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### **How to summarise and report written qualitative data from patients: a method for use in cancer support care.**

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**How to summarise and report written qualitative data from patients: A method for use in cancer support care**

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## **Abstract**

*Goals of work:* Determination of key themes to aid the analysis of qualitative data collected at three cancer support centres in England, using the Measure Yourself Concerns and Wellbeing (MYCaW) questionnaire. *Patients and methods:* People with cancer who use complementary therapies experience and value a wide range of treatment effects, yet tools are urgently required to quantitatively measure these outcomes. MYCAW is an individualised questionnaire used in cancer support centres providing complementary therapies, scoring ‘concerns or problems’ and ‘wellbeing’ and collects qualitative data about other major events in a patient’s life and what has been most important to the patient. Content analysis on 782 MYCaW questionnaires from people at these cancer support centres was carried out. The “concerns”, “other things going on in their life” and “important aspects of centre” were thematically categorised, externally validated by a focus group and the inter-rater reliability calculated. *Main results:* Clinical information from a cancer patient’s perspective was collected that is not measured on standard quality of life questionnaires; furthermore some themes acknowledge the multifaceted aspects of CAM provision, rather than information only relating to the therapeutic intervention. Categories for qualitative MYCaW analysis have been established providing a tool for future research and/or service delivery improvement within cancer support centres such as these. *Conclusions:* The established themes provide a framework to aid analysis of qualitative aspects of complementary therapy care for people with cancer, improving our understanding of how the patient’s cancer experience can be aided by complementary therapies in specialized cancer centres.

**Keywords:** Cancer, Complementary therapies, MYCaW, Qualitative analysis, Outcome measures

## **Introduction**

Complementary and alternative medicine (CAM) is being increasingly used in Western countries, mainly in a complementary and supportive role after a cancer diagnosis [4, 7, 16]. In the UK, cancer support services have developed as a result of the needs of people with cancer and these centres often use complementary therapies and self-management techniques as part of individualized patient-centred care. This care can address patient needs on a physical, emotional, psychological and spiritual level.

From experience, staff at these support services understand the necessity of evaluating the internal quality of their service for clinical improvement, as well as the outcome of the care provided for future patients, potential funding and regulatory bodies. The use of Integrative Health Care (IHC) in the field of cancer support therefore requires tools that can encompass the whole range of benefits and problems that are important to patients.

Research on CAM and cancer has described a range of different outcomes experienced by cancer patients usually using self-report questionnaires that have collected quantitative data [3, 5, 6, 8, 9, 11, 21]. Not initially designed for CAM and cancer research, these questionnaires, such as traditional quality of life measures, are ill suited to capture the range of likely treatment effects from CAM experienced by people with cancer [3, 8, 21]. It is increasingly recognized that these measures do not capture the complete range of benefits reported by patients, such as spirituality [5, 6, 9, 11]. To illustrate this point further, a recent systematic review of 52 quantitative studies, including a range of methodologies from standardised questionnaires to semi-structured interviews, cited 'a perceived beneficial response, wanting control, a strong belief in CAM, CAM as a last resort, and finding hope' as the main reasons that people with cancer give for using CAM [17].

In order to augment the evidence base for the use of CAM in the cancer setting all aspects of the experience of receiving cancer support care are recorded. Self-report

questionnaires aim to encompass the main patient-reported outcomes, but essentially do not allow patients to define their own priorities nor to describe their experiences in their own words. Since 1996, 42 qualitative investigations have been published on PubMed explaining why people with cancer seek CAM treatments and the benefits they experience, if any. These studies not only allow the patient's perspective to be expressed more directly and in more depth, but they also extend our understanding of what components of the process and outcomes of CAM are experienced and valued by people with cancer. For example, a study of cancer patients attending an integrative clinic in Vancouver found that participants identified six types of benefits: improved physical wellbeing, change in physiological indicators, improved emotional wellbeing, personal transformations, feeling connected, global state of wellbeing, and cure [18].

[Insert Figure 1 about here]

The Measure Yourself Concerns and Wellbeing (MYCaW) tool is an individualized questionnaire for measuring outcomes in cancer support care (See Figure 1)<sup>1</sup>. It was developed and piloted at the Cavendish Cancer Centre and Penny Brohn Cancer Care (PBCC) (formerly Bristol Cancer Help Centre) to evaluate the complete experience of a patient with cancer using complementary therapies [12]. The main difference with this tool and other self report questionnaires is that it allows the cancer patient to describe and score the severity of their most pressing concerns and their wellbeing. Written qualitative information regarding other major events going on in their life and what has been most important to the patient is recorded at the end of their treatment package. MYCaW is also quick to fill in, so it does not interfere with the therapeutic consultation.

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<sup>1</sup> The inclusion criteria category information and instructions for new users can be accessed on the MYMOP website: <http://www.hsra.ac.uk/mymop/MYCaW.htm>

MYCaW has now become a popular tool to obtain patient reported outcomes regarding many aspects of complementary therapies, being used in at least 10 other cancer care centres in the UK and a few centres in North America. Currently the MYCaW tool is recognised as appropriate to the cancer service offered, acceptable to patients, practitioners and researchers and responsive to change. Because of the inherent difficulty in summarising written qualitative data, much of the data that is collected is not systematically reported and therefore is lost in terms of research and evaluation outputs. Not only is this wasteful, but unacceptable in terms of asking patients their views and then not reporting them.

This paper draws on the data from 782 patients, collected over the years of 2004-2006 during the systematic use of MYCaW as an evaluation tool in 3 cancer support centres in England. Breast Cancer Haven (BCH) is a registered charity that runs two 'day centres' offering support, information and complementary therapies to anyone affected by breast cancer. The Haven Programme has been designed to help patients feel better and develop a healthier lifestyle. BCH works with the NHS and other healthcare professionals to promote and provide responsible and effective integrated breast cancer care. PBCC is the UK's leading holistic cancer charity working hand-in-hand with medical treatment, to provide a unique combination of physical, emotional and spiritual support using complementary therapies and self-help techniques, including practical advice on nutrition for all types of cancer.

This study describes the method by which we have conducted a thematic analysis of the MYCaW qualitative data and used this process to develop robust categories. These category systems are provided as a tool to use alongside the MYCaW questionnaire, so that future use of MYCaW will result in an analysis of both the quantitative and qualitative data, thus providing richer and more meaningful outcomes. A more extensive analysis of the

quantitative and qualitative data from this study will be reported in a subsequent paper (Seers H et al. in preparation).

## **Patients and methods**

### Administration of the questionnaire

Data were collected from 782 patients between 2004-2006 at BCH in London (n=268) and Hereford (n=153) and at PBCC (n=361). At Breast Cancer Haven the MYCaW form was completed between September 2004 and January 2006, and, at Penny Brohn Cancer Care the data were collected between January 2004 and December 2005. At Breast Cancer Haven Centres the baseline MYCaW form was administered during the therapy assessment (prior to receiving therapies) and subsequently at the end of the therapy programme. The follow-up MYCaW form was sent with a stamped addressed envelope, when a patient had received 10 hours of individualised therapies or had not returned for three months. There is no time limit on when patients take their appointments, as the programme is designed to fit around the conventional cancer treatment regime, hence the duration between the forms ranged from 2 months to 12 months. For PBCC, the baseline MYCaW was sent out in the post prior to arriving at the 2 day or 5 day residential course for the person to reflect on prior to their visit and then filled upon their arrival. The Follow-up MYCaW form was sent out with a stamped addressed envelope 4 weeks after the residential course was completed.

Briefly, a patient recorded 'one or two concerns or problems' that they most wanted help with and scored the severity between 0 (not bothering me at all) to 6 (bothers me greatly). 'Wellbeing' was also scored using 0 (as good as it can be) to 6 (as bad as it can be). On the follow-up MYCaW questionnaire the patient rescored their concerns and wellbeing without seeing their original scores (they could refer to the concerns they described). Patients

also had the option of completing two additional questions ‘other things affecting your health’ and ‘what has been most important for you?’

### Qualitative analysis of the data

Three aspects of the MYCaW form required qualitative data analysis - the ‘concerns and problems’ category on the first form and ‘other things affecting your health’ as well as ‘what has been most important for you?’ from the follow-up form.

Inductive content analysis was performed first independently and then together by two researchers, one at BCH and one at PBCC. Inductive analysis was used alongside the researcher’s own contextual understanding and experience of working at the centres which allowed the qualitative data to be interpreted in a meaningful way. It was acknowledged that the diversity of backgrounds, experience and qualifications, as well as the research views of the wider team broadened our perspective on the research data and their categorization. As a tool for examining our theoretical stance to ensure clear communication within the research team, reflective questions developed by Barry et al. were used [2, p. 38]; these were answered by each member of the research team and circulated for discussion.

Initially, BCH’s London data (n=268) was analysed independently by each researcher from BCH (MJP) and PBCC (HS). The researchers then compared their results to define the emerging themes and a set of categories were recorded. During the independent coding, there was an initial overlap in emerging themes of approximately 90% by the researchers. The differences in categories were discussed in detail during weekly phone meetings until agreement was reached and improved categories developed. Each researcher then independently applied the improved categories to the data set from BCH in Hereford (n=153). The process of comparing results and discussing amendments between the



researchers was repeated and the amended categories were once again tested independently, but this time using the data set from PBCC (n=361). Minor adjustments were made to some categories to ensure that the categories were suitable to all cancer types and were clear for the researcher who worked at the 'other' cancer support centre.

Detailed descriptions of what the researchers included in each category were recorded as the categories were developed to enable a set of 'category inclusion criteria' to be developed. For example, Figure 2 shows a section of the inclusion criteria for categorising 'body image concerns' and 'confidence issues' in the Psychological and Emotional Concerns Supercategory (see Table 1). The instructions describe what other words may be associated with the category, how broad the remit of the category is and in some cases when to refer to a different category.

[Insert Figure 2 about here]

#### Internal validation by service-user focus group

To ensure that the internal validity of the qualitative categories derived from each aspect of the questionnaire, five women (age range 49-71) who were previous users of PBCC (4 had a previous diagnosis of cancer, 1 was a supporter of a person with cancer), attended a focus group. Recruited was facilitated through posters in the PBCC building, advertising for a focus group needing people who were previous service users. The focus group was also attended by one of the authors of this paper (HS) and was facilitated by a researcher from the University of West of England who had extensive experience of working with people with cancer. Specifically, the language used to name and describe each category was assessed for acceptability to the users. The definitions derived for each category were then reviewed and

discussed for clarity of language and appropriateness of interpretation of the comments. Finally, the group members were asked to create supercategories from the number of categories of ‘concerns and problems’. This was done by forming two subgroups with enlarged cut-out photocopies of the categories with their corresponding definitions. The cut-out categories were re-arranged into “supercategories” by the two groups for 10 minutes; groups were free to create as many supercategories as they wanted. The groups were also told there was no right or wrong answer. They then fed back their supercategories to the group facilitator who wrote them on a flip chart.

## **Results**

Content analysis and categorisation of the qualitative MYCaW data

### *‘Concerns and Problems’*

The concerns and problems section was filled in by a total of 782 patients (268 from BCH in London, 153 from BCH in Hereford and 361 from PBCC). Figure 3 shows the type of concerns and problems that were recorded by the patients. The patients were encouraged to be succinct in their answers; even so, some answers that on the surface constituted one concern actually represented multiple key concerns. In that case, each subject/category was treated as a separate concern when categorising the data. Table 1 shows the categories of the ‘concerns and problems’ and how they were subsequently arranged into supercategories by the service-users focus group.

[Insert Figure 3 about here]

[Insert Table 1 about here]

*‘Other things affecting your health’*

Figure 4 records a few of the comments made by the cancer patients in this section. Clear themes emerged from this data which were organised into categories and then supercategories upon advice from the service-users focus group (Table 2). The data were derived from London (n=101), Hereford (n=69) and PBCC (n=237); the numbers of responses were lower for this question, as not all follow-up forms were received and not every person felt that they had anything relevant to insert in this section. The categories were generally either negative or positive in inference although this was impossible to determine for approximately 15% of the data.

[Insert Figure 4 about here]

[Insert Table 2 about here]

*‘What has been most important for you?’*

The data came from BCH (n=151), Hereford (n=86) and PBCC (n=351). Not every person felt the need to fill out this section which is reflected in the lower numbers involved. This section yielded some of the longest reflective data about the important aspects of the centre that was visited (See Figure 5 for examples). These rich data support the multifaceted benefits derived from complementary therapy interventions as a whole, as well as highlight the importance of the environment, the attitude of the therapists and other staff, as well as the benefit of being able to communicate with other patients in similar circumstances. The themes that emerged in this section are in Table 3. As only 11 themes emerged, it was felt unnecessary to create supercategories.

[Insert Figure 5 about here]

[Insert Table 3 about here]

#### Feedback from the service-user focus group

After the initial content analysis had been performed a focus group was convened to externally validate details of these categories. The group considered the appropriateness and acceptability of category names, for instance the word ‘Tamoxifen’ was changed to hormone treatment to be more inclusive of different cancer types and hormone-based treatments. Service-users also created a set of supercategories for the ‘concerns and problems’ data. Although the suggested supercategories initially overlapped, a single set of supercategories were easily agreed on by all in attendance. Finally, the focus group debated the usefulness of organising the ‘what else is going on in your life’ categories as positive and negative experiences. The group agreed that this was a useful distinction to make even though it risked classifying experiences in a polarised way.

#### Inter-rater reliability

After validating the content and language of the established categories with the focus group, the inter-rater reliability score was calculated to establish the consistency of the content analysis of the data by two different researchers. The kappa value was 0.85, representing excellent agreement between the coding of the categories by the two researchers.

## Discussion

Content analysis of the data and perspective of the researcher

The researchers (MJP and HS) both found that the approach in which the data were categorised was influenced by their differing academic perspectives. HS had a background in psychological research and MJP had a biomedical background, hence, the categorisation of words was influenced by the perspective of these academic disciplines. This was the primary reason for a 10% difference in category derivation for the initial analysis of the ‘concerns and problems’ data. To reach agreement, extensive negotiation was carried out which usually consisted of each researcher explaining their rationale for the categorisation to the other researcher. Detailed notes made to reflect how this final decision was made were used to construct the ‘coding inclusion criteria’ (Figure 2). Similar observations were made by Waitzkin [19] when describing two research assistants ‘thrashing out’ their agreements and disagreements in coding qualitative data. The difference in academic backgrounds again created conflict between the researchers when deriving supercategories for the ‘concerns or problems’ data (Table 1), and ‘other things affecting your health’ (Table 2). Armstrong et al. demonstrated that when 6 researchers analysed one transcript they derived “*consensus in the identification of themes between different analyses but that the ‘packaging’ of the themes showed a number of different configurations*” [1].

MJP and HS had a similar experience when trying to configure the 32 initial categories into supercategories for the ‘concerns or problems’. In fact, when the wider research team was consulted, no complete agreement on organisation of supercategories was reached, as everyone had a different academic perspective. The importance of involving the ‘users’ in this research was recognised as essential [10, 15], and to resolve the supercategory derivation, the researchers felt it was necessary to let the service-users make the decision

within a focus group setting, hence reflecting upon their own experience of cancer. The benefits of focus group methodology are succinctly described by White and Verhoef [20]. During the focus group, participants also discussed whether the interpretation and use of language in the categories was acceptable to them. Very few changes in language or categorisation were suggested which demonstrated external validation of the content analysis, and reassured the researchers that the qualitative analysis accurately reflected the experiences of the cancer patients.

Elucidating what had been most important for the patient (Table 3) was dependent on the knowledge of how the therapy programmes worked in each cancer support centre. Inductive content analysis was used to evaluate the qualitative data on the MYCaW forms as the researchers recognised that some of the analysis could be dependent upon the research training and perspective of the researcher within each organisation. During the initial content analysis of the question: *'what had been most important for you?'* separate categories of 'individual therapies' and 'group therapies' were created. Some complementary therapies can be practised on an individual basis or as a group, and unless the researchers knew the details of a centre's therapy programme, they found it difficult to accurately distinguish between these categories.

The researchers were particularly keen to construct a tool that is meaningful beyond an individual organisation or the background of a researcher, thus not requiring a researcher to work within the organisation to accurately use the qualitative analysis tool. In the example highlighted above, the 2 categories relating to therapies were merged to create the final category 2 - 'individual and group therapies'. It would be possible for a researcher to further analyse the 'individual and group therapies' category should their particular organisation want more detail, although it was noticed that some comments pertained to particular therapists rather than the therapy. Identifying particular therapists could create a difficult

atmosphere in a group of therapists within an organisation, if some therapists are mentioned when others are not. Further analysis of this category should therefore be carried out with discretion if the cancer setting employs many different therapists.

The deliberate step of forming supercategories where possible was taken to provide a relatively quick and easy method of analysis, for an organisation that may not have a researcher available but still wants to monitor their data. This approach further helped to create a tool that could be generalised to different research and evaluation contexts. Furthermore, the analysis framework has now been used by an independent research group to analyse their data evaluating healing for cancer in a community setting (Vaghela C et al. in press). The categories proved very useful in analysing their data and very few problems were encountered by this independent group. The feedback received from the group was very useful in clarifying minor details on 'coding inclusion criteria'.

Several studies have picked up on similar categories to those derived in this research study. Most notably Peace and Manasse [13] used MYMOP to measure the outcome of cancer patients using the Cavendish Cancer Centre, and, Paterson et al. [12] went on to report the use of MYCaW in the 2 cancer support centres in England. Both studies reported similar 'concerns and problems' data which were categorised into 'Physical, Emotional, Stress Management, Support, Hospital related and Need for a Positive Outlook'. These categories concur with our own findings.

Verhoef et al. reviewed the reasons and characteristics associated with CAM use in adult cancer patients [17]. Of the 52 studies reviewed, 60% had reasons for CAM use associated with them and the majority of reasons stated across the studies can be found within the MYCaW analysis framework. These include Supportive practitioner (category 1, Table 3); Avoidance of progression or recurrence (S2g Table 1); Build inner strength, Improve wellbeing, increase quality of life (S4b, Table 1); Physical distress (S2, Table 1); Searching

for psychological support (S1l, Table 1); Pain control (S2d Table 1); Relieve symptoms (S3 Table 1); Increased coping (S1a Table 1); Want to feel hopeful / Increase feelings of hope (S1 Table 1); Stress reduction (S1k Table 1); Relaxation (S4f Table 1); Lessening menopausal symptoms (S2b or S3d Table 1). The studies reviewed were from Britain, Germany, Italy, Finland, Australia, New Zealand, Canada, United States and China. Risberg et al. [14] also examined why cancer patients in Norway use non-proven therapies, but since predetermined reasons were provided on a multiple choice list, the range of possible answers is limited. The study cited issues pertaining to progression and recurrence of the disease and improvement of general condition; again these were also identified in our content analysis.

Further work by Verhoef et al. evaluated how one determines whether patients of integrative healthcare benefit [18]. Six types of benefits were determined from 42 personal interviews. Although our MYCaW study was not evaluating benefits in the same manner, similarity between can be drawn Verhoef et al. [18] and the concern or problems our participants reported. Verhoef's categories were: 'improved physical well-being, change in physiological indicators, improved emotional well-being, personal transformation, feeling connected, global sense of well-being and cure'. Feeling connected was cited by Verhoef as a benefit of integrated health care and was also stated as a benefit in our study (see Table 3), being with other visitors.

It is important for research and evaluation in the CAM field to acknowledge the wider context of people's lives. If no change or a decrease in scores on an outcome measure is observed after a therapy package, it is very important to understand why this might be. The initial conclusion may be to suspect that the therapies did not have their desired effect and this may truly be the case; however, the ability to elicit wider information in order to draw a firm conclusion is dependent on the design of the research study or the outcome measure being used. Many other life events affect peoples' quality of life at that point in time that may



also act as a negative confounding factor in their CAM treatment. It is important to understand that these other situations may have equal or greater bearing on how a person scores his/her wellbeing compared to the experience of having cancer. The MYCaW tool is partly made up of scales to quantitatively measure the changes in the concerns and wellbeing but participants are also asked to state if there were any other things affecting their health, such as other things happening in their life. Table 2 clearly demonstrates how many categories were cited for this question, many of which, such as bereavement, divorce, lack of social support, family problems and change in work situations can be very stressful situations (see Figure 3 for examples).

For many organisations, understanding the reasons for use and benefits of their service can be essential. The information derived from the ‘concerns or problems’ can enable an organisation to understand the breadth of problems for which help is being sought and thus provide therapies addressing all patients’ needs. Being aware of wider issues in a person’s life as well as their cancer has an important bearing on the perception of wellbeing for the patient and the therapist. The benefit of complementary therapies is, however, more than just the specific therapy. Qualities such as professionalism, experience, kindness, and understanding were all important aspects of the whole therapeutic experience; in addition, the environment, the resources provided, building relationships with other patients in similar situations and stopping to listen to their own needs also contributed to this healing experience.

## **Conclusion**

MYCaW is quick to administer and an analysis can be carried out at 2 levels of depth depending on the resources available. A good inter-rater reliability has been established for the qualitative analysis, and good external validity demonstrated via a service-user’s focus group, the analysis of data from 3 cancer support centres covering all cancer types and 3

geographical locations. Furthermore the analysis tool has already been used by an independent research group to analyse their MYCaW data (Vaghela C et al. in press).

Despite the numerous outcomes and quality of life questionnaires available MYCaW is the only tool specifically designed for CAM and cancer support settings that can now provide systematic and rigorous reporting of the patient's experience of cancer through their own words. Given the different research settings, methodologies and qualitative analysis styles [14, 17, 18] similar themes are now being reported worldwide for cancer patient's experiences, all of which should be heard and recognised when carrying out research in this area and taken into account in the clinical setting.

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**Table 1** Breakdown of the supercategories of ‘*concerns and problems*’ stated on the first MYCaW form

<b>Supercategory (S)</b>	<b>Breakdown of Supercategory</b>	
<b>S1. Psychological and Emotional Concerns</b>	a. Adapting and coping b. Body image concerns c. Confidence issues d. Depression e. Emotional problems f. Family and relationships g. Fear and anxiety	h. Psychological issues i. Regaining balance and normality j. Sleep problems k. Stress and tension l. Support m. The future
<b>S2. Physical Concerns</b>	a. Arm problems b. Hot flushes and night sweats c. Fertility d. Pains / Aches	e. Physical problems f. Poor energy levels g. Recurrence and spread
<b>S3. Hospital Cancer (Medical) Treatment Concerns</b>	a. Cancer treatment in general b. Lymphedema	c. Side effects of chemotherapy d. Side effects of hormonal treatment
<b>S4. Concerns about Wellbeing</b>	a. Exercise b. General wellbeing and mind/body connection c. Healing	d. Information and guidance on complementary therapies e. Nutrition f. Relaxation

The categories were derived using independent content analysis of two data sets from Breast Cancer Havens in London (n=268), Hereford (n=153) and from one data set at Penny Brohn Cancer Care (n=361).

**Table 2** Breakdown of the supercategories from the data regarding “*other things affecting your health*”, stated on the follow-up MYCaW form

<b>Supercategory (S)</b>	<b>Breakdown of Supercategory</b>	
<b>S1. Awareness of Wellbeing</b>	a. Taking exercise b. Improved awareness of own wellbeing	c. Improved nutrition d. Difficulties in maintaining change
<b>S2. Receiving complementary therapies</b>	a. Benefit of therapies at the centre	b. Benefit of therapies outside of the centre
<b>S3. Major Life Events</b>	a. Positive change of environment b. Negative change of environment	c. Bereavement
<b>S4. Social Support</b>	a. Increased social support b. General lack of support	c. Family problems
<b>S5. Work Situation</b>	a. Changed work set-up	b. Work problems
<b>S6. Health Issues</b>	a. Cancer related and positive b. Cancer related and negative	d. Non cancer related
<b>S7. Other</b>		

The categories were derived using independent content analysis of two data sets from Breast Cancer Havens in London (n=101), Hereford (n=69) and from one data set at Penny Brohn Cancer Care (n= 237). Not every person felt the need to fill out this section which is reflected in the numbers involved.

**Table 3** The categories from the question ‘*What are the important aspects of the centre you have visited*’, stated on the follow-up MYCaW form

1. Support and understanding received	6. Being with other people with cancer
2. Individual and group therapies	7. Relaxation and time for ones self
3. Access to therapies	8. The environment and atmosphere
4. Confidence in the therapists	9. General appreciation of the centre and its resources
5. Care and kindness	10. Negative feedback

The categories were derived using independent content analysis of two data sets from Breast Cancer Havens in London (n=151), Hereford (n=86) and from one data set at Penny Brohn Cancer Care (n=351). Not every person felt the need to fill out this section which is reflected in the numbers involved.

**Figure 1** The MYCaW tool – Follow-up form

**Measure Yourself Concerns and Wellbeing (MYCAW )**  
**Follow up form** (self completion version)

Today's date .....

Look overleaf at the concerns that you wrote down before (please do not change these).

On this side of the form, circle a number to show how severe each of those concerns or problems is now:

**Concern or problem 1:**

	<b>0</b>	<b>1</b>	<b>2</b>	<b>3</b>	<b>4</b>	<b>5</b>	<b>6</b>
Not bothering me at all							bothers me greatly

**Concern or problem 2:**

	<b>0</b>	<b>1</b>	<b>2</b>	<b>3</b>	<b>4</b>	<b>5</b>	<b>6</b>
Not bothering me at all							bothers me greatly

**Wellbeing:**

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

	<b>0</b>	<b>1</b>	<b>2</b>	<b>3</b>	<b>4</b>	<b>5</b>	<b>6</b>
As good as it could be							As bad as it could be

**Other things affecting your health**

The treatment that you have received here may not be the only thing affecting your concern or problem. If there is anything else which you think is important, such as changes which you have made yourself, or other things happening in your life, please write it here.

**What has been most important for you?**

Reflecting on your time with this Centre, what were the most important aspects for you?  
( write overleaf if you need more space)

Thank you for completing this form.



**Figure 2** An example of the coding inclusion criteria

**b. Body Image Concerns** – *often breast cancer specific due breast surgery. Anything with direct reference to body image, appearance or ‘looking’ different/better i.e. acceptance of new body.*

**c. Confidence Issues** – *include direct references to confidence or self-confidence. If the comment refers to confidence in the physical self then go to category S1b*

**Figure 3** Examples of ‘concerns or problems’ that patients wanted help with (stated on the first MYCaW form)

**Taken from Breast Cancer Haven data set:**

Concern 1. *“Feelings of anxiety”*

Concern 2. *“Stress and worry”*

Concern 1. *“To reduce my stress levels and I need a boost”*

Concern 2. *“Make sure my nutrition levels are OK, i.e. If there is anything I can do to reduce my hot flushes”*

**Taken from Penny Brohn Cancer Care data set:**

Concern 1. *“Helping me to find ways of dealing with my dominant emotions of anger and grief”*

Concern 2. *“Helping me to find ways of coping with my fear of the future”*

Concern 1. *“Pain control”*

Concern 2. *“Energy levels”*

**Figure 4** Examples of “other things affecting your health” (stated on the follow-up MYCaW form)

**Taken from Breast Cancer Haven data set:**

*“Other illnesses, Unemployment due to inability to be confident with lymphodema as a major reason for being afraid to return to full time work.”*

*“Have decided to let more go and generally to slow down, accept that I am tired and not to worry so much about what others think. I have a new enthusiasm for feeding myself and family well and lots of new interests.”*

*“General support dealing with having problems, mentally I feel anxious and depressed due to my operation, feel very depressed.”*

*“Keeping a family going (children and elderly father) inevitably take up time alongside treatment, but are also important in keeping me strong.”*

*“I stopped eating all dairy products, which has made a quite improvement in my digestion system. My mother has got terminal cancer and is dying any day - Her sister died already (3 breast cancers between two sisters).”*

*“I reorganised my working hours in order to have an afternoon free each week.”*

**Taken from Penny Brohn Cancer Care data set:**

*“I have some anxiety regarding my parents who are both physically disabled and becoming more frail - they are both at a point at which they need to decide whether to move home (and nearer to us) but can't seem to reach a decision.”*

*“Stress and sadness due to recent divorce.”*

*“I have been having some financial problems, with 2 out of 3 bosses not paying me full pay, national insurance contributions gone missing and can't get incapability benefit, car accident, GP told me to get another GP.”*

*“Bereavement and family illness concerns.”*

*“I married my long term partner 2 weeks ago and we are expecting a grandchild in the next week or so - both very happy events.”*

**Figure 5** Examples of “What has been most important for you?” (stated on the follow-up MYCaW form)

**Taken from Breast Cancer Haven data set:**

*“A wonderful calm place to be able to go to. The opportunity to try things that were new to me. Such enjoyable and beneficial treatments. Information learnt and meeting other people affected . Only place I learnt about food and diet for during treatment and onwards.”*

*“Having someone that understands me more.”*

*“Getting the advice and support to help me to help myself i.e. feeling that I could do things to promote my recovery/healing ( in small senses) rather than just feeling like an NHS patient on the receiving end of medical treatment. So thank you Haven!”*

*“The mind body spirit therapy was a very powerful transition point. Following this my healing has been accelerated with cranial therapy. I will soon be able to leave the Haven and Marsden and walk on my own. "I bless the day I got breast cancer" now I am living" Thank you”*

*“Support help with nutrition and wellbeing, hope I can continue relying on it especially as the medical after care is none existent.”*

**Taken from Penny Brohn Cancer Care data set:**

*“Meeting other people who are in similar situations and the incredible warmth and supportiveness of all the "staff" who made it so much more possible to be positive and optimistic about the future.”*

*“The most important aspects of my time at the Centre were the individual interviews with practitioners. I have never had the chance to discuss myself holistically; to really stop and consider all my needs, physically, mental and spiritual. THANK YOU FROM THE BOTTOM OF MY HEART.”*

*“Impartial information and advice - holistic approach!! Having someone to check in with re personal/medical path. Meeting other women with breast cancers - have kept in touch - invaluable! Safe haven from the traditional medical realm - being able to relate to people who speak the same language.”*

*“The most important aspect is the change in the way I think about myself and the compassionate caring I had - I couldn't have made these changes without support and I found the group work especially valuable.”*