



Heart of Birmingham Teaching **NHS**
Primary Care Trust



Living Choices

End of Life Complementary Therapy Outreach Project

End of Year: 1st April 11 – 31st March 12

For more information about this project, please contact: 0121 415 6670



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Executive Summary

2011-12

- A total of 84 clients received a service in the year 2011-12, of which 67 were new clients.
- Economic analysis indicates a cost savings of £221,177 on the basis of increased home deaths, reduced hospital deaths, preferred place of care and symptom improvement from the investment of £26,723 we receive to deliver the project.
- Home death is consistently high at 45% which is the highest ever in 2011- 12. On average 65% of clients died in their preferred place of care.
- Females constituted the majority (64%) of the clients.
- 85% of clients were 51yrs and older, while 73% were 61 yrs and above and 73% are from BME communities.
- Cancer diagnosis makes up 52% of client's primary diagnosis with lung cancer being the most common. The non-cancer diagnosis includes neurological and heart disease, COPD, renal disease and others. 12% were carers.
- A total of 534 activity sessions were delivered with massage being the most common type of complementary therapy.
- Majority of referrals were from community matrons/nurses and district and specialist nursing teams (37%).
- The largest number of referrals was for GP post codes B19, B5, B20.
- Most are from the areas of Handworth, Handsworth Wood, Lozells, Ladywood and Aston.

Background

In partnership with HOBt PCT the project aims to support the NHS End of Life Strategy 2008. The objective being to;

“Reduce the need for intensive medical, nursing and social care by enhancing quality of end of life phase, therefore minimising overall cost of medical services and facilitating patient’s choice of location to die”.

The Living Choices project is a complementary therapy service that has been delivered by Freshwinds since the last 9 years (since 2003) to patients who are in the End of Life stage of their illness. It was initially piloted through a Big Lottery Grant and the extended through support of HOBt PCT based on the positive impact and outcomes of the project on the challenges of;

- Improving End of life patient care
- Enhancing patient choice for additional supportive care for symptom control and well-being
- Enhance quality of life for end of life patients
- Offering patients a choice to die at home or in a place of their choosing
- Offering patients options to receive care in their own home and with their families
- Reducing the need for hospitalization and therefore the cost of medical services

Target Group

The target client group are all end of life patients under the care of HOBt PCT GPs who have an end of life care need to improve comfort and quality of life and where implemented for patients to be entered on the Palliative or GSF register.

Services

The project service constitutes the provision of a range of therapy services that:

- Provide alleviation from persistent pain and discomfort.
- Provide preparation and support prior to, during and after Radio/Chemotherapy by raising energy levels and strengthening the immune system. This relates specifically to side effects e.g. nausea, pain, vomiting, fatigue, loss of appetite constipation, diarrhoea, improved sleep, relaxation and healing.
- Provide confidential therapeutic services to help deal with emotional and psychological issues e.g. body image, self worth, anger and fear.
- Provide advice on conditions, and treatment options.
- Provide enhanced psycho-social support to increase client awareness and involvement in care that is both integrated and fully complementary to conventional medical treatment.

Target Outcomes

This includes both qualitative and quantitative outcomes for the service. These are collected through standardised patient information and a series of questionnaires that have been designed specifically for the service to monitor symptom control, emotional state and overall quality of life.

Quantitative Outcomes

- Minimum of new 40 individual clients registered.
- Minimum of 500 activity sessions (Assessments, reviews, therapies, advocacy/advice and other).

Qualitative Outcomes

- Reduced physical symptoms such as fatigue, pain, nausea/vomiting, shortness of breath, and gastro-intestinal symptoms.
- Enhanced comfort and relaxation.
- Enhanced psycho-emotional state by reducing anxiety, fear and stress.



Project Outcomes

1. Client Outcomes

Client Profile

At the end of 2011-12 a total of 67 new clients were registered on to the project (27 above our annual target: 40), with the highest number of referrals being received in the 2nd Qtr (25). A total of 84 clients received a service. Of these 19 clients were carried over from the previous year. There were a greater number of females (64%) to males (36%) ratio, and 73% were 61 years and above, while 12% were between 51-60 years.

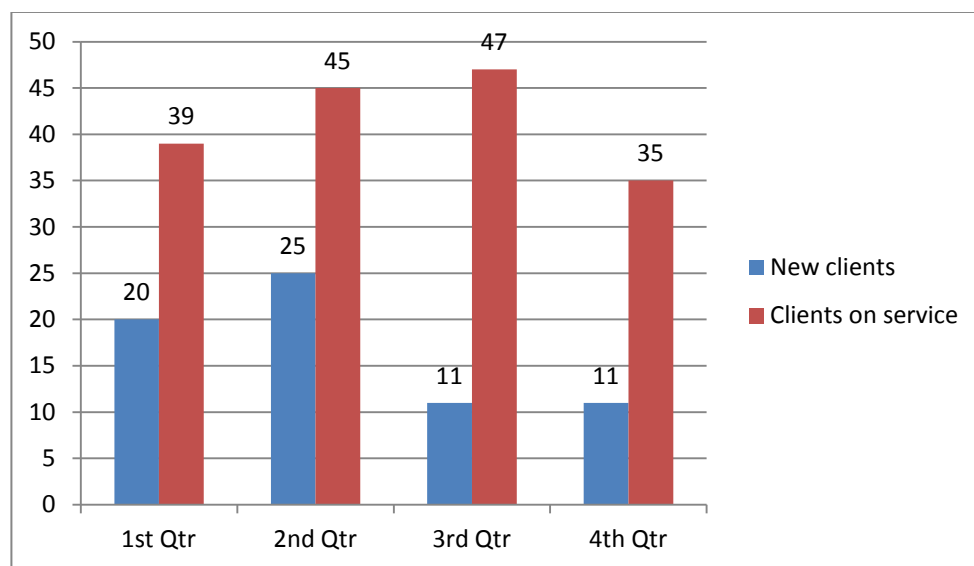


Figure 1: New Clients and Clients on Service 2011-12

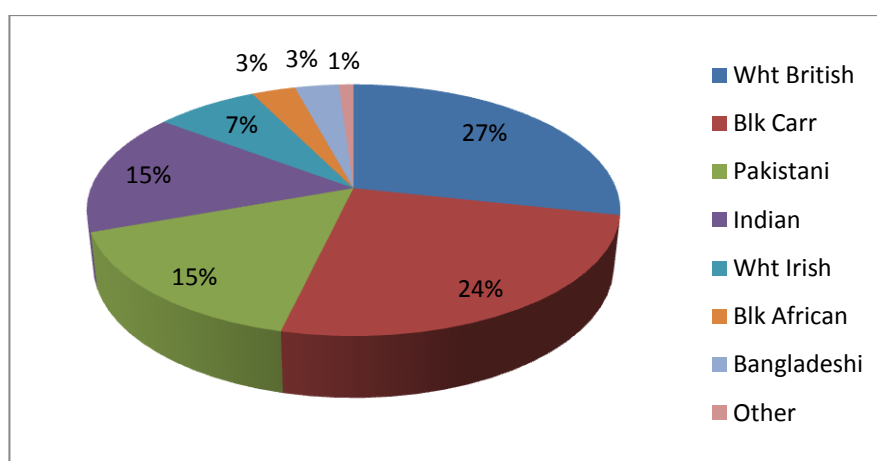


Figure 2: Ethnicity of New Clients 2011-12

Diagnoses

In the Primary diagnosis, 52% of clients had cancer, a considerable improvement from last year where cancer diagnosis was considerably higher 76% demonstrating our improved reach and referral pathways for other end of life conditions. Amongst the 17 different types of cancer diagnosis, lung cancer (20%) was the most common, followed by breast (11%) and bowel (11%). 48% of non-cancer diagnosis includes a combination of neurological (10%), heart disease (10%), COPD (7%), renal disease (3%) and other (4%). 12% were carers.

Co-morbidities in end of life are common. Many of whom have multiple underlying conditions that present health difficulties in addition to the primary diagnosis. Apart from the primary diagnosis the most common co-morbidity is heart disease (30%), diabetes (19%) and COPD and other respiratory diseases (16%). Other conditions are arthritis, cancer, renal disease and depression.

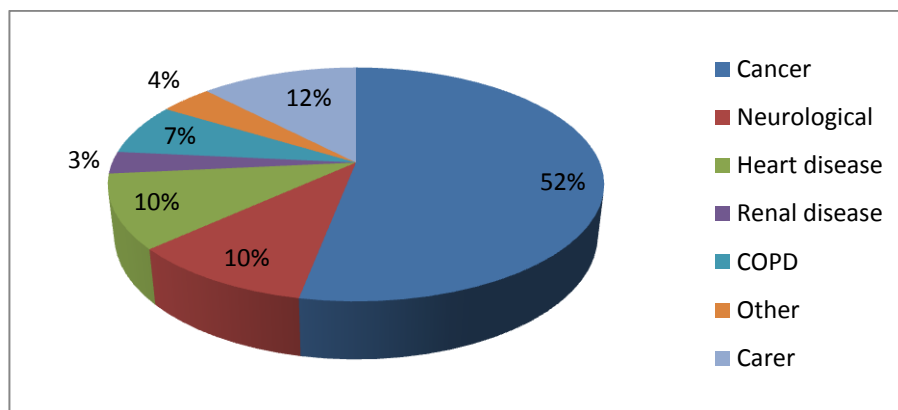


Figure 3: Primary Diagnoses of new Clients 2011-12

2. Activity Outcomes

A total of 534 activity sessions were delivered (annual target: 500), equating to an average of 6.4 sessions per client. The 2nd and 3rd quarter has the most sessions delivered. Revision of the service provision guidelines in the previous year has positively allowed us to focus the services on the most vulnerable. From the five types of complementary therapy sessions delivered the most common is massage (19%), reflexology (12%) and aromatherapy (11%).

An additional 65 advocacy and information services were provided by Freshwinds as in-kind support towards the service beneficiaries further demonstrating the value for money this service provides.

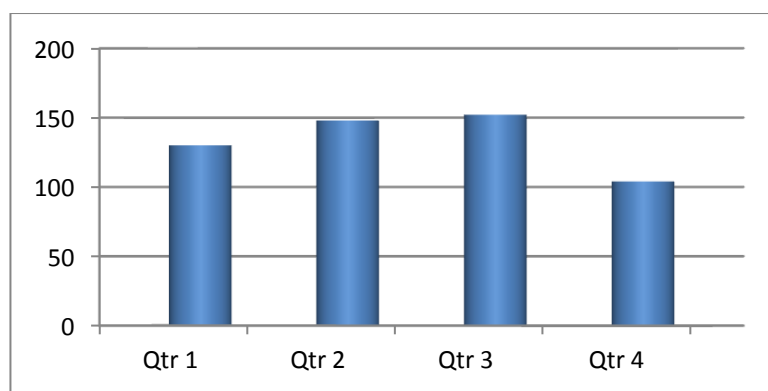


Figure 4: No of Sessions delivered 2011-12

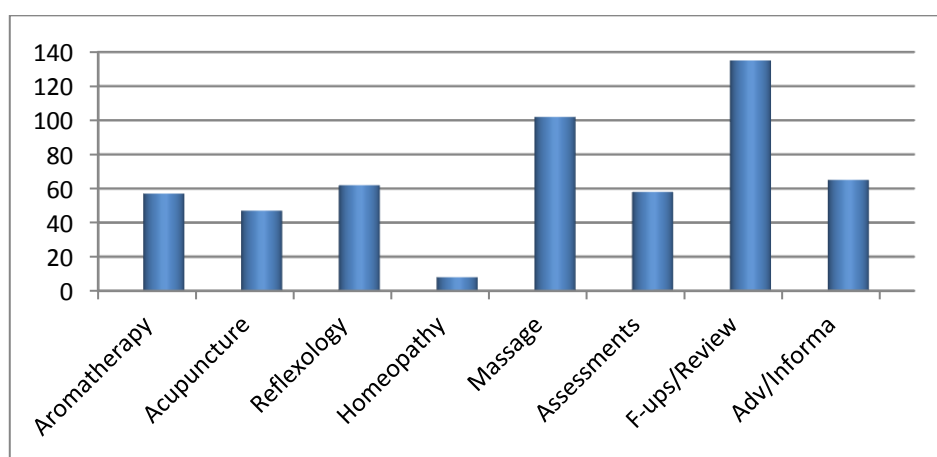


Figure 5: Types of activities delivered 2011-12

3. Referral Sources

This year there has been a considerable shift from the traditional hospice referrers who accounted for around half of all referrals. Instead in 2011-12 the community matron/nurses and district nursing teams have been highly proactive in referring into the service. They now account for a total of 37% of referrals (2010-11: 17%). We believe that this is because of the considerable trust gained and relationships that have developed over the years.

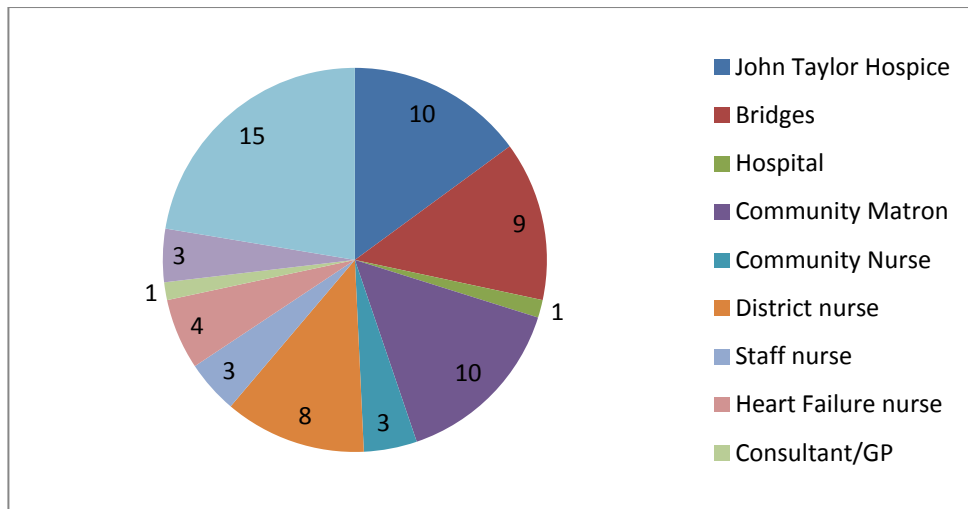


Figure 6: Number and Types of Referral Sources

4. Client Deaths

HOBt PCT data indicates that cancer deaths at home are 24%, in hospice, 16% and in hospital 54%. In comparison to this, our Living Choices data show considerably enhanced performance with 66% of clients who died over 2011-2012 (41 people) did so in their preferred place of care. 45% died in their own home which is an improvement from the previous year (2010-11: 40%), and small reductions in hospice deaths at 24% (2010-11: 26%) and 32% (2010-11: 34%) in acute hospital settings.

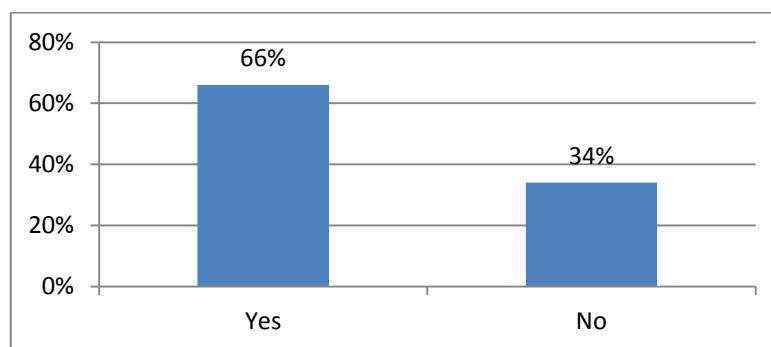


Figure 7: Died in Preferred Place of Care 2011-12

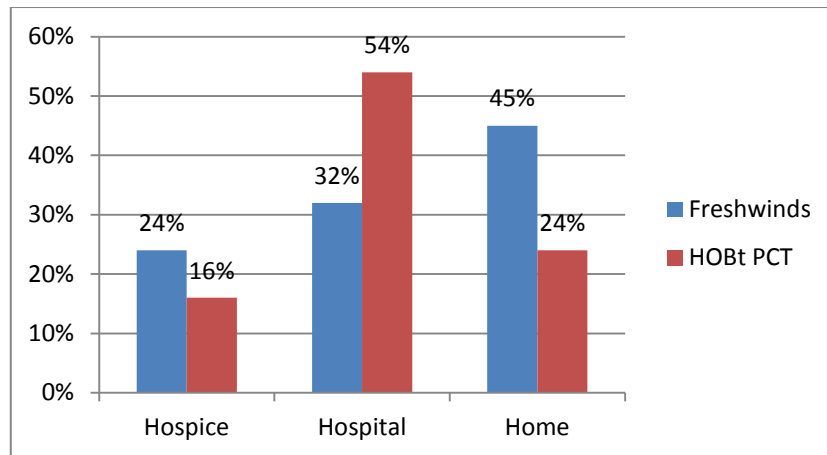


Figure 8: Place of Deaths 2011-12

5. Client Feedback

Key client symptoms at the start of service provision include complaints of fatigue, lack of energy, stress, anxiety and frustration. They experienced problems with a range of symptoms such as mobility, shortness of breath, sleep, constipation and nausea/vomiting. Although despite these some continued to be positive, calm, comfortable and cheerful. The follow-up questionnaires indicate improvements in all of these areas.

Clients at Baseline:

- 79% have lack of energy
- 52% experience pain
- 52% have anxiety
- 41% feel frustrated.
- 34% have issues with mobility
- 31% have difficulty with shortness of breath
- 31% were stressed
- 31% were worried
- 31% were tearful
- 31% felt positive
- 28% were calm
- 28% were comfortable
- 28% were cheerful.



Clients Follow-up after 6 sessions:

- 38% have improved energy levels
- 75% have had pain relief
- 50% are less anxious
- 12% are still frustrated
- 53% have better mobility
- 38% have reduced shortness of breath
- 12% were still stressed
- 12% were still worried
- 12% were still tearful
- 63% were positive
- 88% felt calm
- 100% felt comfortable
- 63% were cheerful

Case Study 1

Summary

A 25 yr old lady **Amal** of Indian descent, diagnosed with muscular dystrophy as a child. She regularly uses a wheel chair and has found that she is progressively getting weaker as a result of which her mobility is limited and she is gaining weight. On presentation to Freshwinds she was unable to lift her arms and only walks short distances e.g. from her house to the garden. She was receiving physiotherapy but finds that her shoulders, back, neck and legs are usually painful, heavy, stiff and achy. Her legs are swollen and she described them as being “hard and stiff”. She finds that the muscle weakness restricts her breathing and is usually fatigued and tense even after a reasonable night’s sleep. Emotionally she gets anxious and frustrated. She has been prescribed medication for pain control and breathing, but despite this she was referred to Freshwinds for further support for the pain, poor circulation, mobility, breathing difficulties and anxiety. **Amal** was started on monthly massage sessions.

Patient Safety: A number of safety issues were identified which contraindicated massage on a number of areas of the body due to implanted medical devices. In regards to the use of essential oils some guidance was also implemented.

Following are the result of Amal's monitoring questionnaires.

1 st Baseline Questionnaire	After 6 sessions questionnaire	After 12 sessions questionnaire
0 months Problems with: Lack of energy, anxiety, pain, mobility, anger, distress, frustration, tense, tearful and worried.	5 months Treatments Benefited: Pain, depression, mobility, shortness of breath, calm, cheerful and comfortable, happy, peaceful and relaxed. No reduction in medication, but benefited in overall well-being. Client Comments <i>“I suffer with limb girdle muscular dystrophy. I’m wheelchair user I can weight bear and walk short distances with help. The treatments I have been having has helped a lot. I would like the treatments to carry on. I would also like to say a big thank you to “Therapist”.</i>	8 months Treatments Benefited: Lack of energy, anxiety, pain, sleep, calm, comfortable, happy, peaceful, positive, relaxed, satisfied. No reduction in medication but benefited in overall well-being. Client Comments <i>“Because I suffer with limb girdle muscular dystrophy and I feel that the massages are beneficial and I would like to continue with my treatments.”</i>
12 months Client comments <i>“Since I have been having those massages I feel that they have been beneficial. The massage help for the muscular dystrophy I have. I would be very please if I could continuing with my treatment I am having”.</i>		

Case Study 2

Summary

A White British lady **Beatrice** aged 87 yrs referred by the Community Staff Nurse in Jan 2012. She had been diagnosed with rectal cancer in early 2011, diabetes and osteoarthritis. Her main complaints were pain in her upper spine, shoulders, knees and coccyx, which restricts her mobility. Since the last 6 months she has been having cold and numb feet. She gets fatigued easily and general weakness. **Beatrice** is positive despite her diagnosis and supported by her husband. She was on a 14 different types of drugs. **Beatrice** received monthly massage treatments to which she responded very well and felt that her pain was more manageable and the numbness in her legs and feet improved. **Beatrice's** condition gradually deteriorated over a period of 6 months and finally passed away peacefully at home in June 2012, which was her preferred place of care. Her husband thanked Freshwinds for the support offered.

1 st Baseline Questionnaire	After 6 sessions questionnaire
0 month Problems with: <ul style="list-style-type: none">• Pain, lack of energy, fatigue.• Anger, anxiety, worried, confident, comfortable and positive.	5 months Treatments Benefited: <ul style="list-style-type: none">• Pain, lack of energy, mobility and eating.• Encouraged, relaxed, optimistic, comfortable and happy. <p>Doctor reduced medication, but queried if it is a direct result of the massage.</p> <p>Overall benefited from the treatments.</p> <p>Comments <i>"I have benefited so very much so, it leaves me feeling so positive. My movement is especially helped in my arms and hands and I can feel my muscles and limbs better".</i></p>

Client and Carer Comments after six sessions;

"In less pain (lungs, lower back) helped circulation (hands and feet are warmer after) very grateful for help."

"Max is very tired all the time. He greatly enjoys the treatment as it helps with his pain and stiffness in his muscles and makes him less anxious. This helps him sleep better and he feels more relaxed."

"I feel relaxed and comfortable following my therapy. I am able to enjoy the feeling for a while and normally go to sleep I'm so relaxed. I feel content for a couple of days following."

"I have benefitted emotionally more composed and at least trying to be calm thinking of positive thoughts although I might need help from Freshwinds."

Economic Cost analysis

There were a total of 534 activity sessions delivered. On average each client received 6 sessions, each session costing on average £27 (direct costs + travel + equipment), with visits lasting between 1-2 hrs long. The unit cost per client is calculated to be around £162 p.a. (direct costs + travel + equipment) which is cost effective when compared to unit costs for high community nurse care of £1,248 p.a. (Curtis, 2008).

Economic benefits of the service can be considered using the following:

- Reduction in the number of hospital deaths.
- Increase in the number of home deaths
- Quality adjusted life years (QALY)

The project outcomes indicate a 22% lower hospital death rate as well as a 21% higher home death rate. Both of which have prevented higher rates of hospital related deaths. In addition to this we believe that the enhancement of quality of life offers even greater value to the service outcomes.

The National Institute for Health and Clinical Excellence (NICE) defines the QALY as a *'measure of a person's length of life weighted by a valuation of their health-related quality of life'*. It offers a common currency for measuring the extent of health gain that result from healthcare interventions. Quality of life measurements embrace a whole range of different facets of people's lives, not just their health status. We use a simple measure taking into consideration the impact of health problems not just on the client but also on the quality of life of carers and family members c. There is a degree of consensus that one QALY should generally be between £20,000 and £30,000, however higher thresholds have been advocated for end of life care.

For the purposes of this report we will use the average QALY value of £25,000 in relation to the project aims of 'dying in the preferred place of care', 'symptom improvement' and 'overall benefit'. We will use the following data outcomes.

1. Clients who were supported to die in their preferred place of care (66%)
2. Clients who felt they benefited from the service (100%)
3. Improvements in key common symptoms of pain (75%), mobility (63%), sleep (38%), fatigue (38%), depression (63%) and anxiety (50%).
4. EQ-5D health state valuations of 33332; 23322; 21123 (Phillips, 2005) of extreme or moderate pain and anxiety, leading to improvement states of 12321; 2222 of moderate or some pain and moderate or not anxious or depressed. Collectively these indicate a health improvement range of 0.29 – 0.95 (Avg: 0.33).

Table 1: Economic Cost Analysis

<i>Home and Hospital deaths</i>	<i>Potential savings if clients had died in hospital</i>
Reduction in Hospital death rates HOB PCT- Freshwinds = 22% (8.4 deaths) @£2,500 per admission	£ 21,000
Increase in home deaths Freshwinds – HOB PCT = 21% (7.6 deaths) @£2,500 per admission	£ 19,000
Improvement in QoL for 66% (25.2 clients) with an average of 0.33 QALY improvement @ £25,000 per one QALY. (0.33 = £8,250 x 25.2)	£ 207,900
Subtotal (A)	£ 247,900
Cost of the Service to HOBt PCT (B)	£ 26,723
Cost Savings (A – B)	£ 221,177

References:

- Curtis L. (2008). Unit costs of health and social care. PSSRU, University of Kent, pp. 42.
- Sarafina et al. Key health data for the West Midlands- 2007/08. University of Birmingham; 2008. BHWP. Birmingham Health & Well-being Partnership: Long Term conditions. [Online].; 2011 [cited 2011 Feb 18. Available from: <http://www.bhwp.nhs.uk/Apps/Content/HTML/ViewContent.aspx?id=200>.
- Phillips C. (2009). What is ...? Series: What is QALY?. Hayward Medical Communications. Available from: <http://www.medicine.ox.ac.uk/bandolier/painres/download/whatis/QALY.pdf>



Data Sheet 2011-12

1st Qtr	2nd Qtr	3rd Qtr	4th Qtr	
01-Apr-11	01-Jul-11	01-Oct-11	01-Jan-12	
30-Jun-11	30-Sep-11	31-Dec-11	31-Mar-12	TOTAL

NO. OF CLIENTS SEEN

39	45	47	35	84
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NEW BENEFICIARIES

20	25	11	11	67
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AGE (yrs)

18 -30

31- 50

51- 60

61 +

Total

2	2			4
2	0	2	2	6
2	5		1	8
14	18	9	8	49
20	25	11	11	67

%

6%

9%

12%

73%

CLIENT ETHNICITY

White British

White Irish

White Other

Black Caribbean

Black African

Indian

Pakistani

Bangladeshi

Asian

Mixed

Other

Unknown

Total

				TOTAL	
4	9	4	1	18	27%
0	1	1	3	5	7%
0	1			1	1%
4	6	3	3	16	24%
2	0			2	3%
3	4	1	2	10	15%
5	3	2		10	15%
2	0			2	3%
0	1		1	2	3%
0	0			0	0%
0	0	0	1	1	1%
0	0	0	0	0	0%
20	25	11	11	67	

TOTAL

%

27%

7%

1%

24%

3%

15%

15%

3%

3%

0%

1%

0%

SEX	1st Qtr	2nd Qtr	3rd Qtr	4th Qtr	Total	
Male	9	8	1	6	24	36%
Female	11	17	10	5	43	64%
Total	20	25	11	11	67	

CLIENT CONDITIONS (Main diagnosis)					TOTAL	%
Cancer	8	10	8	9	35	52%
Neurological Conditions	1	5	1		7	10%
Heart Disease	4	2	1		7	10%
Renal Disease	1	1			2	3%
COPD	3	1	1		5	7%
Other	0	2		1	3	4%
Carer	3	4		1	8	12%
Total	20	25	11	11	67	

Co-morbidities (not comprehensive list) (most of the clients have multiple co-morbidities)

Arthritis / ortho	1	1		3	5
Asthma	1		1		2
Cancer	1	3			4
COPD	2	3		1	6
Other lung disease	2		1		3
Depression	1				1
Diabetes	5	4		4	13
Heart disease	6	5	6	3	20
Renal disease	2	1	1	1	5
Stroke					0

SERVICE DETAILS

Aromatherapy
Acupuncture
Reflexology
Homeopathy
Massage
Assessments
Follow up & Reviews
Advocacy & Information

Total

1st Qtr	2nd Qtr	3rd Qtr	4th Qtr
4	10	23	20
22	8	8	9
11	14	19	18
0	4	2	2
25	32	26	19
15	23	12	8
38	36	44	17
15	21	18	11
130	148	152	104

TOTAL

57
47
62
8
102
58
135
65
534

%

11%
9%
12%
1%
19%
11%
25%
12%

CLIENT DEATHS

Died in Preferred Place of Care

Yes
No
Don't know
Total

8	6	5	2
3	2	3	3
1	2	3	3
12	10	11	8

21
11
9
41

% of where it is known if they died in preferred place of care (i.e. yes/no)

66%
34%

Home
Hospice
Acute Hospital
Unknown

Total

6	3	3	5
3	3	2	1
3	3	5	1
0	1	1	1
12	10	11	8

17
9
12
3
41

Freshwinds %
% where place of death is known

45%
24%
32%

HOB PCT %

24
16
54

REFERRAL SOURCES

John Taylor Hospice
St Mary's Hospice
Bridges
Hospital
Community Matron
Community Nurse
District Nurse
Staff Nurse
Heart Failure Nurse
Consultant/GP
Freshwinds
Carer
Other

Total

1st Qtr	2nd Qtr	3rd Qtr	4th Qtr
3	5	1	1
0	0		
1	4	2	2
0	0	1	
3	5	1	1
0	0		3
0	2	3	3
1	2		
2	1	1	
0	0	1	
0	0		
1	1		1
9	5	1	
20	25	11	11

10	15%
0	0%
9	13%
1	1%
10	15%
3	4%
8	12%
3	4%
4	6%
1	1%
0	0%
3	4%
15	22%
67	

AREA OF RESIDENCE ACCORDING TO GP POST CODE

B4
B5
B6
B7
B10
B11
B12
B13
B16
B17
B18
B19
B20

1st Qtr	2nd Qtr	3rd Qtr	4th Qtr
	1		
5	6		
	1	1	1
			1
2	1	1	
2	3		
	1		
	2		
3	2		
5	5	2	5
1	1	5	2

	%
1	1%
11	16%
3	4%
1	1%
0	0%
4	6%
5	7%
1	1%
0	0%
2	3%
5	7%
17	25%
9	13%

B21					0	0%
B23					0	0%
B26					0	0%
B28	2	1			3	4%
B42		1	2	2	5	7%
B43					0	0%
B44					0	0%
Total	20	25	11	11	67	

*Any differences in data when compared to previous reports is due to additional data/information that has been received since.



