Transforming Care After Treatment (TCAT) in the Western Isles

Phase 2 Self-Evaluation
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Background

This is the self-evaluation of NHS Western Isles’ Phase 2 Transforming Care After Treatment (TCAT) two-year project.

The TCAT programme is a partnership between the Scottish Government, Macmillan Cancer Support, NHS Scotland and local authorities which supports a redesign of care following active treatment of cancer. The five year programme launched in 2013, aims to support and enable cancer survivors to live as healthy a life as possible for as long as possible.

The Western Isles have a population of approximately 26,900 (2016) with around 200 new diagnosis of cancer on a yearly basis. The Western Isles encompasses Lewis, Harris, Uists, Benbecula & Barra with Lewis having the highest population therefore the majority of individuals with cancer can be found here with much smaller numbers throughout the rest of the Islands.

Macmillan Cancer Support’s report ‘Life After Cancer Treatment’ describes how many people who have been affected by cancer, either as a patient or a family member, struggle to return to a ‘normal’ life once treatment has been completed. Issues include: financial, benefits advice, self-esteem, body image, inability to relax, change in social standing, employment, nutritional needs, reduced exercise, social isolation, loss of independence and others.

Some individuals find it hard to move away from ‘being a cancer patient’ or the family member of ‘a cancer patient’. They find it difficult to look forward to the future.

The ‘Looking Forward’ programme has been used throughout the Western Isles (WI) for a number of years for women completing treatment for breast cancer. Evaluations have regularly reported a high level of satisfaction from participants. Comments in evaluations included those of a great feeling of being more in control of their lives as well as understanding the importance to eat well and the remain/return to being active.

The question was raised locally ‘could ‘Looking Forward’ be adapted to deliver similar outcomes for men and women with other cancers?’

In an attempt to answer that question, a pilot project, which followed the principles of the breast cancer ‘Looking Forward’ programme for people with a different cancer diagnosis and including men, was delivered in late summer 2014 in Stornoway, Isle of Lewis. This was organised and run by Macmillan Nurses based in Stornoway. Patients who were invited had all completed their cancer treatment before the programme started and some were still experiencing long-term consequences of their treatments. Men and women attended.

The pilot project/programme was run over three consecutive weeks with 14 attending week one, 16 at week two and 18 on the last week. Evaluation forms were given out at the last meeting, i.e. 18 forms. Thirteen were returned (72%)

The organisation and delivery of this pilot project by the Macmillan Nurses was on top of an already very busy caseload so added to their pressure of work.

The pilot project/programme had been delivered in Stornoway, Isle of Lewis. The participants were invited by Macmillan Nurses as people from Lewis or the Isle of Harris who had been on their caseloads and knew they had completed treatment. It was recognised that not all people with a
cancer diagnosis are known to the Macmillan Nurses so there may be people who have had cancer and its treatments who could not be invited.

It was felt that having a Project Officer to scope out the needs of the Western Isles’ cancer population may capture those people who have not had contact with the Macmillan Nurses.

Evaluation of that pilot project showed that it had been highly valued and at a meeting with colleagues employed by Macmillan Cancer Support the NHS Western Isles’ Macmillan Lead Cancer Nurse was strongly encouraged to submit a bid to develop a TCAT project.

That bid was successful and included a key necessity, i.e. that of a Project Officer. It was envisaged that having a Project Officer to move this forward would relieve some of the pressure from the clinical Macmillan Nurses whilst incorporating their knowledge and expertise within the programme.

The remote, rural islands of the Western Isles present challenges to providing cancer care both during and after treatment. The travel links for people delivering a programme as well for those wishing to attend can be difficult, particularly during periods of poor weather conditions.

The project’s aims and objectives

To establish a programme of support such as ‘Looking Forward’, for people affected by cancer when treatment has been completed by means of facilitating participants on to a self management pathway.

To ensure that this could be achieved, preparatory work would need to be done. The following objectives would facilitate that aim:

- To establish a steering group which would involve service users and develop close links between healthcare staff and others, e.g. sport and exercise staff, benefits advisers and complementary therapists. The steering group would help guide the scoping process and support recruitment and ongoing support to Project Officer.
- To employ a Project Officer to scope the needs of people after they have been affected by cancer and its treatment. This would involve contact with patients and families as needs identified may be different for each group.
- To establish whether needs are different in different parts of the Western Isles. A mapping exercise needs to be carried out to identify needs which will help inform the shape of the project.
- To establish that the programme’s content reflects the needs identified.
- To source appropriate venues for delivering the programme.
- To develop a local directory of relevant expertise to facilitate the delivery of the programme, e.g. local Macmillan Nurses, benefits advisers, exercise/sports staff, GPs, etc.

The project’s anticipated outcomes

The following outcomes were anticipated for participants following the programme:

- Regaining independence
• Returning to self-management of their lives
• Remaining well, both physically and psychologically/emotionally
• Having the signposts to direct them to sources of advice and support.

It was hoped that as a by-product of attending the programme, participants would feel less isolated and, indeed, participation may prevent isolation caused, in part, by their diagnosis and/or their treatment.

Local Evaluation of the Western Isles TCAT project: ‘Looking Forward’

This reports sets out what was aimed for, undertaken and reviewed within Western Isles as part of the national TCAT Programme. The benefits, challenges and lessons learned from various components of our work are set out and discussed.

*The views expressed in this report do not necessarily represent those of Macmillan Cancer Support or Edinburgh Napier University.*

The Western Isles’ project involved a small number of patients necessitating this report to be highly qualitative rather than quantitative. Any proposed statistical analysis of our findings would therefore be only indicative and not statistically significant so none has been undertaken. This report has been shared with colleagues at Edinburgh Napier University and colleagues regionally in the North of Scotland for comment.

Local Steering Group for project

A Steering Group was established consisting of representatives from regional and national Macmillan employees, the local Macmillan Lead Cancer Nurse, Macmillan Nurse Specialists, local GPs, non-clinical NHS including Health Promotion and Local Authority employees, NHS Board members, including the Chief Executive, Councillors and patient and local cancer support group representatives. It was decided that a broad range of representatives would benefit the project design and implementation. It was also felt that having the Health Board’s Chief Executive on the Group may help influence future plans.

Videoconferencing would be used as much as possible to engage with members distant from the majority base and to minimise costs for attendance at meetings.

The Steering Group was convened before confirmation of the success of the bid for funding from TCAT. Preparatory work got underway before the project started officially/formally. The Steering Group, for example, were able to collectively agree a job description for the Project Officer and start the process of having it approved and ‘banded’ so work could start as soon as the funding was approved.
The Steering Group met for the first time in March 2015 and continued to meet monthly until 2016 when the frequency decreased to quarterly. Notes from every meeting were made along with action points and shared with the membership as soon as possible after the meeting.

Steering Group members agreed to support the Project Officer as much as they were able when the post was filled.

The Group agreed that the Macmillan Lead Cancer Nurse should chair the Group meetings and provide leadership to the project and line management to the Project Officer when in post.

A small sub-group of the Steering Group was formed in late 2015 and was known as the Working Group (WG). This was formed to move the project forward more quickly and report back to the Steering Group. Membership of the WG comprised the Macmillan Lead Cancer Nurse, Macmillan Nurse Specialists based in Lewis and based in Benbecula, the Healthy Working Lives Adviser from Health Promotion and the Chair of the Hebridean Men’s Cancer Support Group who was also representing the Local Authority, Comhairle nan Eilean Siar.

Benefits

The Steering Group’s Chair was experienced in leading on projects as well as chairing meetings using videoconferencing.

Members had links to other agencies i.e. local authority, the wider NHS, the local Cancer Strategic Steering group.

Members can engage widely and freely with their contacts to share developments and to seek advice.

This was to be a shared plan for those who have experienced cancer themselves, not just the professionals to offer their opinions.

The willingness of members to provide support to and direction for Project Officer.

The Working Group met regularly in between meetings of the Steering Group so could move some aspects of the project on more quickly.

Challenges

The impact of the time required to plan, lead, make notes and distribute notes related to meetings on the Project Leader/Macmillan Lead Cancer Nurse’s time.

Gaining commitment from all members to attend regular meetings and contribute to papers issued in between meetings.

I.T. throughout the islands could be problematic, for example using videoconferencing, to link in with members in the southern isles, i.e. the Uists, Benbecula and Barra, and with TCAT regional and national board members.

Absenteeism of some key members due to ill health, in particular the Macmillan Lead Cancer Nurse and the Project Officer.

Some members not fully understanding NHS structure and processes.
Small numbers of the Steering Group attending some of the meetings.

Discussion/lessons learned

Collectively we had not considered the impact of leading this project on the Macmillan Lead Cancer Nurse’s time. This should have been considered and solutions sought before applying for funding for the project.

Steering Group (SG) members were not always able to attend meetings or contribute fully which meant that there was sometimes no robust discussion with varied representation. This could have been improved by members delegating to a deputy in their absence.

Not all SG members gave apologies leading us to be unaware of numbers attending. This resulted in some meetings going ahead despite very low numbers.

If terms of reference for the Steering Group had been written and agreed, these would have included the number of attendees to make up a quorate. Meetings could then have been postponed rather than continue with very low numbers.

Terms of Reference should have included the role of individual Steering Group members in their support of the Project Officer thereby reducing the burden on the Project Leader.

Recommendations

There is a need to factor in the time required to lead on projects by key personnel where the project is an add-on to their job.

Commitment should be gained from members to attend meetings regularly and contribute towards the programme.

Terms of reference for the Steering Group should be written and agreed at an early stage of the project development.

Ensure members have a good understanding of their role and the topics on the agenda.

Employment of Project Officer

A job description was written reflecting and incorporating some aspects of other Health Boards’ TCAT Project Officers’ job descriptions. This was sent to the local Agenda for Change banding committee within NHS Western Isles. It was banded at 4 which immediately excluded the post being filled by a qualified healthcare professional. Due process was followed for recruitment, shortlisting carried out, interviews took place and a project officer was appointed.

The Project Officer did not have any previous healthcare experience. This was different to other Health Boards who had apparently opted to employ officers with a clinical background and generally with a higher banding.

During her induction period, the Project Officer met with representatives from all the General Practices, the cancer support groups and other NHS services such as mental health. During these
meetings she outlined the forthcoming TCAT project and encouraged their support and contributions.

**Benefits**

The local Macmillan Nurses were able to focus on clinical commitments rather than find time to be able to commit to running the project.

The Project Officer was hosted within the Health Promotion department which provided support and access to links to other services.

The Project Officer was inducted through a variety of NHS processes, such as placing orders, requesting and organising travel, booking of venues, etc.

As the Project Officer had no clinical background it allowed discussions with patients to focus on practical issues rather than health.

Once she had explained her background and role, there were no expectations from patients that the Project Officer could provide clinical advice.

The Project Officer had a good knowledge of island culture and demographics.

She was willing to learn more about the geography of the islands and their transport links.

**Challenges**

Delay in NHS banding job description lead to a delay in the Project Officer starting work.

The Project Officer had little understanding of health-related jargon and the interpretation of clinical staff’s terminology.

The Project Officer’s remit to cover the whole of the Western Isles in a part time post (22.5 hours) when travel to some parts of the islands necessitated overnight stays. (See map below.)

The Project Officer came into post in November 2015 at the start of the ‘bad weather season’.

Unpredictable weather causing disruption to travel plans, particularly to the southern isles of the Uists, Benbecula and Barra.

Unplanned absence of project officer towards the end of the project.
Map 1: Geography of the Western Isles and its travel links.

<table>
<thead>
<tr>
<th>Islands</th>
<th>Links</th>
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</thead>
<tbody>
<tr>
<td>Lewis (Stornoway environs)</td>
<td>HS1 One land mass but more than 2 hrs drive time between north of Lewis and North Harris. Most of Lewis is HS2.</td>
</tr>
<tr>
<td>Lewis (outwith Stornoway)</td>
<td>HS2</td>
</tr>
<tr>
<td>North Harris</td>
<td>HS3</td>
</tr>
<tr>
<td>Scalpay</td>
<td>HS4 Linked to North Harris by bridge</td>
</tr>
<tr>
<td>South Harris</td>
<td>HS5 South Harris part of same land mass as Lewis</td>
</tr>
<tr>
<td>North Uist</td>
<td>HS6 Linked to South Harris by ferry</td>
</tr>
<tr>
<td>Benbecula</td>
<td>HS7 Linked to North Uist by causeway</td>
</tr>
<tr>
<td>South Uist</td>
<td>HS8 Linked to Benbecula by causeway</td>
</tr>
<tr>
<td>Barra and Vatersay</td>
<td>HS9 Linked to South Uist (Eriskay) by ferry. Vatersay linked to Barra by causeway</td>
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</tbody>
</table>

**Flight links within Western Isles:**
- Stornoway to Benbecula Tuesday – Thursday only 20-30 mins flight time

**Ferry links between islands:**
- South Harris (Leverburgh) and North Uist (Berneray) 1 hr journey time
- South Uist (Eriskay) and Barra 40 mins journey time

**Flights links with mainland:**
- Stornoway to Inverness daily 40 mins flight time
- Stornoway to Aberdeen Mon – Fri only (one flight each way) 55 mins flight time
- Stornoway to Edinburgh Mon – Friday (reduced service on Fri, Sat & Sun) 1 hr flight time
- Stornoway to Glasgow daily 1 hr 5 mins flight time
- Benbecula to Glasgow daily (reduced service at weekend) 1 hr 5 mins flight time
- Barra to Glasgow daily (reduced service at weekend) 1 hr 10 mins flight time

**Ferry links from WI:**
- Stornoway (Lewis) to Ullapool 2 hrs 30 mins journey time
- Tarbert (Harris) to Uig (Skye) 1 hr 40 mins journey time
- North Uist (Lochmaddy) to Uig (Skye) 1 hr 45 mins journey time
- South Uist (Lochboisdale) to Oban 5 hrs 10 mins journey time
- Castlebay (Barra) to Oban 4 hrs 50 mins journey time (7 hrs if via Lochboisdale)
Discussion/lessons learned

It was advantageous that the Project Officer had no clinical background however experience of procedures and systems within the NHS would have been beneficial to allow her to ‘hit the ground running’.

Anecdotally it has been reported that where a non-nurse facilitates the completion of Holistic Needs Assessments (HNAs) (see Scoping exercise below), practical issues are raised. When a nurse is involved, the focus is mainly on health issues. This was reflected in our experience.

Recommendations

Having a glossary of clinical terms regarding TCAT and cancer would be beneficial for someone with no prior knowledge or understanding.

There is no need to employ a Project Officer from a clinical background for a similar project to be successful.

Scoping exercise

The Steering Group agreed that a poster should be designed and displayed in public places throughout the islands: in local newspapers and social media as well as in cancer support groups’ meeting places and some workplaces. See poster below.

The poster encouraged patients who had completed cancer treatment to contact the Project Officer. Their feedback was captured using the Holistic Needs Assessment Tool: the Concerns Check List. Interviews took place on an individual basis and the project officer travelled to individuals’ homes.
throughout the Western Isles to obtain this information. In total 52 individuals were interviewed (35 female, 15 male. 2 declined to report.

Scoping identified the top 4 concerns as:
- tiredness/fatigue,
- the need for complementary therapies,
- worry, fear or anxiety, memory/concentration, and
- loss of interest/activities.

This information was used to plan the “Looking Forward” event and the booklet.

Chart 1: HNA respondents by gender

Benefits

The opportunity to contribute to the project development was offered to patients throughout the islands.

Individuals from all islands were interviewed.

Able to accurately identify concerns from patients rather than the assumed concerns identified by professionals.

Process to gain insight into concerns held by those who had experienced cancer.

Interviews were private, one to one and that allowed for open discussion. The Project Officer could and did signpost patients to other services if required having gained that knowledge and links during her induction period.

No expectations from patients that the Project Officer could answer any cancer-related questions.

Challenges

Engaging with individuals to carry out HNA and arranging interviews round their availability.

Initially individuals’ (patients and professionals) misunderstanding of the purpose of the project and their unrealistic expectations, e.g. the creation of a Maggie’s Centre in the islands.

Getting other clinical professionals to buy in and promote project with their patients.

Planning travel and obtaining authorisation for travel to be booked was time consuming.
The Project Officer having to juggle her working hours to allow her to be available to meet patients at times suitable to them.

Unsociable hours needing to be worked to allow for those patients who couldn’t make time during the working day.

Fitting travel time and time with patients within the Project Officer’s contracted hours.

Impact on planned travel times due to bad weather causing transport (flights and ferries) to be cancelled.

Impact on the Project Officer and her family when she was stranded on an island away from home due to bad weather and being unable to return home as planned.

Extra costs incurred due to extra hotel stays required due to travel disruption caused by bad weather.

The need to reschedule patient visits and travel due to cancelled transport due to bad weather.

**Discussion/lessons learned**

The benefits of using HNA to identify the most common concerns.

Majority of patients had reported similar concerns which included fatigue, diet, activity and ‘chemo brain’.

Women were more likely to report concerns about changes in their appearance and their emotional status than the men.

Proportionately, there were more respondents per head of population from Barra than the other islands. It is unclear why this may have been.

**Recommendations**

The HNA was an easy tool to complete; its use could be utilised for similar exercises for patients with other health problems.

The HNA could provide the evidence for common concerns from patients with other health problems.

Consider using local staff to distribute the HNAs to minimise the risk to travel plans by bad weather.

**‘Looking Forward’ event in Stornoway**

The content of the programme was developed to reflect the most common concerns identified from the collated HNA results. Posters, social media and local cancer groups were used to promote the ‘Looking Forward’ event. Appropriate facilitators were invited from the mainland and locally to run sessions.

A ‘Looking Forward’ event was held in November 2016 over a 3 week period (for 5 hours on 1 day each week). As Stornoway is the major town on the island with the largest population base and most
convenient transport links it met the needs identified by individuals. Culturally most of the population of Lewis are used to travelling to Stornoway, for example to senior school. Hotel space was used as it had worked well in the pilot project which the Macmillan team had carried out initially. The hotel had ample free parking and was close to the bus station and could provide disability access. Between 12 and 16 people attended the three sessions: some attending all sessions and some attended just one or two. Attendees reported that they attended as many as they were able.

**Benefits**

Programme was based on findings from HNA so should be seen as relevant to attendees.

Well known, comfortable central location provided for friendly atmosphere, good parking and close to bus station.

Refreshment times allowed participants to socialise.

We found that the most successful session was with two local well known GPs allowing participants to challenge them on their apparent lack of contact with the patients after their diagnosis.

**Challenges**

Event being held over 3 weeks posed problems for individuals being able to commit to every session.

The Steering Group suspected that members of local cancer support groups attended to give their support to TCAT rather than through their own need.

Our means of promoting the event to attract those in need may not have been adequate.

There was minimal availability of suitable facilitators from within the islands which led to sourcing facilitators from the mainland and the consequent increased costs to run the programme. The cheapest return air fare from Inverness to Stornoway is approximately £230.00. From Glasgow, the cheapest return air fare is approximately £110.00 (N.B. there are current ‘price wars’ between two airlines for this route so may account for the relative cheapness in comparison with the Inverness/Stornoway costs.)

Co-ordinating times for the programme to accommodate arrival and departure times for mainland facilitators.

Time of event was not suitable for those in full time work.

**Discussion/lessons learned**

Promotion was not sufficient to attract sufficient numbers who could have benefited from attendance.

Holding the event over three days was probably too much.

Participants found it would have been better to have shorter days, suggesting that the programme tried to cover too many topics.
As the most successful session was with local GPs allowing participants to challenge them on their interaction with them this should be included in future events: if GPs would be willing.

Prior to TCAT attendees at the initial pilot event had received personal written invitation from a Macmillan Nurse who they knew. Very few invitations were turned down. No personal invitations were issued for this event. If they had been, there may have been a better turnout. The dilemma for the Steering Group was that:

1. for patients not known to the Macmillan Nurses, they may miss out on the opportunity of attending, and
2. the places might be filled only by those who had been on a Macmillan Nurse’s caseload.

Recommendations

A two-pronged approach to attract participants should be utilised:

1. Personal invitations should be sent out to all who have recently been on the Macmillan caseload and verbally promoted by the Macmillan Nurses.
2. Ways of reaching those patients who had not been on a Macmillan Nurse’s caseload needs to be explored such as posters, social media, cancer support groups, etc.

More targeted approach should be used to promote the event by using contacts in different parts of the island.

Shorter programme and hold at a different time, e.g. evenings or weekends or a choice of daytime or evening, when those sessions are a repeat of each other.

‘Looking Forward’ event in Harris and in Benbecula

The content of the programmes was developed to reflect the most common concerns identified from the collated HNA results. Posters were displayed in GP surgeries and local shops as well as published in local newspapers to promote the ‘Looking Forward’ event. Appropriate facilitators were invited from the mainland and locally to run sessions. Some facilitators would be travelling from Stornoway, Isle of Lewis.

An event in Harris was planned for February 2017. An event was planned for January 2017 in Benbecula however due to issues with a key mainland facilitator’s availability it was postponed till April 2017. Venues in both islands were booked in well known, centrally situated hotels. Each event was planned for 9.30a.m. – 2.30pm due to transport links for the facilitators. Although we had facilitators for a 2 day event (1 day on 2 consecutive weeks) there was only interest shown by 1 individual in Benbecula but no-one from Harris and therefore the events were cancelled.

Benefits

There was wide promotion in GP surgeries, local newspaper and local shops and Post Offices.

With these islands having a smaller population it was easier to promote.
From feedback and lessons learnt from the Stornoway event, a more varied programme with shorter sessions was planned.

**Challenges**

Difficulty engaging with individuals who had received cancer treatment in recent years.

No apparent interest in attending the event.

It was reported by patients that as they lived in a much smaller community that meant they would have little or no anonymity.

However that lack of anonymity may have been an issue for individuals who sought privacy.

Some patients requested one-to-one sessions rather than attendance at an event. This was impracticable for many reasons, e.g. time needed for each facilitator to deliver sessions individually rather than collectively and the cost of facilitators travelling to individuals rather than one base.

Travel throughout the Southern Isles can be challenging due to minimal public transport availability and some poor road conditions, although this did not seem to be the case in Harris.

**Discussion/lessons learned**

The Project Officer contacted some of the patients who had completed HNAs to enquire, sensitively, why they hadn’t been interested in attending an event. Several individuals reported to her that they are not looking for a “programme” rather they are looking for the chance to “drop in” for information, support and signposting. Where this was the case it was not necessarily wanted in a clinical/healthcare setting but somewhere where they could maintain a cloak of anonymity.

Some in Benbecula reported that they didn’t want to travel far to an event and the proposed venue was too far away for them, particularly due to road conditions (lots of single track roads) and minimal public transport availability.

Others would have preferred the offer of one-to-one sessions.

The local TCAT Steering Group were clear that they would not use funds that would only benefit a few. We learned that we had to think differently about how to get the message/signposts across to patients, but without excessive expense, in a way that was useful and sustainable.

**Recommendations**

Due to the small numbers in Harris, they should be invited to an event in Stornoway, Isle of Lewis.

In the Southern Isles, 3 small events in different venues should be considered, i.e. one in North Uist, one in Benbecula and one in South Uist.

Relevant information in written form should be produced and shared with patients finishing treatment by their local Macmillan Nurse and/or their GP if not on the Macmillan Nurse caseload.
Development of ‘Looking Forward’ booklet/ directory

The Steering Group had hoped and planned for face to face events to deliver the Looking Forward programme so were disappointed when this approach wasn’t widely welcomed by people affected by cancer. The Steering Group embraced the development of a written resource for patients which might reach more people throughout the islands than face to face events.

The Working Group members were given topic titles and asked to write a short article describing the issue and offering signposts for self help. The topics chosen reflected the most frequently identified concerns from the HNAs used during the scoping exercise.

The topics were:

- Returning to your GP
- Coping
- Fatigue
- Chemo brain
- Neuropathy (tingling/pins and needles)
- Diet
- Activity
- Financial benefits

Expertise was sought from other professionals to ensure accuracy of the information, e.g. a dietitian was asked to help with the diet section. Local GPs were asked to approve the section about them, which they did.

A list was produced which included contact details for local cancer support groups throughout the islands, Macmillan Cancer Support, Maggie’s Centres in Inverness and Glasgow as well as their online community and local Sports Centres/swimming pools.

Consultation on the draft copies took place with local cancer support groups. They were read by between 30 and 40 people. Comments were received, mostly complimentary but some offered suggested changes. The Working Group considered these suggested changes and made several of them. The booklet was also sent to the Communications team at Macmillan Cancer Support’s Scottish office who offered some suggestions that were included.

The Steering Group approved the content and it then went through local NHS Western Isles processes to be authorised for publication with the NHS Western Isles’ and relevant partners’ logos.

Benefits

Local cancer support groups’ members were willing to engage with us to review the draft booklet.

Knowledge that the contents were approved by a significant number of people who have had cancer.
Information to help address the most commonly reported concerns by patients is contained in an information booklet.

The booklet to be readily available to patients at the end of treatment from their Macmillan Nurse and/or from their GP and several public places, e.g. local libraries.

At the time when the Macmillan Nurse is discharging a patient from her caseload, she will provide the patient with the booklet and will be able to discuss its contents and their relevance to that individual.

If GPs are doing Cancer Care Reviews with their patients, the contents of the booklet should provide potential topics for discussion.

Development and printing of a booklet is cheaper than holding face to face events throughout the islands: there is no inequity of access to the information with a booklet.

Challenges

Writing patient information in appropriate language, i.e. no jargon or ‘medical-speak’.

Writing at a level that most patients would understand.

Ensuring booklet didn’t become too big which might put patients off reading it.

Time taken for the Working Group to produce their content.

Time taken for the cancer support groups’ members to review and comment.

Time taken to have the booklet approved through NHS Western Isles processes.

The disappointment of the Steering Group membership that initial plans of delivering face to face events hadn’t worked out successfully and to reignite their enthusiasm for the project.

Discussion/lessons learnt

During our planning, we had thought that face-to-face events would be welcomed however we learned that many patients across the islands didn’t want them.

We learned to write at a level that was suitable for most readers.

We learned that our plans for Looking Forward could and should change in response to patients’ views and opinions.

We learned that one of our aims, i.e. that of ‘To develop a local directory of relevant expertise to facilitate the delivery of the programme, e.g. local Macmillan Nurses, benefits advisers, exercise/sports staff, GPs, etc.’ was achieved but in a different format to a true directory.

Recommendations

Anyone embarking on a project that relies on different patients’ wishes and opinions needs to be flexible to meet most patients’ needs.
'Looking Forward’ event on Barra

The Project Officer had visited Barra several times which may have led to more patients on Barra being involved with the scoping exercise per head of population than any other part of the Western Isles: 0.8% compared to 0.002% from Lewis.

Due to the disappointment of cancelled events in Harris and Benbecula, the Steering Group had to seriously consider the potential loss of substantial amounts of money for the running the event if this was cancelled. This led to a delay in offering an event on Barra whilst developing the ‘Looking Forward’ booklet.

However the Steering Group had been convinced that an event on Barra would be attended by several people, making it worthwhile to organise. The Barra Cancer Support Group members were aware of events delivered in Stornoway and planned for Harris and Benbecula. The Steering Group didn’t want to disappoint cancer patients on Barra by not offering an event. However with lessons learned from the Stornoway event and the cancelled Harris and Benbecula events, a short programme was planned.

The Steering Group discussed how to launch the ‘Looking Forward’ booklet and agreed that holding an event on Barra would be an ideal opportunity for the launch.

The Barra Cancer Support Group was contacted to advise them of the plan for an event and the launch of the booklet. From our understanding most people affected by cancer on Barra are known to the Support Group membership and have regular contact with each other. The date, time and venue were suggested by the Support Group and we duly planned around their suggestions. Membership of the group offered to advertise the event locally and help with its organisation which they did. Health professionals were also advised of the event’s venue, time and date.

The Macmillan Lead Cancer Nurse/Project Lead was accompanied by a Macmillan Nurse Specialist whose remit covers Barra. Several Macmillan booklets were made available to attendees, including ‘Coping with Fatigue’, ‘Worrying about cancer coming back’ as well as information about Move More.

The event was held in a local venue in Castlebay. The owners of the venue provided home baking as well as tea and coffee for attendees. The venue was suitable for people with disabilities with ramps at both doors. The event ran from 17.00 - 19.00 with six attendees all arriving just after 17.00. The Macmillan Lead Cancer Nurse provided an overview of the concept of TCAT and the rationale for the booklets’ content.

The attendees all had chance to look through the booklet and make any comments and to ask questions. The consensus was that the booklet looked very useful and they wanted to have a small stock of them to provide to others affected by cancer on Barra who had not attended. We were informed during the evening that the event had clashed with a regular locality planning group meeting which could account for a few people being missing.

As this was an informal drop-in event, the Macmillan Lead Cancer Nurse explained the origins of the project which lead to conversations so no formal presentations were delivered. The attendees were very interested to hear about the forthcoming Move More programme.
The evening ended with the secretary of the Support Group requesting and taking all the Macmillan booklets that had been brought to the event. She planned to have them available for the membership.

**Benefits**

Encouragement to deliver the event from local people affected by cancer.

The local cancer support group are very proactive so it was easier to promote the event.

Holding an event on Barra ensured that events have been offered throughout the Western Isles.

Holding an event on Barra demonstrated to patients there that they have not been forgotten despite the delay.

Using that event as the launch of the ‘Looking Forward’ booklet combined sharing information about the project with interested people receiving the first booklets on the islands.

**Challenges**

We expected the likely challenges would be similar to those of Harris and Benbecula, i.e.

- Difficulty engaging with individuals who had received cancer treatment in recent years.
- No apparent interest in attending the event.
- It was reported by patients that as they lived in a much smaller community that meant they would have little or no anonymity.
- Some patients requested one-to-one sessions rather than attendance at an event. This was impracticable for many reasons, e.g. time needed for each facilitator to deliver sessions individually rather than collectively and the cost of facilitators travelling to individuals rather than one base.
- Travel throughout the Southern Isles can be challenging due to minimal public transport availability and some poor road conditions, although this did not seem to be the case in Harris.

The actual challenge was that the other large public meeting was held at a similar time so some people affected by cancer attended the other event.

**Discussion/lessons learned**

We learnt that engaging with the local cancer support group ensured that all their membership was aware of the event.

We learnt that trying to hold an event at the same time as another public meeting probably reduced the numbers of people attending.

We learnt that the people on Barra seemed to have few, if any, issues about their privacy as had been experienced in trying to organise the events in Harris and Benbecula.
Recommendations

We would ensure that no other public meeting was scheduled for the same time and date as our planned event.

We would highly recommend engagement with supportive local people to encourage their peers’ attendance at events.
Conclusions drawn from developing ‘Looking Forward’ in the Western Isles

The original objectives for the project were:

1. To establish a steering group which would involve service users and develop close links between healthcare staff and others, e.g. sport and exercise staff, benefits advisers and complementary therapists. The steering group would help guide the scoping process and support recruitment and ongoing support to Project Officer.
2. To employ a Project Officer to scope the needs of people after they have been affected by cancer and its treatment. This would involve contact with patients and families as needs identified may be different for each group.
3. To establish whether needs are different in different parts of the Western Isles. A mapping exercise needs to be carried out to identify needs which will help inform the shape of the project.
4. To establish that the programme’s content reflects the needs identified.
5. To source appropriate venues for delivering the programme.
6. To develop a local directory of relevant expertise to facilitate the delivery of the programme, e.g. local Macmillan Nurses, benefits advisers, exercise/sports staff, GPs, etc.

Each of these six objectives was successfully completed:

The project set out to scope the needs of people affected by cancer in the Western Isles and to meet these through a programme of sessions based on the original pilots. The numerous and challenging reasons detailed in this report resulted in the project being ‘reframed’ away from face to face engagement with patients and their families. The resultant booklet was written to address the most commonly identified needs reported by patients. It also provides equity of access to those sources of information and signposting for anyone affected by cancer in the Western Isles. In addition the risk of a patient’s privacy being compromised is eliminated by not providing events in small localities.

References
