

The Cancer Journey in the Western Isles
**A Study Investigating the Impact of the Diagnosis and Treatment of
Cancer on the Patient and their Family and Friends**

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1. Executive Summary

Aims

To investigate the emotional and physical impact on people who receive a diagnosis of cancer, and the impact on their family and friends on the Western Isles.

Design

An exploratory qualitative study.

Setting

The Western Isles NHS Board area.

Sample and Recruitment

People at various stages of treatment for cancer and those in recovery were recruited through the GPs on the Islands. In all, 77 people returned their consent form. Fifty-four people agreed to take part in the study. Twenty people with cancer were recruited into focus groups and individual interviews, 3 relatives were interviewed on a one to one basis, 12 people responded too late to take part in the study and 19 were away from the Islands when the study took place. Eight of the participants were men and 15 were women, aged between 30-70 years with the majority over the age of 45 years. There was a wide range of cancer diagnoses.

Methods

One focus group was held on Benbecula and two on Lewis. All were conducted in environments considered neutral. Interviews took place in the person's own home face to face or by telephone; at the Health Promotion office on Benbecula or at Grianan Day Care Centre, Lewis.

Analysis

A range of data were transcribed and subsequently analysed. Data sources and transcripts included:

- Three focus groups with patients comprising a total number of 15 participants
- Four in-depth interviews with patients
- Four in-depth interviews with relatives
- Five in-depth interviews with health care professionals; four were one to one interviews and one a group interview with two Macmillan nurses

In addition, field notes were kept on the geography, travel and a range of practical issues that might impact on diagnosis and treatment.

Analysis of qualitative data is an iterative process, and was on-going throughout the fieldwork. It was based upon a thematic analysis of verbatim transcripts supported by the fieldnotes and observation by the research team (Bowling, 1997). Transcripts were read and re-read in different 'cuts'. (Silverman, 2000). Accounts necessarily reflect a diversity of experiences and expectations within the sample but also provide a basis to

the development of policy and practice by establishing key factors for future work (Mason, 1996).

Resume of Key Findings and Recommendations

- Travelling to the mainland for a possible diagnosis without a family member or friend/escort is both stressful and difficult.
- Travelling to the mainland for investigations and follow up appointments causes a range of stresses for many ranging from the practical to emotional.
- Likewise travelling to the mainland for longer-term treatment can have practical, emotional and economic implications for the patient, their escort and family.
- Accommodation on the mainland whilst receiving treatment raises issues about comfort and security, especially when the patient must stay in a hostel or hotel of bed and breakfast standard accommodation.
- Limited communication between health care professionals on the Islands can lead to confusion about access to services and treatment for the patient, as well as frustrations for health care workers.
- Communication between health care professionals on the mainland and in particular the Beatson Oncology Centre, Western Infirmary, Stobhill Hospital and Glasgow Royal Infirmary and the Islands should be enhanced. There remain inaccuracies regarding skills and service provision, which may result in unnecessary travel for patients. This may also lead to additional costs to the health service.
- An appreciation of Island life and health care facilities by mainland health service providers is necessary so as to promote treatment plans that are sympathetic to the practical and emotional issues for patients and their escort.
- Referral system to Macmillan Nurse Service on the Islands should be clearer for both patient and health care professionals with guidelines agreed among all parties.
- Communication of bad news was at times very distressing suggesting that continuing professional development must be offered to staff working in the area.
- Information sources and types must be improved. These include treatment, financial, travel and information on the hospital or clinic where much treatment will be provided. In addition, the mechanisms for distributing information should be standardised and monitored to ensure appropriate information is received and updated on a regular basis.
- Professional emotional and psychological support services are limited and access to these requires review.
- Greater liaison between Western Isles NHS Board and the Beatson Oncology Centre, Greater Glasgow Health Board and West of Scotland Cancer Advisory Network on strategy and policy development that affect people from the Western Isles

2. Aims

The overall aim of the study was to investigate the emotional and physical impact on people who receive a diagnosis of cancer, and the impact on their family and friends.

Within this overall aim, the following questions were addressed:

1. What were the perceived strengths and weaknesses of current services?
2. What was the impact of receiving services away from the Islands on the mainland?
3. What changes did patients and family members perceive needed to be made to improve services?

3. Methods

Norma Neill, Senior Health Promotion Officer based on Benbecula initiated the research. The proposal was submitted via Brian Liddel, then chairperson of the Western Isles Cancer Network (this position is now held by Dr. Sheila Scott, current Director of Public Health), and funding was obtained from the North of Scotland Cancer Network. Ethics approval was submitted to Dr. Mike George, ex Director of Public Health, and the appropriate Ethics Committee granted approval for the study. After further discussion the proposal was returned to the Ethics Committee for approval to use the Macmillan Nurse Service to contact people with cancer and their families. This method of recruitment was agreed.

A sub group composed of the Western Isles Cancer Network supported and advised on the proposal. This included Norma Neill, the Macmillan nurses from the Uists, the Planning Officer for the Western Isles NHS Health Board based in Lewis and a General Practitioner from Benbecula. The study went out to tender and the Director of Public Health, the Western Isles NHS Health Board Planning Officer and the GP from the sub group approved the tendering process and made the award to Benn & Associates.

Throughout the Western Isles there are 28 GPs working out of 15 practices. All GPs were contacted at the end of August to inform them of the research and asking for their support. They were again contacted in December to inform who had been awarded the tender. Information was sent to GPs at the beginning of January asking them to give patients with cancer and their relatives information about the research and inviting the patients and their relatives to contact Linda Benn of Benn & Associates. Each GP practice was contacted by telephone to ascertain if they had any queries about the research. Information was also placed in the Stornoway Gazette and local community newspapers on Barra, Benbecula, Harris and west side of Lewis and Ness.

The methodological approach to the research is qualitative and comprised focus groups, one to one interviews and telephone interviews, and fieldnotes. The amount of time given to the research was limited and this was exacerbated by the Christmas and New Year holiday period and having to do the research management across the

islands in the Western Isles. The research, rather than depending on the gathering of data from pre-coded questionnaires, emphasises the importance and value of people as receivers of services giving their views and sharing their knowledge, perceptions and experiences. This method allows information to be gathered quickly without the use of vast amounts of scarce resources; namely patient's and professional's time and finance.

Consent was sought by letter. Each person consenting to participate in the study was contacted by telephone to discuss the proposed venue, date and time of the focus group or interview. This was followed up with a confirmation letter.

One focus group of people with cancer from the Uists was conducted at a health service meeting room in Benbecula and two focus groups of people with cancer from Lewis were conducted at meetings room at the Voluntary Action and the Grianan Day Centre. Individual one to one interviews were conducted in the person's home or an outside venue.

The focus groups and interviews were carried out over a two-week period in early February 2003 on the Western Isles.

3.1 Sample

General Practitioners on the Western Isles were invited to send the research information to all people on their list who had a diagnosis of cancer within the past three years. General Practitioners selected patients who in their opinion would be suitable to receive the information and invitation to participate in the study. The Macmillan Nurse Service also approached people they were in contact with and again the Macmillan nurses, as with the GPs, selected those people, who in their opinion would be suitable. **As a result of this selection process people who were newly diagnosed, experiencing advanced disease or dying or who were deemed 'fragile or vulnerable' were not invited to participate in the research.** This method of sampling has implications for the findings limiting data collection to those in mid to late treatment or in remission. While recognising the ethical issues of contacting other groups it would not be unreasonable to presume that the findings cited below do not do justice to the depth of stress and emotion associated with the long-term process from diagnosis to remission or death. The person with cancer was invited to make the decision whether or not to invite a family member or close friend to participate in the study.

In all, 77 people returned their consent form. Fifty-four people agreed to take part in the study. Twenty people with cancer were recruited into focus groups and individual interviews, 3 relatives were interviewed individually, 12 people with cancer responded too late to take part in the study and 19 were away from the Islands when the focus groups and interviews were taking place. Twenty-three people refused to participate. Eight participants were men and 15 women, an age range of between 30 to 70 years; with the majority over 45 years. Patients presented with a wide range of cancer diagnoses and at different stages of treatment and recovery.

At the time of the focus groups and interviews it was not possible to recruit a focus group in Barra, due to limited numbers of patients. Two individual telephone

interviews took place. The focus group on the Uists was held on Benbecula. Two one to one interviews, one in the Sonas Health Promotion Office, was conducted on Benbecula with a further interview taking place in the home of a patient. One telephone interview took place. Two focus groups and one individual interview were held on Lewis, in Stornoway, and two individual interviews on Harris in the homes of the people with cancer. There were insufficient people willing, able or available to facilitate a focus group for relatives on any of the Islands. Time and resource constraints also impacted on the potential to collect data from relatives and friends.

Additionally three individual interviews and one team interview were arranged with the Macmillan nurses on the Uists and on Lewis. Two interviews took place on Benbecula with a GP and a discussion about the research with a GP on Lewis. One interview took place with the Director of Public Health on Lewis and the researcher attended the Breast Cancer Care Committee meeting on Lewis. A meeting was held with Ray Strachan, Volunteer Co-ordinator for Scotland from 'Cancer Voices' a project set up to establish Cancer Patient Networks, supported by Macmillan Cancer Relief.

In addition, meetings were held at the Beatson Oncology Centre and the Western Infirmary, Glasgow, with the Director, Clinical Director and Professor of Surgery together with a meeting with the Director of Public Health, Greater Glasgow NHS Health Board. A meeting was held with Jane Bradburn, User Involvement Advisor/Cancer Patient Networks, Macmillan Cancer Relief, London.

3.2 Data Collection

Qualitative methods were used to identify the person with cancer's agenda. In the development of the research protocol Dr. Neil Campbell, Cancer Research Campaign, Clinical Research Fellow, University of Aberdeen was consulted, as was Penny Kocher of East Sussex Research Associates. The three focus groups lasted up to 90 minutes each. The groups were invited to write down five aspects of their care/cancer journey that worked for them and five that could be improved upon. These notes formed the basis to the discussion. Permission was received from each group for the discussion to be audiotaped and participants were assured of their anonymity and confidentiality.

3.3 Focus Groups

Focus groups are group discussions that are set up to explore a specific set of issues. One of the strengths of focus groups is that they encourage and support people to explore their own experiences, opinions, wishes and concerns in their own terms, and in their own vocabulary. Participants are not asked questions in turn instead they are encouraged to talk to one another; asking questions, exchanging anecdotes and commenting on others' experiences and points of view. The role of the researcher is to actively encourage and be attentive to the group interaction. Focus groups also allow researchers to explore the different perspectives that emerge as people participate in a social network. Focus groups are particularly suited to the study of attitudes and experiences around certain specific topics (Barbour and Kitzinger, 1998). A possible weakness of focus groups is that quieter participants will not be allowed a voice. The role of the researcher is to encourage the group to be inclusive and the invitation at the beginning of each session is for the group to allow each person to have their share of space and time. A further weakness is that participants

may hold back from sharing intimate details of their experiences. This could be the case of this research and research carried out in similar communities. As one participant succinctly stated “everyone knows everyone’s business here; the Islands are a small place”. So it is important to adopt a range of methods to collect data and thus elicit the range of issues and experiences.

3.4 Individual Interviews

These took place when there were insufficient people to hold a focus group and also allowed the research team to limit the possible weaknesses of reliance on just one method. As noted at the time of this research project there were insufficient people on Barra and Harris to hold a group, making one to one and telephone interviews the only method for data collection. Each person was interviewed by telephone or in his or her own home. The focus group procedure and topic guide were adapted.

3.5 Data Analysis

The tapes were transcribed and the data analysed from the dialogue in the focus groups and individual interviews for recurring themes and issues relevant to the participants’ perceptions of all aspects of their cancer care and the cancer journey.

Analysis of qualitative data is an iterative process, and was on-going throughout the fieldwork. It was based upon a thematic analysis of verbatim transcripts supported by the fieldnotes and observation by the research team (Bowling, 1997). Transcripts were read and re-read in different ‘cuts’. (Silverman 1998). Accounts necessarily reflect a diversity of experiences and expectations within the sample but also provide a basis to the development of policy and practice by establishing key factors for future work (Mason, 1996).

In addition the analysis looked for consensus and differences within groups and interviews. Evidence exists that if there is a strong consensus within a group then it can be predicted that the views expressed are likely to be expressed by other groups experiencing the specific topic in question. However, the research team also noted where views differed markedly.

3.6 The Topic Guide

A topic guide was devised to enable the researcher to facilitate the discussion with the focus groups and individual interviews (Appendix 2). In addition the researcher explained who she was, why the research was taking place, who was funding the research, the value of their contribution and how the draft report, final report and the on-going involvement of participants in the research was planned.

Respondents from the first group were invited to write down, anonymously, up to five aspects of care that was good and five areas that could be improved. The researcher then collated the comments on a flip chart and they were incorporated into the topic guide of questions for each group. All the focus groups and individual interviews followed the topic guide. Although there were instances when a particular group or individual wanted to spend time discussing a topic that was relevant and appropriate for them and was not on the topic guide.

4. Findings

For the first time people with cancer, their family and friends, living on the Western Isles were invited to express their views of the service and care they had received and its emotional and physical impact.

The findings are drawn from an analysis of the transcripts of:

- Three focus groups with patients comprising a total number of 15 participants
- Four in-depth interviews with patients
- Four in-depth interviews with relatives
- Five in-depth interviews with health care professionals; four were one to one interviews and one a group interview with 2 Macmillan nurses

In addition, field notes were kept on the geography, travel and a range of practical issues that might impact on diagnosis and treatment.

Access to, and the delivery of services, differs according to the locality of residence, and this was evident in the findings. Those residing in Lewis with access to treatment services in Stornoway had somewhat differing experiences to those living elsewhere many of whom found the emotional and practical stresses of travel to receive treatment much greater than others.

Data sources are listed in Appendix 1. Where quotes appear in the text below the source is identified as follows:

- Focus group: FG.
- Interviews with patients: Pat.
- Interviews with relatives: Rel.
- Health care professionals: GP; Mac Nurse.

An interim version of the findings was circulated to those who participated and comments received taken into account in the contents and emphasis of this and other sections.

4.1 The emotional and physical impact on people who receive a diagnosis of cancer.

Participants in focus groups and interviews debated how the **geography and culture** of the islands impacted on the experiences of diagnosis. A diagnosis of cancer becomes public knowledge fairly quickly and for some this visibility can be viewed positively:

You hear it very, very quickly ... nobody dies on their own or are left in a house like you have on the mainland. [Man, FG]

For a minority it was viewed less positively as a potential intrusion of *privacy*:

*Bush telegraph and the phones I suppose you could say it is intrusive
[Woman, FG]*

In all the focus groups and interviews and those who had moved to the isles spoke of the **support networks** in largely positive terms while noting the possible challenge to privacy. Visiting of the sick was said to be a social responsibility and few felt isolated. However, at times when treatment made patients feel tired and sick it could be hard to cope with visitors.

Historical, economic and family interconnections continue to have an impact on how the cancer patient may be viewed and supported. Differences in attitudes and levels of knowledge of neighbours were drawn out across the islands as well as between the Western Isles and the mainland. While there was some debate on this a range of ideas were exchanged in focus groups. For example, family connections and links between neighbours were said to be stronger on those islands that had limited connections with outside influences. Thus the existence of the airport and army base on Benbecula were said by some to result in people there being ‘not quite so friendly’ [Woman, FG].

Living on the islands could impact on the **speed and manner in which a diagnosis was delivered**:

I got a letter telling me to attend the hospital in Uist but unfortunately I didn't get over there because the weather was really bad. I got a phone call ... and they suggested me going over ... I knew nothing of what to expect... maybe at the back of my mind I did maybe have an idea.... Yes, it was surprise. [Woman, Pat]

The **weather** could also be a factor but being away from home, even with a relative or escort, meant many felt isolated at a time of great anguish. These issues were discussed in all the focus groups and the majority of interviews. Of particular note is the process of diagnosis when some participants did not have a friend or relative present as travel warrants are not available for escorts until a medical condition has been confirmed.

Shock and surprise were said to accompany many diagnoses. Participants spoke of suspecting all was not well but most were ‘shattered’:

Oh diagnosis. [on returning from the hospital] I phoned the Macmillian nurse and within half an hour she was over. She called the local surgery and the doctor came too because I was shattered ... I was shattered. [Woman, FG]

The process of **breaking bad news** caused concerns among many. Communication skills with regard to the breaking of bad news were said to vary somewhat with more appreciation necessary for the impact on patients away from their home, family and friendship networks. This finding related to both mainland and island health care professionals, albeit to varying degrees.

Patients then had to consider ‘*how much they wanted to know*’:

Woman 1: I think all patients should inform the doctor whether he wants to be told the truth Some doctors are anxious to protect the patients. I always said 'tell me the truth and I can cope with that.'

Woman 2: the choice is to stand out and you know try to accept it. It might take forever to accept it, however the truth is quite acceptable. [Women in FG]

Most participants commented on the processes of and context to communication between health care professionals and patients. While some praised the communications skills of health care professionals the most proffered examples were of encounters that proved to be difficult for patients:

Woman: I was still under the effect of the anaesthetic and I couldn't cope.... And he told me while he had seven or eight students with him at the time standing around the bed, stuck to a drip and stuff, when he announced the news. It was hard.

Man: there were three doctors there and I asked the one doing all the talking did he have anything to tell me and he said 'do you really want to know?' So I said yes and he said well it looks as if you have. I am 99% certain, I can't say about the 1% until you get the results. [Women in FG]

Fears of pain and death were closely followed by **anxieties** about telling others and organising treatment; emotional and physical factors inter-twinned. For example, many spoke of finding chemotherapy treatments especially draining in emotional, physical and familial terms citing a range of experiences. The **organisation of visits to the mainland**, the exhausting nature of the treatment, combined with physical changes, made many feel vulnerable in unfamiliar surroundings. Words cited to describe these processes included 'deeply worrying', 'horrendous worry' and 'constant strain'. These pressures, combined with adverse weather could make treatment arrangements stressful and isolating:

I was going away for a check up and the plan was cancelled due to fog. A and B were thinking of going by boat and they would take the car if I would go with them, so I was really pleased .. because otherwise I would have to miss my check up... but nobody from the health board or whatever ever asked [Pat]

This patient also had a husband in care. In fact many had family responsibilities or sick relatives and this meant that their **cancer treatment was not the only major issue** that they, their relatives and friends had to cope with.

For some emotional and spiritual support might have been improved. The potential for a '*nurturing sort of environment*' [Woman,FG] offering counselling, complementary therapies and a one-stop source of information was noted. However, in a number of interviews these issues were not discussed to any depth despite prompting. This suggests that in one off focus groups and interviews it can be especially hard to encourage discussion of intimate and sensitive matters.

Travel to receive diagnosis and treatment received particular comment and raised a number of issues for emotional and physical well-being. Firstly, a quote from a patient that outlines the combination of emotional, practical and treatment issues for many:

Interviewer: What about travelling off the island?

Interviewee: Now that was horrible because it is ripping you from the bosom of your family. Basically to go into a horrible hospital and have poisons pumped into your body when you are not used to taking Paracetamol I was given a few trips that were paid for to come with me initially which was a great help but once that stopped and family pressures and work pressures took over here then I was very much on my own. So yes travelling was horrible but it is something you have to do.... [Woman, Pat]

Most participants voiced the need for emotional support at crucial stages of diagnosis and treatment but at times the provision of this was not practical or could not be resourced. Further, sometimes not knowing what to expect added to stresses. For example, in two of the three focus groups participants debated what they thought they could expect in terms of support with travel. Issues considered ranged from expenses, accompaniment by relatives and friends, to home help services. These debates highlighted the diverse knowledge and ideas about what to expect from the health board and health and social service staff.

A number of participants queried the need to travel for check-ups that might only take a matter of minutes and for aspects of treatment such as chemotherapy, which require rest and support soon after. There were lively debates in focus groups on these issues. For some there was a lack of information on the reasons for the delivery of treatment in a particular location and by certain methods. In a few cases the delivery of care through a number of centres was further complicated by the loss of notes or delays in the transfer of notes. In these situations the accepted need to 'wait around' could become extended and add to general concerns. Lastly, the lack of cleanliness of hospital wards on the mainland caused some anxieties with one person adding that their return to care on the islands had a positive impact on their attitudes; *'it will be healthier over here'* [Pat].

By contrast several health care professionals speculated that late presentations with symptoms might partly result from concerns about the accessing of treatment off the islands. Certainly patients, relatives and health care professionals all agreed that travel off the islands for treatment should be limited as far as possible to specialist needs.

Many felt their individual **religious and spiritual needs** were catered for. However, concerns were expressed by some who received in-patient care in Stornoway that consent was not sought before prayers were said beside beds or prayer meetings conducted in wards. For some this was an added stress and despite the levelling nature of cancer treatment, this was said to highlight differences across the islands.

It should be noted that the overwhelming majority of patients spoke in **positive terms of the care received from health staff on both the islands and mainland**. It was

recognised that many staff did appreciate the issues posed by travel and did try to organise appointments around transport schedules:

he couldn't have been nicer ...and the breast care nurse who came in with him was very supportive... [they] spent a bit of time with me just talking through some of the practicalities of coming off the island and having treatment. [Woman, FG]

4.2 Impact of diagnosis of cancer and treatment on the relatives and friends of a person who receives a diagnosis of cancer.

Findings on this topic may be considered in two sub-sections:

- Information and knowledge to include:
 - Cancer and related services
 - Travel, transport and accommodation
- Emotional support to include:
 - Gender and emotional support for patients and relatives
 - Family pressures and everyday realities
 - Reassurance for the patient, family and relatives

4.2.1 Information and knowledge

Leaflets, posters and conversations were the main methods through which relatives received information. For some this was enough but many expressed a sense of slight confusion about the methods of treatment and prognosis. There was much debate on these issues with consensus that it was difficult to keep up to date with information on diagnosis, prognosis and treatment. Of particular note was limited information on social care services, financial help and counselling. Some commented on the need to talk to other patients and relatives who had been through a similar experience.

Having seen the doctor he thought well I will now try to find somebody else who has been through it

Not surprisingly many commented on travel, transport and accommodation. There were evident differences in knowledge about what and how to claim. Many were too tired, too stressed, *'not wanting to make a fuss'*, to claim everything back and a few just did not know what they or their relative could actually claim for. For example, it was unclear if claims could be made for returning home at weekends. Also some relatives were unsure as to when they might accompany a patient:

I had to arrange his transport ... they (mainland hospital) said to me quite abruptly... they (only) arranged the ambulance to the (mainland) airport. [Woman, Rel]

There are cost implications ... you don't get a travel warrant if you are just going to visit. Maybe I could have. I don't know. [Man, Rel]

Information on travel and transport was the most commonly discussed topic. Often participants expressed confusion and concerns about costs and arrangements. In addition, adverse weather conditions could lead to the cancellation of travel arrangements and in these circumstances it was unclear what they could do. When arrangements went to plan they were generally praised for 'the speed', 'the friendliness' and 'the care from everyone.'

4.2.2 Emotional support

While keen to support the patient at times relatives and friends needed support themselves. Patients and relatives recognised that there are a variety of ways of coping with diagnosis. For some they did not want to talk and the silence marked a coping mechanism that appears gendered; it was most often men whom did not want to discuss either their own diagnosis or that of a relative:

Man: With me it was purely selfish. My family has grown up and the only thing I was worried about was spending five or six weeks in Glasgow or any city which I dreaded...

*Woman: My husband ... I didn't want to over burden him with a lot of details ... feelings that come with cancer diagnosis because I felt he was coping with enough anyway... I would say that support, psychological support really wasn't there for me. My husband gave most of what there was.
[Exchange, FG]*

Some women patients and relatives found the lack of support and information hard but appreciated this resulted from it being 'their [men's] way of coping' and staff being too busy to consider emotional support:

*I didn't really get any support... I mean the nurses were far too busy.. sometimes I was wishing the Macmillan nurse would speak to me ... anybody...
[Woman, Rel]*

A number remarked that living on the islands had a benefit as 'here you can get sent away right away' [Woman, Rel]. Knowing that time scales were shorter than they might experience on the mainland was perceived as positive reassurance for many.

4.2.3 Family pressures and everyday realities

Regardless of tensions and pressures in family life both patients and relatives wanted to be physically close to each other at this time. Discussions about friends also focused on their valuable role in 'just being there'.

To my mind it seems to be when a family most need each other they seem to be separated through no fault ... OK we choose to live here ... but from my point of view I needed support too ... you can draw it [support] from each other. [Man, Rel]

Many had family commitments to manage alongside care for a relative and taking time out from work and family commitments to accompany a patient could be problematic. Thus the tensions between emotional / familial support and the economics of working life became evident for some.

Family and friendship networks on the mainland were drawn upon when they were available. Many spoke of the positive boost from knowing people on the mainland although the expenses available for these arrangements was said to be much less than for those staying in a hotel or bed and breakfast and did not reflect the quality and quantity of care received. Others did not know anyone and for relatives this could make the days long and lonely. This also placed pressures on the patient and relative as they had only each other for support while on the mainland.

4.2.4 Reassurance for the patient, family and relatives

In a number of families knowledge of the previous death or recovery of a relative from cancer had an impact on their perceptions of diagnosis and anticipations of the future:

My husband wouldn't talk about it because he lost his father at a very young age with cancer and his sister and two aunts this year ... he just clammed up [Woman, FG]

Health care professionals also noted that treatments and prognoses change and so past experiences should not necessarily dictate the anticipation of current treatment and care. Lastly, the need to achieve a balance between assurance and the provision of practical information was noted; for some there was too much of an emphasis on practical matters and for others emotional support. Patients and relatives appreciate being listened to and their needs addressed whether these are emotional, practical or a combination of these.

4.3 What would improve the experience:

- a) **For the person diagnosed?**
- b) **For family and friends?**

A range of suggestions were made and these are identified in the following sub-sections:

4.3.1 Diagnosis and treatment

- The lack of support for patients at the pre-diagnosis stage was noted. No escort is allowed until a medical condition is diagnosed. At a time of shock and vulnerability, and immediate treatment a patient may be alone on the mainland; *'patient's need someone with them to take in what's being said as the patient may be in shock' [GP]*. This, and in more general, the need for support through care was noted.

- Communication between patients, GPs, health care professionals and staff on the mainland posed a number of issues. Apart from a few notable exceptions there was said to be little information sharing between staff on the islands and mainland:
 - Doctors on the mainland might not be aware of the issues for patients and relatives on the islands, not least support and travel issues.
 - The flow of information might be made more efficient. It was noted that on occasions it has taken several weeks for information to be sent back to the islands from hospitals on the mainland.
 - The potential to deliver treatment on the islands would appear to be under-estimated and many spoke of travelling for short appointments or forms of treatment that could possibly be offered locally.
 - The role of the nurse practitioner and that of the Macmillan nurses were cited as areas for potential development.
- It was suggested by a few participants that video links and telemedicine might be developed so as to enable services to develop more efficiently. It was argued that medical and nursing staff might need to develop skills in using this equipment. In the long run it would add to their skills and potentially result in less travel for patients and relatives.

4.3.2 Information

- The need for centralised information was noted. The strength of local networks can lead to presumptions that patients and relatives are getting information. Clearly a range of experiences and views were found. So information must be clear and updated on a regular basis. Support for the use of information might also be enhanced; for example, how to access travel warrants or what to do in the event of adverse weather.
- Information issues with patients and relatives need to be re-assessed on an on-going basis so as to avoid over-load and ensure that practical and emotional issues are addressed.
- Files for patients from the islands might be colour coded thus ensuring that as case notes move between the islands and the mainland staff are aware of the where the patient resides and the need to consider an additional range of issues in organising and delivering care.
- The potential of the video that has been produced to inform all groups about the issues for cancer patients and their families needs to be strategically developed. It was also argued that staff on the mainland might benefit from this too as it would '*bring alive*' the issues facing cancer patients in the islands.
- Health care professionals and a number of patients argued that information from voluntary sector and specialised groups in the NHS needs to be updated

and maintained on an annual basis with a person or group named as responsible for that dimension of service provision.

4.3.3 Emotional support

- While counselling services do exist it was unclear how referrals to this operated.
- Support for bereavement was suggested, not only for those who have experienced a recent death in the family but also those who have memories of difficult experiences of nursing someone through a terminal illness. Past experiences informed many ideas on current and future anticipations of treatment.
- For a number of patients there was a sense of being let down by health care professionals and that suggested levels, amounts of care and contact were not kept up. Patients asked for staff to be realistic about the amount of emotional support they might provide.

4.3.4 Practical Matters

- Hostel accommodation in Inverness posed a number of concerns including:
 - Mixed accommodation. Women would prefer single sex facilities or at the very least single sex bathroom facilities.
 - Better lighting for those walking to and from the dining room.
 - Ease of access to food and cooking facilities; this, it was suggested, would help promote a sense of control over aspects of everyday living.

5. Conclusions

All people participating in the study found that their diagnosis of cancer had a major impact on them and their families and friends and, to varying degrees, they experienced difficulties with the delivery of services and care. Each contributed from their own experience as to what and how improvements might take place. However, there was a difference in levels of stress, discomfort and anxiety between those people who received their treatment, care and follow up care in the Western Isles and those who had to travel away from the Islands for treatment. This difference was particularly marked between the experience of those people who had cancer, and their family and friends, who lived on Lewis, who received some, if not all, of their treatment on Lewis and those people who lived on Harris, the islands of Berneray, North Uist, Benbecula, South Uist and Eriskay that make up the Uists and Barra. Those people who lived on the Uists and Barra, and in the main, travelled to the Beatson Oncology Centre in Glasgow for their diagnosis, treatment and follow up care, appeared to experience the greatest emotional, physical and practical impact.

6. Recommendations

Drawing upon the range of data the following recommendations are offered. These are linked to the organisations central to planning and organisation, and the delivery of treatment.

6.1 Western Isles NHS Board

- The offer of a paid escort for people being referred to a cancer clinician on the mainland prior to actual diagnosis. [section 4.1]
- The communication of the standard of care and facilities that are available on the Islands to clinicians and services on the mainland. [section 4.2]
- A review as to whether or not all possible use is being made of Island health care facilities; for example use of the new hospital facility on Benbecula and, more generally, chemotherapy service and health care professionals working in the community. [section 4.2]
- Shared care and collaboration between mainland clinicians and Island doctors: especially for some chemotherapies, investigations and follow up appointments so as to limit travel. For example, GPs and Macmillan nurses could visit the Beatson Oncology Unit to build a relationship and to discuss options and protocols for shared care. In the long run reducing travel would reduce levels of stress for patients and staff as well as costs to all involved. [sections 4.1; 4.2; 4.3]
- Liaison between Western Isles NHS Board and Greater Glasgow NHS Board and the Beatson Oncology Centre [section 4.3]
- A variety of accommodations might be considered for those who stay over on the mainland, especially for long-term treatment. [section 4.2]
- Greater and improved communication between the Macmillan nurse teams. The development of short guidance/protocol on referrals and communication should be considered. This might also be made available to patients and relatives. [sections 4.1; 4.3]
- Further development is necessary for professional cancer counselling. Bereavement support services should be enhanced for people with cancer, their family and friends. Such a service needs to be established in the Uists and Barra. [sections 4.1' 4.3]
- Continuing professional development should be provided on supporting the people with cancer, their family and friends, on the impact of a diagnosis of cancer and throughout the cancer journey. [sections 4.1; 4.3]
- Enhanced awareness and support for the difficulties the post treatment phase of the cancer journey can bring is necessary. [sections 4.1; 4.2]
- As a starting point an audit on information sources and the costs associated with this (for patient and the NHS) should be conducted and inform the development of a strategic approach to practical matters. [sections 4.1; 4.3]
- Access to complementary therapies should be enhanced so as to offer greater choice and emotional support. [section 4.1]
- Communication might be enhanced with Cancer Voices, a user involvement project of Macmillan Cancer Relief (section 4.2)

- Development of patient to patient support systems within the hospital and the community. (section 4.2)

6.2 Beatson Oncology Centre, Glasgow

- Staff and patients should be encouraged to ask ‘are all trips to Glasgow clinically necessary and can some treatments, investigations and follow up care be carried out on the Western Isles?’ [sections 4.1; 4.2]
- Shared care for some aspects of treatment and follow up treatment with Island health care professionals must be enhanced between:
 - Clinicians and General Practitioners on the Islands [sections 4.1; 4.3]
 - Cancer Nurse Specialists and Macmillan Nurse Teams and Macmillan Nurse teams on the Western Isles.
 - The Specialist Chemotherapy Nurse on the Western Isles and mainland [section 4.3]
- When a person is on their own there must be an especially sensitive approach to the breaking of bad news and support for their return journey. [sections 4.1; 4.3]
- Coloured coded casenotes, or other system, for Western Isles patients would ease identification of patients whom have to manage a range of additional factors and stresses while participating in treatment. For example, appointments could be made to fit around flight times and days, when morning appointments will require an overnight stay. This causes particular difficulties for Monday appointments, which necessitate leaving home on Saturday and thus two overnight stays away from home rather than one. [section 4.3]
- Visits to the Western Isles by mainland staff would help to build working relationships with health care practitioners. [section 4.3]

6.3 Greater Glasgow NHS Board

- Liaison and inclusion of Western Isles NHS Board in strategic reviews and policy development that affect people from and services to the Western Isles. [section 4.3]

6.4 Raigmore Hospital

- Women only residential hostel or if shared facility women only bathrooms and lavatories. [section 4.3]
- Ease of access to food and a cooking facility. [section 4.3]
- Better lighting for those walking to the dining room from the hostel. [section 4.3]

6.5 Lewis Hospital

- Lack of patient choice around being visited by unsolicited Church representatives [section 4.1]

7. Future Research

Given the findings and the recommendations above this might include:

- Interviews with clinical staff at centres and hospitals in Glasgow, Inverness and Stornoway.

- Interviews with people who are newly diagnosed, living with advanced cancer or dying of cancer to research their experience of the cancer journey; what works and what could be improved.

8. Dissemination

In mid March an interim version of this report was sent to all participants and the commissioners for comment. On receipt these comments were considered and minor changes made to the emphasis in findings made.

The final report is to be disseminated by the Western Isles NHS Board. This is due to commence in April with circulation of copies to all participants and relevant individuals and groups referred to in the recommendations and other sections.

It is anticipated that the authors of the report will make presentations to interested groups and individuals in June. At that time subsequent arrangements for dissemination will be considered and agreed.

References

Barbour, R. and Kitzinger, J. (eds.) (1998) *Developing Focus Group Research*. London: Sage.

Bowling, A. (1997) *Research Methods in Health*. Buckingham:Open University Press.

Mason, J (1996) *Qualitative Researching*. London: Sage.

Silverman, D. (2000) *Doing Qualitative Research. A Practical Handbook*. London: Sage.

Western Isles NHS Board, (2002) *The Price We Pay : The Patients Journey from Remote and Rural Areas of Scotland* (Video)

Appendix 1

List of Focus Groups and Interviews Conducted in February 2003

Focus Groups with Patients	Cited in Report as
1. Lewis	FG
2. South Uist	FG
3. Uists	FG
Interviews with Patients	Cited in Report as
1. Barra	Pat
2. Eriskay	Pat
3. Harris	Pat
4. North Uist	Pat
Interviews with Relatives	Cited in Report as
1. Barra	Rel
2. Benbecula	Rel
3. Harris	Rel
4. Lewis	Rel
Interviews with Health Care Professionals	Cited in Report as
1. GP Uists	GP Uists
2. Macmillan Nurse Harris	Mac. Nurse A
3. Macmillan Nurse Uists	Mac. Nurse B
4. Macmillan Nurse Stornoway	Mac. Nurse C
5. Macmillan Nurses Stornoway	Mac. Nurses (Group)

Appendix 2

The Topic Guide

1. Please tell us your name and one nice memory of last summer/what it is like living in the Western Isles?
2. What made you decide to take part in this study?
3. What were the best things that happened about the treatment and care?
4. What were the worst things that happened?
5. How were you prepared for what would happen on your first hospital visit?
6. If relevant, what was it like being diagnosed on the mainland?
7. Where you prepared for a diagnosis of cancer?
8. What was it like being treated on the mainland?
9. What was it like for your family / relative?
10. When you were diagnosed how were you told?
11. What information were you give and by whom on:
 - access to information about the cancer and treatments?
 - access to practical information, financial, travel, home help, childcare?
 - access to emotional and psychological support?
12. Did you have access to specialist nurse help and support?
13. What was the communication like between the doctors and nurses on the mainland and the islands?
14. How did you experience the travelling to the hospital?
15. What were the worst things about being treated on the mainland?
16. Were you treated with respect and dignity?
17. Were your religious beliefs respected?
18. What can be done to improve things/what needs to change?
19. If you were asking the questions what would you ask the group?
20. Lastly, have we have missed out anything?

