Appendix IX



## Innovations in lung cancer follow up: the experience and outcomes of lung cancer patients using electronic assessments in post treatment follow up

Authors: Pamela Rose Macmillan Lung Cancer CNS NHS Lanarkshire, Heather Quail Macmillan Project Manager NHS Lanarkshire, John McPhelim Lead Lung Cancer Nurse NHS Lanarkshire, Mhairi Simpson Nurse Consultant Cancer Care NHS Lanarkshire

### Background

More people affected by lung cancer are living beyond first treatment, but despite these improvements, the lung cancer population still continue to have one of the lowest survival rates of any cancer. Follow up care is therefore concentrated in the first two years following treatment and is paramount that all needs, not just medical, are addressed appropriately.

These findings resulted in the development of a two year project which aims to influence changes in the way lung cancer patients are followed up through the testing of digital health technology. The Sheffield Profile Assessment and Referral for Care (SPARC) questionnaire was considering by patients and the lung cancer CNS team to be easy to complete and piloting of the tool in the WoS lung cancer population showed that the use of the tool resulted in patients disclosing needs that they would not previously have raised in a consultation. As part of the project patients complete an electronic SPARC which is reviewed by a lung cancer nurse specialist and allows for the provision of self management information, signposting and onward referral ensuring that patients receive the right care at the right time in the right place for them.

### Demographics

| | Number | Percentage |
|---|---|---|
| Gender | | |
| Male | 10 | 52.6 |
| Female | 9 | 47.4 |
| Age | | |
| 50-59 years | 4 | 21.1 |
| 60-69 years | 7 | 36.8 |
| 70-79 years | 7 | 36.8 |
| 80+ years | 1 | 5.3 |
| SIMD | | |
| 1 (most deprived) | 4 | 21.1 |
| 2 | 6 | 31.6 |
| 3 | 5 | 26.3 |
| 4 | 2 | 10.5 |
| 5 (least deprived) | 2 | 10.5 |
| Cancer Stage | | |
| Primary | 7 | 36.8 |
| Secondary | 12 | 63.2 |

### Material and Method

One hundred lung cancer patients living in Lanarkshire will be recruited to complete an electronic SPARC tool, monthly for six months, provided by telehealth company Docobo. The patient will report their level of concern by scoring them between 0 (not at all) and 3 (very much). The FACT-L, Memorial Symptom Assessment Scale and the Supportive Care Needs Survey quality of life questionnaires will be completed every two months in addition to a patient experience questionnaire, following completion of the sixth SPARC tool.

### Results

At this interim stage complete data is available for 19 patients that have been using the electronic SPARC for 4 months with 18 patients completing 2 FACT-L, MSAS and SCNS quality of life questionnaires.

**1074** concerns identified using the eSPARC.

**30** onward referrals have been made to **12** support services.

**75%** of reviews have been carried out by telephone as preferred by patients.

The number of moderate and high concerns identified reduced by **45%**.

**17%** increase in the number of patients who are not at all worried that their condition will get worse following completion of second FACT-L

**17%** increase in the number of patients reporting being quite a bit and very much **content with their quality of life** following completion of second FACT-L.

### Patient Feedback

I can't begin to thank you enough for the great advice and information. You have no idea how this has changed my life

Thank you for all the help and guidance we have received. We have had amazing support

It's very easy and convenient to take part in. You just fill in some information online about how you are feeling and have a chat and get some advice from the lung cancer specialist nurse. It's a fantastic initiative and I'd definitely recommend it to other people

This service provides good practical help and emotional backup

It made me feel like a person not just a patient

### Conclusion

The early results of this project indicate that the electronic SPARC is an effective tool to identify unmet needs in lung cancer patients following completion of primary treatment. At this stage it appears to be equally accessible to patients regardless of gender, age and SIMD group.

The data suggests that not only do patients prefer telephone review but this is an effective model of working to reduce the number of high concerns experienced by patients and improve their quality of life.

A full evaluation of the project will be provided by Edinburgh Napier University in August 2017.

### Contacts

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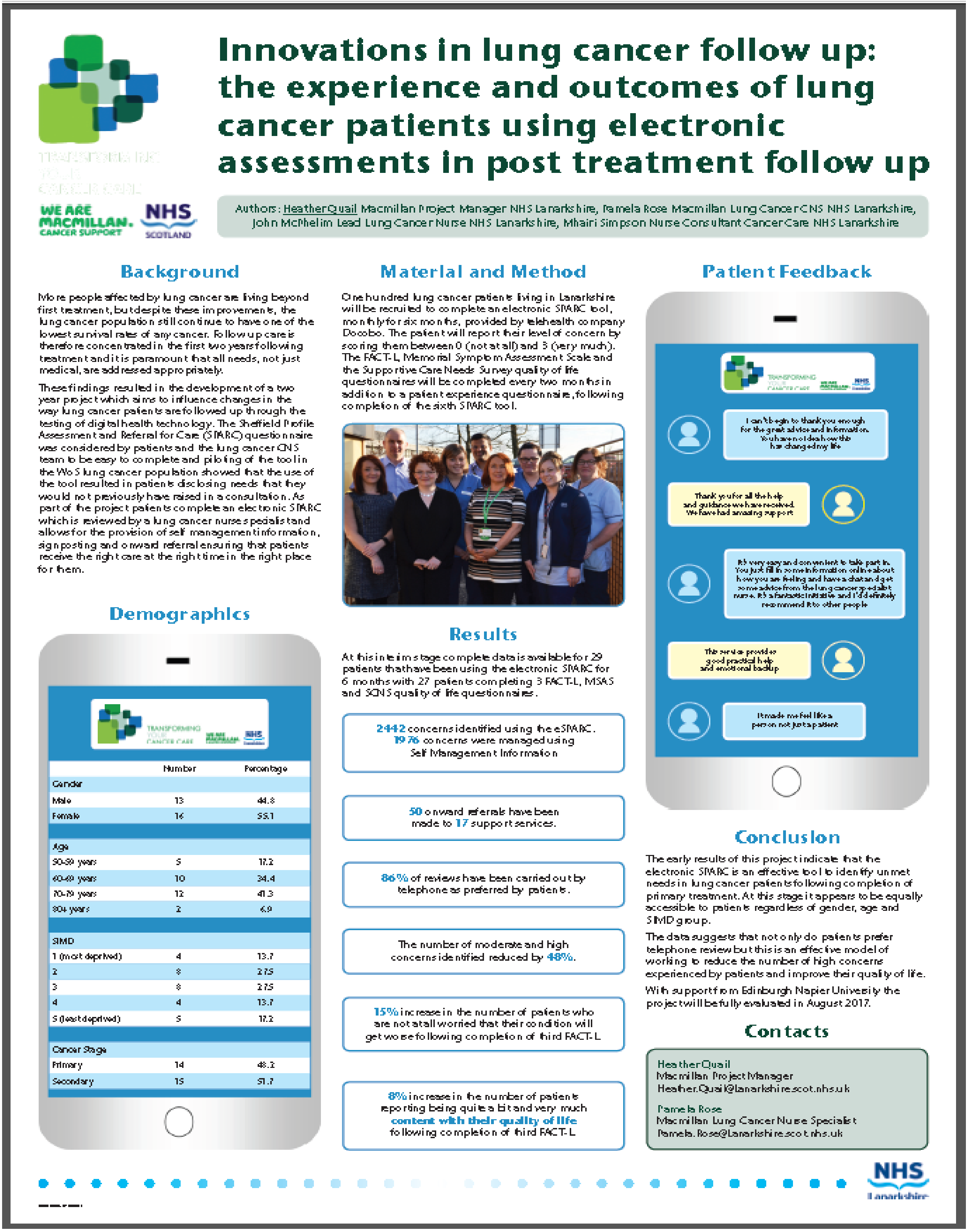
**Pamela Rose**
Macmillan Lung Cancer Nurse Specialist
Pamela.Rose@lanarkshire.scot.nhs.uk

# Appendix X



# Innovations in lung cancer follow up: the experience and outcomes of lung cancer patients using electronic assessments in post treatment follow up

Authors: Heather Quail Macmillan Project Manager NHS Lanarkshire, Pamela Rose Macmillan Lung Cancer CNS NHS Lanarkshire, John McPhelim Lead Lung Cancer Nurse NHS Lanarkshire, Mhairi Simpson Nurse Consultant Cancer Care NHS Lanarkshire

## Background

More people affected by lung cancer are living beyond first treatment, but despite these improvements, the lung cancer population still continue to have one of the lowest survival rates of any cancer. Follow up care is therefore concentrated in the first two years following treatment and it is paramount that all needs, not just medical, are addressed appropriately.

These findings resulted in the development of a two year project which aims to influence changes in the way lung cancer patients are followed up through the testing of digital health technology. The Sheffield Profile Assessment and Referral for Care (SPARC) questionnaire was considered by patients and the lung cancer CNS team to be easy to complete and piloting of the tool in the WoS lung cancer population showed that the use of the tool resulted in patients disclosing needs that they would not previously have raised in a consultation. As part of the project patients complete an electronic SPARC which is reviewed by a lung cancer nurse specialist and allows for the provision of self management information, signposting and onward referral ensuring that patients receive the right care at the right time in the right place for them.

## Demographics

| | Number | Percentage |
|---|---|---|
| Gender | | |
| Male | 13 | 44.8 |
| Female | 16 | 55.1 |
| Age | | |
| 50-59 years | 5 | 17.2 |
| 60-69 years | 10 | 34.4 |
| 70-79 years | 12 | 41.3 |
| 80+ years | 2 | 6.9 |
| SIMD | | |
| 1 (most deprived) | 4 | 13.7 |
| 2 | 8 | 27.5 |
| 3 | 8 | 27.5 |
| 4 | 4 | 13.7 |
| 5 (least deprived) | 5 | 17.2 |
| Cancer Stage | | |
| Primary | 14 | 48.2 |
| Secondary | 15 | 51.7 |

## Material and Method

One hundred lung cancer patients living in Lanarkshire will be recruited to complete an electronic SPARC tool, monthly for six months, provided by telehealth company Docobo. The patient will report their level of concern by scoring them between 0 (not at all) and 3 (very much). The FACT-L, Memorial Symptom Assessment Scale and the Supportive Care Needs Survey quality of life questionnaires will be completed every two months in addition to a patient experience questionnaire, following completion of the sixth SPARC tool.

## Results

At this interim stage complete data is available for 29 patients that have been using the electronic SPARC for 6 months with 27 patients completing 3 FACT-L, MSAS and SCNS quality of life questionnaires.

2442 concerns identified using the eSPARC. 1976 concerns were managed using Self Management Information

50 onward referrals have been made to 17 support services.

86% of reviews have been carried out by telephone as preferred by patients.

The number of moderate and high concerns identified reduced by 48%.

15% increase in the number of patients who are not at all worried that their condition will get worse following completion of third FACT-L

8% increase in the number of patients reporting being quite a bit and very much **content with their quality of life** following completion of third FACT-L

## Patient Feedback

I can't begin to thank you enough for the great advice and information. You have no idea how this has changed my life

Thank you for all the help and guidance we have received. We have had amazing support

It's very easy and convenient to take part in. You just fill in some information online about how you are feeling and have a chat and get some advice from the lung cancer specialist nurse. It's a fantastic initiative and I'd definitely recommend it to other people

This service provides good practical help and emotional backup

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## Conclusion

The early results of this project indicate that the electronic SPARC is an effective tool to identify unmet needs in lung cancer patients following completion of primary treatment. At this stage it appears to be equally accessible to patients regardless of gender, age and SIMD group.

The data suggests that not only do patients prefer telephone review but this is an effective model of working to reduce the number of high concerns experienced by patients and improve their quality of life.

With support from Edinburgh Napier University the project will be fully evaluated in August 2017.

## Contacts

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