

# Improving cancer care

*A partnership project between service users and healthcare professionals to identify potential improvements to cancer services*

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Heather Goodare

I have worked for many years as a micro-biochemist researching natural ways to break down harmful environmental pollutants. I conducted research for The University of Texas and a major American power company. Moving back to England enabled me to help care for my parents, both with terminal cancer, and I became acquainted with Bristol Cancer Help Centre and Crawley Cancer Contact. Since then, I have become increasingly involved in complementary therapies and their value in facilitating the individual healing process.

Louise Nadim

## Summary

*We studied ways of improving cancer care by identifying local problems and facilitating co-operative working between healthcare workers and service-users.*

*We sent questionnaires to 1,000 professionals and 1,000 patients and carers, asking for their views on local problems and how to solve them and held focus groups to discuss the main points raised by the questionnaires. We found striking agreement between professionals and patients on the issues discussed. Holistic healthcare involves all stakeholders working together, and this is achievable.*

## Wounded healers as researchers

*A personal account by Heather Goodare*

The story of the genesis of this study may be of interest. The work was not just a step on the academic ladder, but part of the patient's journey, as the four people who conceived the idea all had personal experience of cancer in themselves or a close relative. Two were doctors: one had undergone treatment for testicular cancer as a young man, the other's mother had suffered terminal cancer. Two were patients: one with breast cancer, the other with cancer of the prostate. How could they make things better for future patients?

In 1990 I experienced the devastating *débâcle* of the publication in *The Lancet* of the Bristol Survey<sup>2</sup> appearing to show that breast cancer patients attending the centre 'fared worse' than those who did not attend. I was a participant in that study, and as an insider realised that something had gone wrong. From the outside, doctors and

statisticians complained to *The Lancet* about the methodology. I co-founded the campaign to challenge the purported results and enable the Bristol Centre to regain its good name,<sup>1</sup> and learned a lot about medical research in the process.

Over the next few years, work with the support group highlighted certain key issues as being important to patients, and evidence was gathered about deficiencies in local cancer services. The plan was made to find solutions to problems already identified by the National Cancer Alliance as needing attention,<sup>16</sup> with the help of patients, carers, and healthcare providers.

A solid scientific structure for our work was provided by Louise Nadim, a research scientist and a member of our support group. She provided the statistical analysis and graphs representing our data. At all stages of our research we drew on the advice and inspiration of the two doctors, the members and friends of the support group, and, as the study progressed, the local hospital consultant in charge of cancer services.

We all felt that the process of conducting this research was as important as the results. The fact that healthcare providers and users worked together as a team, on an equal footing, particularly in the focus groups (where we used first names) was important, as was the fact that our research was respected and regarded as professional by the local NHS trust. The evolution of a not untypical cancer support group, from a meeting in a patient's front room to a fully accepted adjunct to hospital services, able to undertake a serious piece of research, illustrates what can be done if the motivation is there.

Our personal experience of cancer services as 'consumers' gave us insights that perhaps might not have been obvious to researchers coming from a different perspective: but we still had to jump through all the usual hoops, and particularly that of the Local Research Ethics Committee, who approved our protocol and also audited our work. We think that it is unusual for such a piece of work to be entirely 'user-led', though at present patients are certainly sometimes consulted about research. One serious drawback with such projects is that the long-term health of patients cannot be reliably forecast: there is thus a certain urgency to complete and disseminate the work. We are therefore happy to be alive to see the publication of our study, and to report back to participants that this has been achieved.

## Introduction

The NHS Cancer Plan states: 'At a local level cancer networks will be expected to take account of the views of patients and carers when planning services.'<sup>3</sup> Little is known about the best way to do this, despite efforts to draw up recommendations for good practice:<sup>4, 5</sup> so far such work has been undertaken largely by healthcare professionals.<sup>6, 7</sup> Genuine partnership with patients has been difficult to achieve, and the 1995 proposal that 'patients should help to decide which research is conducted, [and] help to plan the research and interpret the data'<sup>8</sup> is still rarely realised. This action research project, undertaken by service users, aimed to find some positive recommendations for improvements to cancer services, which in the UK still lag behind other countries in western Europe, resulting in lower survival rates.<sup>1, 9, 10</sup> National programmes have been launched to improve matters,<sup>1, 11, 12</sup> but it takes time for national recommendations to be implemented locally.

Genuine partnership with patients has been difficult to achieve

Active partnerships with patients have 'become essential for all health care providers',<sup>13</sup> and in cancer care there has been progress, with the setting up of the Cancer Partnership Project. But in evaluating this it became clear that some healthcare professionals lack

commitment to such work, attending meetings 'as part of their job rather than through personal conviction'.<sup>14</sup>

This project was originally conceived by two doctors and two patients, who thought that 'creating the means for trying to reach agreement between consumers and doctors is important',<sup>15</sup> and that it was essential to have a power balance between participants, that is, users and providers. This was the rationale for sending the same questionnaire to all potential respondents, and for inviting equal numbers of patients and professionals to take part. All the work was done by volunteers, except for the professional facilitation of the focus groups and the transcription of the tapes. NHS staff contributed as part of their normal duties.

## Methods and participants

### Questionnaire

The main instrument used was a questionnaire survey, setting out issues identified as significant in previous work with cancer patients in a local area.<sup>16</sup> Such issues remained of concern according to the national survey carried out in 1999–2000.<sup>17</sup> The questionnaire was originally compiled by patients (members of the Crawley Cancer Contact [CCC] support group), piloted among group members and interested local professionals, and revised in consultation with hospital staff.

Respondents were asked to rank on a five-point Likert scale from 'very important' to 'not important' 17 known problem areas in cancer care and 15 possible strategies for improving services. Ample space was provided for free comment, especially for positive suggestions for improvements to the service. Participants were also invited to take part in focus groups. The same questionnaire was sent during July and August 2002 to 1,000 service users and 1,000 healthcare professionals of all kinds including ancillary staff. Completed (anonymous) questionnaires were returned direct to the researchers.

### Focus groups

Respondents who volunteered to take part in focus groups returned their personal contact details separately from the questionnaires, thus ensuring anonymity of their comments. Travelling and out-of-pocket expenses as well as refreshments were offered to focus group members. Discussions took place on weekdays from 6 to 7.30 pm, to ensure that people could take part after normal working hours, and that weekends would not be affected.

The purpose of the discussions was not so much to air grievances as to make positive recommendations for reform. Each group discussed a topic for 90 minutes, though there was some overlap of subject matter between groups, and all participants had the opportunity

to comment on themes discussed in other groups. Each group contained both healthcare workers and patients/carers, though the balance varied. All gave written consent for recording. The main facilitator for the discussions was an independent consultant, assisted by two volunteer counsellors from CCC. Private professional counselling was offered should any topic prove distressing, but this offer was not taken up.

It was emphasised that participants could withdraw from the group at any time without giving a reason. In the event none did. All the discussions were recorded and transcribed under conditions of confidentiality. They were analysed and a detailed report was written, taking account of participants' comments (see *Feedback*). The protocol was approved and the project audited by the Local Research Ethics Committee of Surrey & Sussex NHS Healthcare Trust.

**Results**

**Questionnaires**

The response to the questionnaires (without any coercion or reminders) was 256 (26%) from patients/carers (including 15 professionals who had been cancer patients) and 185 (19%) from healthcare workers (n=441). The balance between patients and professionals was thus fairly even.

**Focus groups**

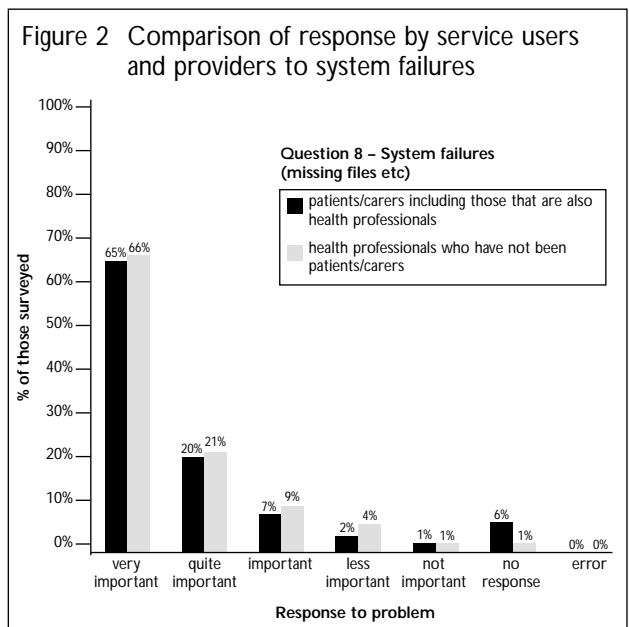
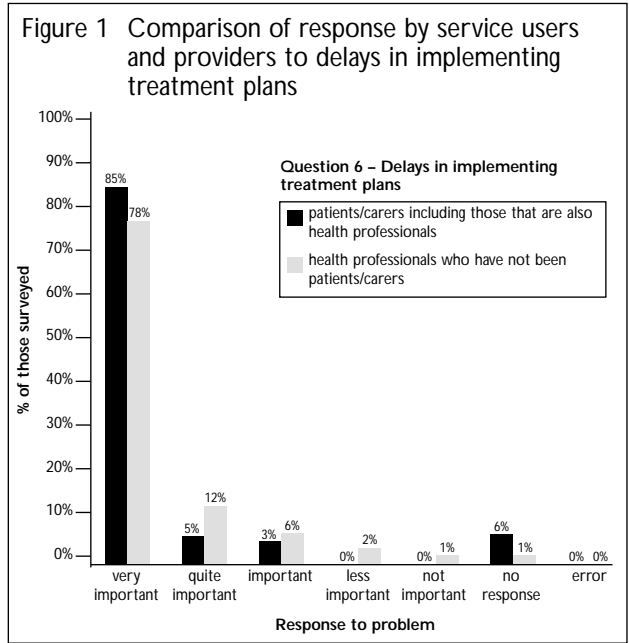
After initial analysis of the free comments in the questionnaires, six key themes emerged: communication; management of the environment; a patient-centred approach; delays; training; and resources. These formed the themes for the six focus groups, with a maximum of 12 participants in each, which were arranged in the autumn of 2002 (see table). Seventy-three respondents volunteered, and in the event 58 people took part: 33 patients (of whom 7 were also healthcare workers) and 25 professionals. There was thus again a good overall balance between professionals and patients. The professionals who had also been patients made a particularly valuable contribution, and their distinctive views are reflected in the statistical data.

**Feedback to and from participants**

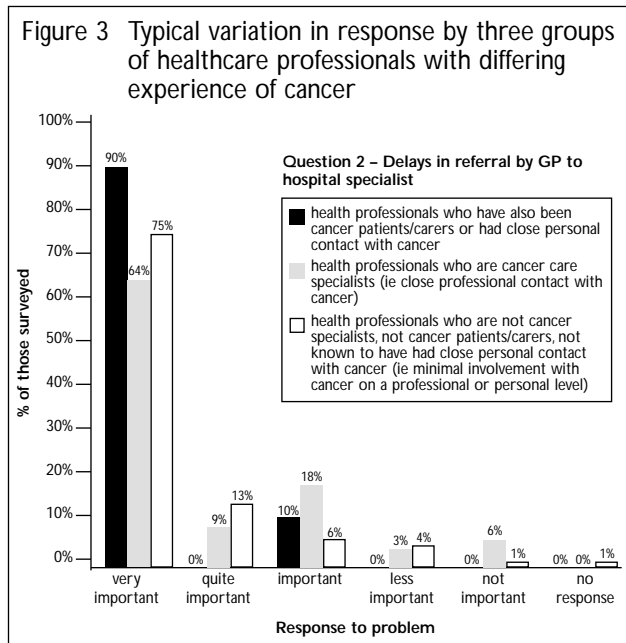
Any participant could ask to be kept informed of the progress of the project, and 142 did so (32%). A summary report of the project was sent to these participants in March 2004. The consent form for the focus groups encouraged participants to request a copy of the report of their own discussion for checking, if they wished, and 32 (55%) did so. Their comments were taken into account in the final report. All focus group members were given the opportunity to evaluate their experience by filling in a simple form: 51 did so (88%), and the responses were generally very positive.

**Analysis of questionnaires**

The free comment sections were qualitatively analysed and the main themes and issues extracted. The Likert scale questions were quantitatively analysed and the results presented in chart form to compare the responses from service users and providers. A striking finding has been the close correlation between the views of these two groups on the relative importance of the main topics of the questionnaire. Two charts showing particularly close correlation are given as Figures 1 and 2.



“ A striking finding has been the close correlation between the views of service users and providers ”



There were however 13 issues out of 32 (40%) on which there was a statistically significant difference between the views of users and providers on the 'very important' response, and in some cases the difference went in a counter-intuitive direction. For example, 46% of patients thought that 'lack of skill in delivering bad news' was very important, against 58% of healthcare professionals. Also significant was the difference between users and providers on the question about delays in referral by GP to a specialist, where 89% of users rated it 'very important', against 73% of providers ( $p < 0.005$  using a chi-squared test): but in both groups the 'very important' response predominated (see also Figure 3). Overall there was remarkable similarity of view between the two groups, on the majority of topics.

From the 32 areas highlighted as needing attention, the top 10 that were rated most often as 'very important' by professionals were: delays in reporting symptoms to GP; delays in referral by GP to hospital specialist; delays in implementing treatment plans; lack of equipment and facilities; poor communication between professionals; systems failures (missing files etc); lack of staff time; lack of staff; lack of appropriate information for doctors; lack of skill in delivering bad news. Key recommendations included better health education and more equipment (radiotherapy machines, scanners etc).

The users of cancer services also put these issues in their top 10, except 'lack of skill in delivering bad news' and 'lack of staff time', (though 'lack of staff' was included); they added 'more funding for expensive drugs', 'more opportunities and facilities for research', and 'better hospital management' to their recommendations.

The issues causing most concern were those directly affecting a patient's chance of recovery, eg delays in diagnosis and treatment (Figures 1 and 3). Support services were seen as less important: eg lack of

appropriate information for patients and/or professionals, systems failures etc. (Figure 2). Least important were emotional issues and back-up services, for instance provision of complementary therapies by the NHS, or better liaison with social services and benefit agencies.

“The issues causing most concern were those directly affecting a patient's chance of recovery”

One group stood out as consistently ranking issues as very important: these were the healthcare professionals who also had personal experience of cancer, having been patients themselves or having personally cared for family members with cancer (Figure 3). The cancer care specialists consistently gave a lower ranking than their colleagues.



### **Analysis of focus group work and qualitative material**

The main recommendations made in the focus groups are given in the table overleaf, together with further points abstracted from the free comments section of the questionnaires. We must stress that most of the patients and carers who responded to the questionnaires said that on the whole their care had been good; 36% specifically mentioned their warm appreciation of the care received.

## Analysis of focus group work and qualitative material

Focus group themes	Communication	Management of the environment	A patient-centred approach	Delays	Training	Resources
<i>Respect for the patient</i>	Honesty and clarity essential	Hygiene and cleanliness standards to be monitored by supervisors	Holistic approach needed, to include partnership with complementary therapists	Listening to the patient is important, to avoid referral delays	Communication skills training essential for all doctors and nurses	Make full use of existing services: use the local chemo ward as a 24/7 resource
<i>Consideration for all stakeholders</i>	Referrals to be speedy and patients to be copied into correspondence	Noise to be minimised (eg earphones for TVs)	Written care plan given to patients	Keep the patient informed truthfully about unavoidable delays in treatment	GPs CPD should include updating knowledge of referral guidelines	Time is precious: clinic bookings should be realistic, in accordance with each consultant's practice
<i>Patient autonomy</i>	Patient-held records should be introduced	Patients with a similar diagnosis should be grouped together in small wards	A second opinion should be offered if required	In outpatients, keep patients informed of delays by message boards etc	Junior doctors to practise practical skills before treating patients	Recruit more clinical nurse specialists: this would give nurses a higher profile and more job satisfaction
<i>Sensitivity to individual needs</i>	'Bad news' interviews to be carefully handled and the patient supported	Privacy for consultations essential	Everyone must be treated as an individual	Discharge to be a team decision (healthcare staff, patients and carers)	Nurses and radiographers encouraged to train in complementary therapies	Staggered working hours, so as to use equipment fully, reduce waiting lists, and fit in with patient and staff requirements
<i>Support requirements</i>	Support groups to be used and encouraged	Waiting rooms to be comfortable and welcoming	Carers to be given equal consideration with patients	A discharge pack should include information about local and national support organisations	Clinical supervision, counselling and support to be provided to all staff	Patients need both a key worker and trained volunteers who can offer support – these are not mutually exclusive
<i>Imaginative use of resources</i>	Carers to be allowed to accompany patients when using hospital transport	Car sharing to be promoted and parking improved	Home care and community support is appreciated and would relieve hospital beds	Long term care in special wards to avoid blocking acute facilities	Opportunities for research should be offered and patients consulted about the research agenda	Do any tests in advance of clinics to avoid unnecessary travelling and hospital time
<i>Administration</i>	An effective complaints procedure needed	Constant NHS restructuring is inefficient and confusing for both staff and patients	All patients to have access to a key worker (clinical nurse specialist) who would ensure continuity of care	Clinics should not be over-booked, and patients should be reminded of appointments by phone	Assistant radiographers to be trained to help with shortage of full radiographers	Internal NHS politics are damaging and waste resources – these issues must be resolved



## Discussion

This work illustrates that when service users and providers meet on equal terms, in a positive environment, to discuss common problems, they can find mutually acceptable solutions. Interestingly, we did not find that people with cancer saw emotional support as a high priority (which would have boosted our status as members of a support group) so much as speed in the delivery of clinical services. Although some recommendations have major cost implications, most would make better use of scarce resources and could be seen as 'savings'. For example, it is cheaper to extend the hours of operation of existing expensive equipment to reduce waiting lists, than to purchase, house, operate, and maintain additional machines. Flexible working can also be very popular with staff.

Patients and carers were generally appreciative of the NHS care they had received; their concern was to make it better. They saw the service as staffed by people who were usually caring and compassionate, working under constant pressure, with insufficient time and resources. Staff members were also keen to improve matters, and in some respects were more critical of services than were the patients: for instance, they were more conscious of their need for training in communication and supportive skills. Issues affecting only a minority of respondents, such as hospital transport and financial and social benefits, were not highlighted by the statistical methods used; but for those affected these issues were hugely important. With the trend towards centralisation of services transport problems and car parking will become even more significant in future. There is frequently tension between providing a standard of excellence at a cancer centre and providing local services at a cancer unit.

It is clear from this work that more attention has been paid recently to patients' emotional needs: the emergence of the clinical nurse specialist has been warmly welcomed, and the work of support groups is valued. However, no amount of emotional support can

compensate for delays in diagnosis and treatment. Our statistics show that all those surveyed, patients and professionals alike, agreed that issues directly affecting patients' chances of survival were of the highest priority, yet in some areas delays seem to have become worse in recent years.<sup>18, 19</sup>

Although there have been improvements in initial referral to specialists for some cancers, there are still unacceptable delays in implementing treatment plans. The delays in starting radiotherapy after breast cancer surgery, for instance, are getting longer, with 39% of treatments given 'beyond the maximum acceptable delay';<sup>19</sup> in some areas the delay has increased to three months or more,<sup>20</sup> and this will inevitably affect outcome.<sup>21</sup> Counselling cannot solve this problem: to try to do so presents role conflict for healthcare workers. The solution suggested by the participants in this study was to extend working hours into evenings and weekends to reduce existing waiting lists, and make better use of scarce resources.

## Current developments

Since 18 months elapsed between carrying out our survey and writing up our report, we felt we should check that our findings remained relevant to the current situation in local cancer care. We therefore conducted telephone interviews in March–June 2004 with four people who had volunteered to take part in the focus





groups but in the event had not been able to do so. These were a patient, a carer, a general practitioner, and a hospital doctor. All four confirmed our original findings, and it was suggested that in some areas the problems had worsened.

Since the completion of this work, the local healthcare trust has also run into serious financial difficulty, there has been a series of changes in the executive management team and inpatient hospital services have been moved away from the area served by CCC. This has meant that the group has an even more important role than before in supporting the local community. In 2004 it took over premises (The Olive Tree) on the local hospital site, and in 2005 a manager funded by Macmillan Cancer Relief was appointed. During the period from 1990 when the group was founded, cancer support services have greatly improved, with the appointment of clinical nurse specialists and the growth of cancer support groups, many of which offer complementary therapies, as does The Olive Tree. But the delays in implementing treatment plans are a serious problem for many patients.

Thus a major concern for us has been implementation. Despite attempts to communicate our findings to those who can influence changes in NHS cancer care, the ongoing upheavals in local healthcare have meant that only a few of the recommendations made by participants have been implemented by local management. We have therefore not yet been able to report back to our participants that their work has been as valuable as we believe it to be.

## Key issues

The key recommendations of this group of people – service users and healthcare professionals – in one cancer unit, united by their common desire to improve

cancer services and provide an integrated, holistic programme of cancer care, were as follows:

- 1 *Staggered working hours:* if cancer care working hours were extended, this would make better use of scarce resources (expensive equipment, ancillary services, and facilities such as car parking) and could offer more congenial work patterns for some staff. It would also be better for patients and families in many cases.
- 2 *Patient-held records:* the use of a patient-held record, such as is now standard in maternity care, would help to avoid delays, aid communication, and put the patient at the centre. This would not be instead of, but as well as, the development of centralized electronic records.
- 3 *A 24-hour 7-day-a-week helpline:* a telephone cancer helpline staffed by knowledgeable healthcare professionals, situated in a local hospital ward, would be invaluable for people with cancer, particularly those undergoing chemotherapy, who might need specialist advice and practical help out of office hours. It could also help non-specialist professionals.
- 4 *Staff training:* many of the recommendations involve training and supporting staff in admittedly stressful work, particularly in communication skills and delivering bad news, and keeping abreast of medical and technical advances. IT training will become increasingly important, together with a programme to train operators for specialist cancer care equipment and the financial incentive to retain their services.
- 5 *Freeing up hospital beds for acute care:* recommendations included streamlining the patient release procedure, providing more beds for long term patients in hospices and intermediate care, and increasing care in the community so that more patients, particularly young people, could be treated in their own homes.



## Conclusion

It is possible to achieve co-operative and productive work between the various stakeholders involved in healthcare, and ethical issues are surmountable. Holistic cancer care is 'joined-up care': it can and should involve partnership between patients and professionals, and voluntary services offering complementary therapies can work alongside statutory provision. Where a voluntary group has gained respect from local healthcare professionals it is capable not only of providing services that are valued, but also of conducting user-led research that can contribute to the improvement of healthcare generally.

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