Westerhaven TCAT
Final Evaluation
May 2017
Introduction

Westerhaven Macmillan Cancer Information and Support Service (Westerhaven) opened in September 2011. Over the last 6 years, it has established itself as a trusted resource for people living with cancer in South West Edinburgh. It provides people affected by cancer and their family with a range of practical, medical and emotional support services.

This service is now co-located within the Wester Hailes Healthy Living Centre, which was set up to address the health inequalities in an area of multiple deprivations using a collaborative approach between health, social care and the third sector. Wester Hailes Medical Practice is also co-located here and this multi-disciplinary ‘hub’ constantly strives to devise innovative solutions to the ingrained medico-social issues that complicate the lives of people living in this community.

There is a political imperative to shift the balance of care and to deliver care closer to people’s homes and in their communities. Better Cancer Care (Scottish Government Cancer Action Plan 2008), highlights the increasing number of people living with cancer in Scotland. In its foreword, Harry Burns (Chief Medical Officer) highlights deprivation as one of the key risk factors for cancer and calls for targeted action to tackle persistent inequality. As highlighted by the Detect Cancer Early campaign, people with cancer in more deprived areas are more likely to present later and suffer worse outcomes as a result. The incidence and death rates from cancers linked to smoking or high alcohol consumption are 3 times higher in the most deprived areas of the UK compared to the most affluent. The Long Term Conditions Alliance Scotland published the Self Management Strategy “Gaun Yersel” in 2008, encouraging interventions to empower people living with cancer with information and support. In 2011 the Christie Commission identified failure of public services to work together in a preventative fashion as a key factor underpinning poor outcomes in our most vulnerable communities, urging Scottish agencies to embrace “a radical new collaborative culture throughout our public services”. Wester Haven responds to these priorities and embodies this ethos as an interagency model for collaborative working and integrated care.

This report sets out the findings of an evaluation of the testing of an ‘Active Inclusion Protocol’ and ‘Holistic Needs Assessment’¹. This was an innovation proposed by GP Sineaid Bradshaw and subsequently funded by Macmillan Cancer Support as part of their Transforming Care After Treatment Programme (TCAT) - known as Westerhaven TCAT.

Westerhaven TCAT was devised in the context of a wider understanding among health and social care professionals from a range of disciplines that there is a need to create pathways of care to meet the needs of local people using community resources, rather than the inadequate fallback position of a purely medical model of care. Embedded within the work of Westerhaven (and therefore also within

¹ The data presented in this report is from the period April 2015 to January 2017
Westerhaven TCAT) is a holistic ethos, which encompasses the psychological, physiological, emotional, social and financial needs of people affected by cancer. It operated for two years (April 2015 to April 2017).

Aims and objectives

The overall aim of the Westerhaven TCAT project is to empower people after cancer therapy ends to optimise their wellbeing whether they are rehabilitating back to normal life or entering the palliative phase of their illness.

The objectives of the Westerhaven TCAT project were to:

a) Devise a care pathway within Wester Hailes Medical Practice to standardise more pro-active access to Holistic Needs Assessments (HNA) for all people who have completed their cancer treatment and their carers - Active Inclusion Protocol. Related to this was the intention to raise awareness among other local GP practices of the protocol/referral pathway being developed.

b) Ensure the new pathway was entirely inclusive – all Westerhaven users (patients at other stages of their cancer journey and carers) will have the opportunity for a holistic assessment of their needs

c) Develop a facility for outreach to housebound patients so that nobody is excluded from the HNA opportunity

The New Active Inclusion Protocol and HNA for All

People completing cancer therapy registered with Wester Hailes Medical Practice were proactively identified and invited for an HNA. This invite was originally planned to be triggered by an End of Treatment Summary from the treating hospital.

The postal invitation was followed up by a GP telephone consultation 2 weeks later. This proactive follow up demonstrated the clinical endorsement of the intervention to enhance patient confidence. This telephone contact also elicited any obstacles and
barriers such as mobility problems or language difficulties, and with the patient’s permission arrange for Wester Haven to contact them and help them overcome these issues (see Outreach Work).

The HNA was delivered by Macmillan trained staff in the safe and familiar environment of the Westerhaven Cancer Support Centre via a one to one interview. The assessment resulted in a tailored care plan targeted at person centred priorities.

### Evaluation approach and methods

The evaluation of the TCAT project was conducted in collaboration with Edinburgh Napier University. The approach was designed to assess the extent to which the objectives of the project had been met and to determine from the service users’ perspective the value and benefits of the service.

Between April 2015 and April 2017, 148 people attended Westerhaven and were holistically assessed. Data was not available for all 148.

This mixed methods service evaluation used various sources of quantitative and qualitative information including:

- Demographic data on service users (n = 117)
- Records of the process of each HNA and the actions taken by the assessor (n = 117)
- Collation of the concerns identified by service users (n = 95)
- Resource utilisation for attenders (n = 10) and non attenders (n = 22)
- Feedback from service users gathered from
  - A postal survey (n = 28). A response rate of 47% from 60 issued.
  - A group discussion (n = 7)

The following report sets out the evaluation findings.

The statistics in this report are the results of a self-evaluation carried out by local project staff with support from Edinburgh Napier University TCAT Evaluation Team. The views expressed in this report do not necessarily represent those of Edinburgh Napier University or Macmillan Cancer Support.
Valued - Proactive - Inclusive - Empowering

Valued and Empowering

Summary

- To date 148 people have been holistically assessed and co-produced a care plan.
- Data from a small number of patients indicates that Inclusive HNA and Care planning for non-palliative patients at Westerhaven had a positive effect on number of contacts with the doctor (telephone calls and consultations), reduced contact with NHS24 and reduced unscheduled admissions to hospital when compared to those who did not attend.
- Primary care professionals depend on this service to support patients and their families who are dying of cancer in an area of high multiple deprivation. The majority of users of Westerhaven are palliative cancer patients, or carers looking after a patient at this stage in their journey.
- Westerhaven meets the needs of these people that otherwise would have to be addressed by Primary Care services. Among the most frequently reported concerns of patients and carers relate to emotional needs such as sadness, fatigue, practical issues such as caring responsibilities and housing/money worries.
- 60% of users rate the support received very highly – scoring it as a 9 or 10 out of 10.
- Aspects of the service most valued by users were found to include
  - Linking patients and carers to services
  - Skilled staff – knowledgeable, perceptive
  - Location – being accessible as within Wester Hailes the local community, not being based at a hospital
  - Holistic – provision of a range of services
  - Listening – providing time for people to talk and be heard
- Westerhaven connects clients to services in their community and in Edinburgh by appropriately signposting and referring to other agencies. For example Westerhaven works with the 'Local Opportunities for Older People' (LOOPS) Community Wellbeing Team to help facilitate Hospital Discharge back into the community and help prevent patient’s re-admission to hospital.

Highly regarded and required by patients, carers & professionals

Valued by patients and carers

Most important to any assessment of a service are however the views and experiences of those who use that service. This is where we start.
Valued - Proactive - Inclusive - Empowering

Via a postal questionnaire, service users rated out of 10 the support they received from Westerhaven. Overall 79% of users rate the support received very highly – scoring it as a 8 or higher. Both carers and patients rate it highly.

Table 1: Support received from Westerhaven out of 10

![Pie chart showing support ratings]

Given the type of service and support provided, it is impossible to convey in one graph the extent to which service users ‘rate’ Westerhaven. One carer scolded the University researcher saying “you cannot put a value on care and support and you should not try”.

With the aim of understanding better what was driving the reported high scores, participants in the group discussion were asked to describe the characteristics of Westerhaven that they particularly valued. The adjectives and descriptions given are shown below.
Analysis of the group discussion also sheds further light on the type of support the project actually provided, that patients and carers value so highly. Five key ‘themes’ were found:

- Bridging a gap – to other services and between treatment and survivorship
- Skilled staff – knowledgeable, perceptive
- Location – being accessible as within Wester Hailes the local community, not being based at a hospital
- Holistic – provision of a range of services
- Listening – providing time for people to talk and be heard

One person who had cause to use Westerhaven over a number of years described powerfully how highly he regarded the service. He explains the high value of Westerhaven, that despite secondary cancer, he was not disappointed to return.

(I first came here)......It was about five years ago, actually, having contracted leukaemia,.....and it was great then, we engaged in the services for about a year. Sadly relapsed about a year ago, so I've had cause to not disappointingly come again, well, disappointingly from a medical point of view, but quite pleased to come again and get in touch with those services again, and it's again been a big help since last year”.(focus group participant)
Below are two real life stories, written by a patient and a carer that illustrate exactly how this service is valued - for its proactivity, its inclusivity and ability to empower people affected by cancer to optimise their wellbeing.

**A Patient’s Story**

My name is CD. I first came here at the start of 2016 with my wife who had cancer. We needed help with benefits to start with. The first person we spoke with was really helpful and went out of his way to help. After the initial help, we both kept coming for counselling and massages until June that year when my wife went for a major operation. Sadly my wife died in October that year. I came back in November to try and get some help. The people were really friendly. To start with I got massages and reflexology, and starting at the end of January 2017 I am starting to get counselling again. Again, the people are so friendly and helpful, and their help is invaluable to lot of people out there.

**A Carer’s Story**

I have been using Westerhaven since September 2014. When my wife was recovering after surgery to remove a brain tumour it felt that there was no support available. Luckily, after a G.P. told us about Westerhaven we became regular visitors. We used Westerhaven in a few very beneficial ways including; advice on benefits, Qui Gong classes which helped my wife get more mobility and balance confidence and the massage was very good for us both. I particularly liked the chance to try to relax in a very stressful period of time. It was good to be able to talk to people with both empathy and understanding of our situation. I cannot thank the staff at Westerhaven enough for the support that we got. I don’t know how we would have coped without it.

Thanks again.

**Valued by professionals**

The testimonials from GPs below illustrate the value primary care professionals place on the work of Westerhaven with their patients and family members. Much of this regard is fuelled by the way in which Westerhaven supports GP and primary care team’s workload.

A small scale evaluation of resource use was undertaken as part of the overall evaluation to quantify this support and impact. This analysis indicated that non palliative patients who attend Westerhaven had reduced contacts with the doctor (telephone calls and consultations), reduced contact with NHS24 and reduced unscheduled admissions to hospital². While the first two findings were not statistically

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² The small sample size should be considered at all times when interpreting the results.
significant, the reduced number of unscheduled hospital admissions was statistically significant.

**GP Testimonial**

We in the Wester Hailes Medical Practice are very appreciative of the support offered by Westerhaven, as they allow us in primary care to be linked with a whole systems approach that better identifies the psychosocial and spiritual requirements of our patients and addresses them in an accessible and cohesive way.

**GP Testimonial**

We all know that it is good to have services in the area for our patients who often do not have the finances or means to travel far from home. We have found the service extremely useful for our patients.

The majority of users of Westerhaven are palliative cancer patients (or carers of someone in this stage). In 2014 only one in ten patients (9%) using Westerhaven were ‘dying with cancer’ compared to one in two in 2016 (54%).

Primary care professionals depend on this service to support patients and their family members. Westerhaven meets the needs of these people that otherwise would have to be addressed by Primary Care services.

Clients who are in the palliative stages of their disease may not have their physical health improved through support from projects such as Westerhaven but have been
shown to be able to cope better with their diagnosis and disease through the social, emotional and practical help they receive to help them manage the impact their disease has had on them and their family.

Supporting self care, enhancing wellbeing, meeting need

As a result of having a HNA patients and carers work with the Macmillan professional in Westerhaven to develop a care plan. This care planning process places an emphasis on asset-building with local community resources to enhance health and wellbeing.

Each client is given a holistic needs assessment and an opportunity to discuss their concerns and anxieties in a comfortable and relaxed setting. At this assessment a range of services are offered to clients, including their carers; including specialist cancer massage and reflexology, counselling service, access to a physical activity programme specifically designed for people who have or have had cancer, dietetic advice and a welfare benefits advice.

This project is entirely inclusive, so that every person who is affected by cancer in South West Edinburgh can have the opportunity to explore their anxieties and aspirations with a professional during an initial assessment. The implementation of the holistic needs assessment and care plan for every client in contact with Westerhaven results in a package of care encompassing a personalised range of services provided by the project.

As well as in house support services the Westerhaven also connects clients to services in their community and in Edinburgh by appropriately signposting and referring to other agencies or on to the NHS, Social Care or another third sector organisation to provide support. For example Westerhaven works with the 'Local Opportunities for Older People' (LOOPS) Community Wellbeing Team to help facilitate Hospital Discharge back into the community and help prevent patient's re-admission to hospital.
Within the postal survey patients were asked “As a result of attending Westerhaven please list the support agencies of services you have actually made contact with or used a result of attending this service”. The responses from ten patients is shown below – illustrating the range of community resources patients engage with as a result of an HNA at Westerhaven. This community connectivity is also illuminated by the examples of care planning actions given below.
Example of care planning at Westerhaven

B.B. was referred for Massage therapy to aid relaxation, help to reduce his pain and help with his mobility. B.B. was identified as being suitable to receive Out-reach support from the Student Social Workers who have placements at Westerhaven to provide emotional support and ‘Buddying’, practical support in driving him to appointments and to attend Westerhaven for Massage therapy. He also has had input from the Out-reach Massage therapist from Westerhaven when he is unable to attend the Centre for treatments. One of the Social Work Students also acted as an advocate by writing to a local Councillor on B.B’s behalf to speed up the Care package which he had been waiting on being allocated to him since May 2016. B.B. had been paying for carers to visit him privately which was not adequate for his increased needs. B.B. now has a 3 times daily Care package funded by the Council.
Example of care planning at Westerhaven

E.W. was placed on the Westerhaven Counselling waiting list for counselling sessions to help her discuss further her concerns and anxieties and cope better with the emotional effects of cancer. She was booked in for a massage therapy session to help her relax and cope with stress, anxiety and pain. She was referred to the Emotional Freedom Technique therapist for symptom relief and self-management. She was also referred to the Herbal Clinic which is held in the Health Agency which Westerhaven works in partnership with.

She was identified as being suitable for receiving help from Westerhaven Out-reach service where Social Work students can visit vulnerable clients who are house bound at home to help them with emotional and practical issues. A student was allocated to provide Out-reach support for E.W. including help with housework due to her fatigue and was very important due to her compromised immune system and also befriending emotional support.

She was also referred to the Westerhaven volunteer dietician for dietary advice to help her cope with her chemotherapy treatment and maintain a healthy weight. She was keen to become more active when she felt well and was given the contact details of a local community project which holds classes including mindfulness meditation and stained glass window classes.

Figure 2: Care plan actions with carers
A Carer’s Story

My mother was diagnosed with terminal cancer seven months ago. She is 85 and lives with me and my husband. I was at my GP surgery as I was really struggling with the situation. She gave me a leaflet all about Westerhaven and suggested I call them. She said she had heard excellent reports about the services provided to people like me. I am so glad I did. I have received the most wonderful care. Everyone is so warm and friendly. My first encounter was with a lady who basically asked me lots of questions. She wanted to determine through our discussion the best way in which Westerhaven could help me. Massage was suggested, plus seeing a counsellor. I have had two massages, both of which were very relaxing and uplifting too. An appointment with a counsellor came up very quickly. I have had five sessions now with her and it has been so helpful and I cannot speak more highly of all the people associated with Westerhaven who are helping me through this traumatic time in my life.

A key aim of Westerhaven is to empower people to optimise their well being. One aspect of this is understanding ways to cope and knowing where to seek help if needed. Patients were asked the extent to which attending Westerhaven had affected this. When asked about their confidence to now manage their condition by themselves patients rating this on average at 7.6 out of 10.
The table below illustrates that the input from Westerhaven is meeting needs in a range of empowerment / self-management related areas.

**Table 2: percentage whose needs met completely, or to some extent**

<table>
<thead>
<tr>
<th>Need Description</th>
<th>Patient</th>
<th>Carers</th>
</tr>
</thead>
<tbody>
<tr>
<td>Managing the side effects of treatment</td>
<td>85%</td>
<td>80%</td>
</tr>
<tr>
<td>Knowing where to seek help if you need it?</td>
<td>75%</td>
<td>70%</td>
</tr>
<tr>
<td>Understanding who to ask for help if you needed it?</td>
<td>70%</td>
<td>65%</td>
</tr>
<tr>
<td>Awareness of support available to family/carers?</td>
<td>77%</td>
<td>75%</td>
</tr>
<tr>
<td>Knowing about other support services or groups you could use?</td>
<td>72%</td>
<td>68%</td>
</tr>
</tbody>
</table>

Two fifths (67%) service strongly agreed (score of 8, 9 or 10) with the statement “Westerhaven helped me to get other services and help and put it all together”. A key theme from the analysis of the group discussion was the role Westerhaven plays in ‘connecting people’ to community resources and activities. One carer described this
saying “what they don’t know, they know somebody that does know”. A patient described the holistic nature of the support provided.

“It’s the whole, it’s having the chance to go to different things, if you need counselling or if you need massage, if you need to talk to someone, and also groups as well, looking after yourself, it is a whole. I mean, you may think one particular thing is your favourite, but then you have access to the other things that you need to go to, should you wish to”.

Through participation in the out-reach service and the care exchange clients can become volunteers themselves which enables them to feel more empowered and confident in becoming an active participant in their community and providing them with the opportunity to give something back to their community.
Proactive

Standardising and increasing access to support at end of treatment

Summary
- The new protocol has improved the identification and/or referral of both patients and carers at ‘end of treatment’
  - However evidence emerged that for a significant proportion of service users ‘end of treatment’ does not mean living with and beyond cancer - but dying with cancer.
- Over half the patients using Westerhaven are in the palliative stages of cancer. Similarly, over half of carers using Westerhaven are caring for someone in the palliative stages of cancer.
- Awareness raising of TCAT has resulted in higher levels of GP referrals into the project
- Westerhaven is a key source of support to people affected by cancer who are registered with other GP practices across South West Edinburgh who do not offer this holistic, specialist service in their immediate locality

Identifying people at the end of treatment

Over 21 months Westerhaven TCAT completed HNAs with 117 people affected by cancer. Of these 66 (56%) were people with a diagnosis of cancer and 51 (44%) were family members/carers of people diagnosed with cancer.
Valued - Proactive - Inclusive - Empowering

The Proactive Inclusion Protocol resulted in the identification and invitation of 32 Wester Hailes registered patients who had completed their treatment. Of these 12 (37.5%) attended for an appointment.

Wester Hailes registered patients attending Westerhaven TCAT, as a result of the new protocol accounted for almost 1 in 5 (18%) of all new patient contacts. In addition, ten patients from other local Health Centres were identified by their GP at the end of their active treatment and referred to Westerhaven TCAT.

Although the protocol was designed to identify patients primarily at the end of their treatment, the increased awareness of this key transition time for all people affected by cancer ensured that carers/family members were also identified by GPs. Eleven (11) people who were caring for a person at the end of their treatment were referred directly to Westerhaven TCAT.

End of treatment in Westerhaven? Living with and dying with cancer

Westerhaven has always provided support to patients and carers at all stages of the cancer journey. TCAT placed an emphasis on people at the end of treatment for cancer.

Data on the profile of service users over the last 2 years illustrates that whilst a significantly increased proportion of patients are at ‘the end of treatment stage’ (as would be expected given the identification priorities of the protocol) this for most is actually ‘end of curative treatment stage’ - with 54% of all patients receiving palliative/supportive care.

Table 3: Stage of cancer journey for patients using Westerhaven

<table>
<thead>
<tr>
<th></th>
<th>2014</th>
<th>2016</th>
</tr>
</thead>
<tbody>
<tr>
<td>Just been diagnosed</td>
<td>5</td>
<td>0</td>
</tr>
<tr>
<td>In active treatment</td>
<td>55</td>
<td>5</td>
</tr>
<tr>
<td>Living with cancer</td>
<td>31</td>
<td>41</td>
</tr>
<tr>
<td>Dying with Cancer</td>
<td>9</td>
<td>54</td>
</tr>
</tbody>
</table>

All patients were ‘scored’ using the ECOG Performance Status Tool. This assesses how the disease affects the daily living abilities of the patient. Only 20% of patients were assessed as having an ECOG score of 0 - meaning they are fully active and can perform activities of daily living without restriction. Underlining the identified stage of disease many patient users are at, 14% have much lower scores being capable only of limited or no self care.
Table 4: Performance status of patients.

<table>
<thead>
<tr>
<th>Category</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>ECOG 0-Fully active, able to carry out all pre disease performance without restriction</td>
<td>20%</td>
</tr>
<tr>
<td>ECOG 1-Restricted in physically strenuous activity but ambulatory and able to carry out work of a light or sedentary nature (light house work, office work)</td>
<td>39%</td>
</tr>
<tr>
<td>ECOG 2-Ambulatory and capable of all self-care but unable to carry out work activities. Up and about more than 50% of waking hours</td>
<td>27%</td>
</tr>
<tr>
<td>ECOG 3-Capable of only limited self care, confined to bed or chair more than 50% of waking hours</td>
<td>11%</td>
</tr>
<tr>
<td>ECOG 4- Completely disabled. Cannot carry on any self care. Totally confined to bed or chair</td>
<td>3%</td>
</tr>
</tbody>
</table>

**Increasing referrals from neighbouring GPs**

Over the last two years the Westerhaven Project team have proactively carried out a number of activities to raise awareness among GP in South West Edinburgh as to the developing protocol and the support services available to patients and carers within Westerhaven and the Wester Hailes Healthy Living Centre overall. Awareness raising meetings and use of other communication vehicles to share development of Protocol/Pathway with other GPs in South West Edinburgh to encourage adoption and referrals to Westerhaven have taken place. The Westerhaven team spoke at the following GP practices:

- Wester Hailes Medical Practice in June 2016
- Colinton Medical practice in August 2016
- Whinpark Medical Centre in March 2017
- Ratho Medical Centre (Practice Manager) in April 2017
- District Nurses from Sighthill Medical Centre (District Nurses) in November 2016
- A visit is planned to Pentlands Medical Centre in July 2017.

This awareness raising work has been highly successful as patient referrals by both in house GPs and GPs from other practices has increased greatly.

Table 5: % of users referred by Wester Hailes GP and other South West Edinburgh GPs 2014 compared to 2016
A service meeting wider demand from out with immediate service locality

People affected by cancer (patients and carers) who use Westerhaven support and services are therefore not just registered patients of the ‘host’ medical centre (Wester Hailes). Westerhaven has a visible ‘wider than boundary reach’ and patients and carers who use this service are registered with a wide variety of other GP Practices - who do not have such a service in their immediate locality.

Figure 3: Registered GP of Westerhaven service Users
Valued - Proactive - Inclusive - Empowering
Meeting complex, enduring needs in an area of high multiple deprivation

Summary

- Inclusivity of opportunity, access and support is a cornerstone of this service, based as it is, in an area of multiple deprivation. The success of this is shown in the profile of users.
- Based in an area of high and multiple deprivation Westerhaven is providing support and services to people affected by cancer with complex and enduring needs.
- The most frequently reported concerns of patients were tiredness/exhaustion/fatigue and worry/fear/anxiety.
- For carers worry, fear or anxiety and sadness/depression were the ‘top two’ concerns.
- Patients reported an average of over 10 concerns. This is the highest number across all reported TCAT projects to date and higher than the interim average reported for ICJ participants in Glasgow - which was 6.
- Westerhaven is meeting needs in a range of empowerment / self-management related areas.
- Around a quarter of all clients have need for home based services and support and have been provided with this through the development of Westerhaven@Home.

Inclusive

The HNA that was to be offered to those at the end of their active treatment as part of Westerhaven TCAT - was from the start extended to include all new patients and carers coming into Wester Haven. Between April 2015 and April 2017, 148 people attended Westerhaven and were holistically assessed.

A wide variety of service users access Westerhaven. The range of ages that accessed the service was 19-89 and the average age of service users are shown below, with carers slightly younger than patients on average.
This young average age illustrates the “prematurely geriatric” phenomenon that GPs working in areas of multiple deprivation can attest to whereby due to what the Chief Medical Officer referred to as the “Biology of Poverty” life expectancy is significantly reduced in the most deprived areas.

Table 6: Age of patients using Westerhaven

<table>
<thead>
<tr>
<th>Age Range</th>
<th>Number</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Under 30</td>
<td>1</td>
<td>2%</td>
</tr>
<tr>
<td>30-39</td>
<td>6</td>
<td>9%</td>
</tr>
<tr>
<td>40-49</td>
<td>9</td>
<td>14%</td>
</tr>
<tr>
<td>50-59</td>
<td>17</td>
<td>27%</td>
</tr>
<tr>
<td>60-69</td>
<td>15</td>
<td>23%</td>
</tr>
<tr>
<td>70-79</td>
<td>11</td>
<td>17%</td>
</tr>
<tr>
<td>80-89</td>
<td>5</td>
<td>8%</td>
</tr>
</tbody>
</table>

Across patients and carers the percentage of male and female service users was similar and is shown below. Females users dominate, with only 28% of all users being male.

Westerhaven helps patients with a wide variety of cancers. People affected by breast and gynaecological cancers dominate - perhaps explaining the higher percentage of female users overall. Unsurprisingly the third most common cancer among users of Westerhaven is lung cancer. NHS Lothian has a significantly higher incidence of lung cancer in comparison to the rest of the UK\(^3\).

Table 7: Cancer type of patients using Westerhaven

\(^3\) UK Cancer e-atlas
Complex and enduring need

Westerhaven is located in an area of high deprivation. Of all patients using the service one in three (32%) live in an area designated as ‘most deprived’. (see table x). In addition, only one third are in active employment with service users who are economically inactive accounting for nearly 60% of all users.

Table 8: The SIMD of patients who attend Westerhaven
Table 9: Economic activity of people who attend Westerhaven

<table>
<thead>
<tr>
<th>Economic Activity</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Employed</td>
<td>32%</td>
</tr>
<tr>
<td>Retired</td>
<td>30%</td>
</tr>
<tr>
<td>Long term sick or disabled</td>
<td>21%</td>
</tr>
<tr>
<td>Unemployed</td>
<td>8%</td>
</tr>
<tr>
<td>Looking after home/family</td>
<td>6%</td>
</tr>
<tr>
<td>Self employed</td>
<td>3%</td>
</tr>
<tr>
<td>Student</td>
<td>1%</td>
</tr>
</tbody>
</table>

In addition to the dominance of patients not in work a quarter (24%) of all service users live alone.

In relation to ethnicity, practically all service users (89%) are ‘White, Scottish’ or ‘White, Other’. A review of active cases found 15 current service users who are of Polish origin. Work continues to develop access routes and services for people of different ethnic groups.

Using the completed Holistic Needs assessments⁴, we identified further the needs of this population. 60% of Westerhaven assessment consultations lasted over 1 hour.

Table 10: Top 10 concerns reported at HNA

The top 10 concerns for Patients and Carers are shown below.

<table>
<thead>
<tr>
<th>Patients</th>
<th>Carers</th>
</tr>
</thead>
<tbody>
<tr>
<td>Tired/exhausted or fatigued</td>
<td>Worry, fear or anxiety</td>
</tr>
<tr>
<td>Worry, fear or anxiety</td>
<td>Sadness or depression</td>
</tr>
<tr>
<td>Complementary therapies</td>
<td>Caring responsibilities</td>
</tr>
<tr>
<td>Sleep problems/nightmares</td>
<td>Other</td>
</tr>
<tr>
<td>Money or housing</td>
<td>Anger or frustration</td>
</tr>
<tr>
<td>Pain</td>
<td>Loneliness or isolation</td>
</tr>
<tr>
<td>Support groups</td>
<td>Sleep problems/Nightmares</td>
</tr>
<tr>
<td>Exercise or activity</td>
<td>Tired/Exhausted or fatigued</td>
</tr>
<tr>
<td>Eating or appetite</td>
<td>Unable to express feelings</td>
</tr>
<tr>
<td>Getting around/walking</td>
<td>Hopelessness</td>
</tr>
</tbody>
</table>

A high percentage of both patients (38%) and carers (25%) reported being concerned about money and housing issues. Patients reported an average of over 10 concerns and carers 8.5.

⁴Data from completed HNAs is available for 95 service users.
Valued - Proactive - Inclusive - Empowering

Table 11: Average number of reported concerns

<table>
<thead>
<tr>
<th>Concern</th>
<th>Patients</th>
<th>Carers</th>
</tr>
</thead>
<tbody>
<tr>
<td>Average number of</td>
<td>10.23</td>
<td>8.5</td>
</tr>
<tr>
<td>concerns</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

The high number of concerns attests to the fact that we are working with a population who live with multiple comorbidities, which is another feature of the “Biology of Poverty”. This has encouraged the Wester Haven staff to consider extending the service to people with other life limiting Long Term Conditions, in particular those who are housebound.

**Developing Outreach Work**

This Westerhaven service recognises that at the times when a client is perhaps most in need of care & support, they are unable to access the centre due to frailty or fatigue due to cancer &/or its treatment. This lead to patients feeling very isolated and lonely stuck in their homes with little support available. In response Westerhaven developed an outreach service whereby services such as information, practical support, counselling and massage are provided in a person's home.

The Westerhaven service has evolved over the past 5 years to recognise that at the times when a client is perhaps most in need of care & support, they are unable to access the centre due to frailty or fatigue due to cancer &/or its treatment. In response to this Westerhaven developed an outreach service whereby services such as information, counselling/massage are provided in a person's home. Alongside this they have volunteer drivers who can bring people to the centre or to their medical appointments, and volunteer befrienders who provide company, support and assistance, by escorting clients to local resources, helping pick up shopping/prescriptions and with simple household tasks.

From December 2015 to December 2016, a total of 21 clients have received outreach services. In a 12 month period that is around a quarter of all clients who have need for home based services and support.

**Table 12: Use of Westerhaven@Home in one year**
The outreach service aims to reduce social isolation and loneliness for clients who are most vulnerable by providing opportunities to connect up and talk to others and have services within their home. The service also aims to increase community participation by using our members to volunteer their time for people going through the cancer journey. This is then reciprocated when patients/clients feel able to give back their time by becoming befrienders/volunteer drivers, helping to support other clients affected by cancer.

The Canal GP Cluster has identified a gap in services available for those patients that are suffering from Long Term Conditions and are housebound and isolated. Westerhaven’s outreach service could be extended. It has already been established as providing quality care for those affected by cancer, and is well placed to be able to provide emotional & practical help for this very isolated, vulnerable and lonely population beyond those affected by cancer.

### Conclusion

The findings from this evaluation demonstrate that the TCAT project at Westerhaven is a valued, proactive, inclusive and empowering source of support for people affected by cancer in South West Edinburgh.

The G.P.’s in Wester Hailes and South West Edinburgh will continue to champion the need for such a valuable resource to remain in their locality: almost all GP practices in South West, both from the Canal and Pentland Cluster (as well as some farther afield in less well resourced parts of the City) refer to Wester Haven. In addition many have expressed their ongoing need for the service in testimonials and petitions to the Health Board to sustain the project.

This evaluation has concluded that clients who use Wester Haven have been able to access local services within their community and link up with other projects within the Health Agency and beyond. Effective signposting and asset building with community resources has helped to build clients’ Social Capital. This enables clients to feel more connected to their neighbourhood and increase their confidence through participation in community projects.

The Westerhaven TCAT project has highlighted the numerous patients who have finished their treatment and are now in the palliative stages of their disease who
have many unmet needs. Many of the concerns reported by these patients and carers are requirements that without Westerhaven, would otherwise need to be addressed by Primary Care services. These patients require more resources and support to help manage their social and health needs, particularly in areas of deprivation where the incidence of cancer is higher and the socio-economic issues are greater. Almost half of Westerhaven clients are SIMD 1 or 2.

The service itself will close in July 2017 unless an alternative source of funding can be secured to replace the current Macmillan Cancer Support funding. The short-term priority of all staff and stakeholders is therefore to secure a funding source to enable the service to continue.

Recommendations

More medium term priorities are:

- Develop the outreach service to meet the needs of those unable to attend the centre due to ill-health.
- Continue to develop access routes into the service for people affected by cancer who are not registered with the host GP practice.
- Continue to proactively identify people affected by cancer who could benefit from having an HNA, the resulting care plan and implementation of support and services.
- Attract the additional resources needed to help manage the social and health inequalities in an area of high deprivation where the incidence of cancer is higher, clients present later and therefore have worse outcomes and the unmet needs of patients are greater.
- Westerhaven out-reach service which has already been established as providing quality care for those affected by cancer, is well placed to be able to provide emotional & practical help for this very isolated, vulnerable and lonely population. Westerhaven’s outreach service could be extended to include those patients who are in the palliative stages with chronic long term conditions. The Canal cluster has identified a gap in services available for those patients that are suffering from Long Term Conditions and are housebound and isolated.
- Our recommendation and ambition is that Wester Haven should be mainstreamed so that it becomes a sustainable service for the GP practices in South West Edinburgh and a reliable source of support to the people who have come to depend upon it.