



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

*Self Management:
The ability to make wise choices to
achieve a Fruitful and joyous life*



Avoiding Emergency Hospital Admissions "A Self-Management Complementary Therapy Project"

Interim Report
1st April 2011 – 30th June 2012



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Executive Summary

- Since 6th June 2011 a total of 68 referrals have been received on the Avoiding Emergency Hospital Admissions (EHA) project. Majority of clients have multiple co-morbidities, with 75% having between 3-5 diagnoses. The most common diagnosis are 31% COPD and lung diseases, 27% diabetes, 22% heart disease, 12% arthritis, 10% renal disease, 9% stroke, 6% asthma, 4% depression, 3% cancer and others.
- 11 clients declined the service, died or were discharged, thus leaving 57 clients who received a service. 62% are females, 85% of clients are aged 60+ yrs and 56% are 76+yrs.
- 47% are from BAME groups and reside in the areas of Handsworth, Handsworth Wood, Birchfield, Lozells, Perry Barr, Hamstead and Great Barr areas.
- 57% of referrals were from Community Matrons across HOBt PCT, 15% from the respiratory nurse, 9% from Clinical Case Managers. Clients were registered at 31 different GP practices. The most coming from Tower Hill Medical Centre (13%), Bloomsbury Health Centre (9%) and Handsworth Wood Medical Practice (7%).
- A total of 684 activity events were delivered, ranging from assessments, therapies, self-help teaching sessions, telemonitoring, signposting and referrals. 76% are direct one to one client activity. A total of 57 Self-Help Kits and a variety of 30 different types of Self-Help Guides have been distributed to clients.
- In December and January 2012 'Winter Health Checks' were undertaken for more than 40 clients to anticipate potential winter health risks, and relevant referrals, and information leaflets e.g. colds, coughs, flu, falls norovirus, hypothermia, dehydration, seasonal affective disorder and smoke alarms were provided.
- Data analysis for **38 clients who have received a minimum of 3 months service** indicates a total of 127 EHA in the previous year. 16 clients recorded a total of 32 EHA while on the project. Number of EHA reduction is 95. This gives an average reduction of EHA per client has reduced from 3.34 to 0.84. Majority of EHA occurred in the period Oct-Dec (11).
- Data analysis for **29 clients who have received a minimum of 6 months service** indicates a total of 102 EHA in the previous year. A total of 31 EHAs have been recorded for 15 clients who have an average age of 66 years. Average length of hospital stay is 8 days. There is an overall reduction of 71 EHA, with an average EHA risk reduction of 69%.
- Reasons for EHA occurrence range from breathlessness and coughing (12), various types of pain including chest and abdominal (8), chest or urinary infection (7), fall (2), collapsed/passed out (3), and other (1). *3 of these occurred within 15 days of the first assessment.*
- Economic cost-benefit analysis for 29 clients who have received minimum 6 months service delivering a **saving of £101,524.**

- Client outcome measures for symptoms, activity and well-being indicate an average MYMOP clinically significant change score of 1.10 (n=14). The most common symptoms are pain and breathing with 35% having had the symptoms between 1- 5 yrs, and 37% for over 5 yrs.
- Client outcomes for changes in health locus of control shows very little change in the internal locus of control (n=9). This may be partly due to a self selective process where only willing clients accept the service, and explains the high number of clients who declined the service.

There is significant case for the project to have considerable to Birmingham's EHA rates. Based on the results recommendations are made for the project to be continued and expanded. Future programmes should review and consider a shorter intervention period of 6 months to allow flexibility to tailor the delivery of services according to circumstances of the clients.



Avoiding Emergency Hospital Admissions Project

Project Aim

To implement a preventative intervention programme of self-management, education and crisis prevention, to HOBt PCT clients who are at risk of emergency hospital admissions. The focus areas being a reduction in emergency hospital admissions (EHA), and the occurrence of delayed hospital transfers.

Target Group

50 clients diagnosed with long term conditions e.g. respiratory, cardiac and neurological conditions that have had a minimum of one EHA in the last one year and is considered to be at risk of future EHA. This excludes dementia and other neurological conditions where the client is unable to actively partake in learning self-management skills.

Intervention

A 52 week integrated self-management approach that targets both health and social care needs of patients, using a combination of educational, self-help skills and complementary therapies. Provision will be mainly in the home, but could be at a suitable community venue where appropriate.

Target Outcomes

Quantitative Outcomes

- Provision of support to a minimum of 50 new clients and carers seen in the year.
- Reduced condition associated symptoms such as fatigue, pain, nausea/vomiting, shortness of breath and other.
- Minimum of 750 activity sessions (Assessments, reviews, therapies, self-management skills, telemonitoring, advocacy/advice, volunteer support, referrals made and other).
- Minimising carer breakdown, while increasing their ability to manage.
- Reduction of number of client EHAs.
- Reduction in the length of emergency hospital stay.

Qualitative Outcomes

- Enhanced comfort and relaxation.
- Enhanced psycho-emotional state by reducing anxiety, fear and stress experienced by clients and their carers/family.
- Enhanced quality of life, well-being and ability to self-manage condition.

Monitoring & Evaluation

Client data will be collected at the time of assessment, with a baseline of the EHA history in the previous year (more longer if relevant) and other quantitative and qualitative information. Clients will be continually monitored for EHA and other health professional care visits/appointments. This will be followed up at 6 months and then at the end of one year. A combination of MYMOP, MHLoC and AC-QoL questionnaires will be used.

Progress Report (1st April 2011 – 30th June 2012)

Project Development and agreements took place in the first 10 weeks (1st April 2011 to 31st May 2011), with the Community Matron and District Nursing Teams to establish an agreed referral criteria and the relevant referral points. Actual service delivery started on the 6th June when the first client was registered. For the purposes of the pilot the referral points had initially been limited to community matrons and district nurses only, but due to low referral rates in November and December 2011 it was extended to include specialist community, hospital nurses, community organisations and others. Due to the late start of the project the life of the project was extended an additional 3mths to ensure that maximum activity and outcomes could be achieved. **This report was compiled with data collected up to the 30th June 2012, and is therefore subject to changes as not all clients have completed the programme. Full deliver of the project is expected to be completed by June 2013.**

Clients

Client Numbers: In the period 1st April 2011 to 30th June 2012 a total of **68 referrals** were received. The most referrals were received in the 1st quarter (17) and the lowest was in the 4th quarter (9). 11 were discharged (9 declined the service, while 2 decided to withdraw for personal reasons) and 7 died whilst on the project (1- 5 months). A total of 57 clients received a service.

Client Profiles: Majority of clients are over the age of 60 years (85%) of which 76+ years was highest (56%). The average age of clients is 73 year (Range: 27- 90 years) and 62% are female. Clients come from a wide range of ethnic backgrounds (Figure 3).

Post code distribution of clients is highest from B20 (19%) and B21 (15%), followed by B42 (13%) and B19 (9%) which is the Handsworth, Handsworth Wood, Birchfield, Lozells, Perry Barr, Hamstead and Great Barr areas. The most referrals were of clients registered from Tower Hill Medical Centre (13%), followed by Bloomsbury HC (9%), Handsworth Wood MC (7%), Laurie Pike HC (6%), Newtown HC (6%), Soho road Primary Care Centre (4%), St Clements (4%), Colston HC (3%), Dr JK Bansal-Handsworth (3%), Great Barr Surgery (3%), Hockley Medical Practice (3%), Holyhead Primary Health Centre (3%), St James MC (3%) and others.

Majority of clients has multiple health conditions with 75% having 3-5 diagnoses. COPD and lung diseases (31%) being the most prevalent, followed by diabetes (27%) followed by heart disease (22%), arthritis and osteoarthritis (12%), renal disease (10%), stroke (9%), asthma (6%), cancer (3%), depression (4%), Parkinson's (3%) and others.

Figure 1: New Clients

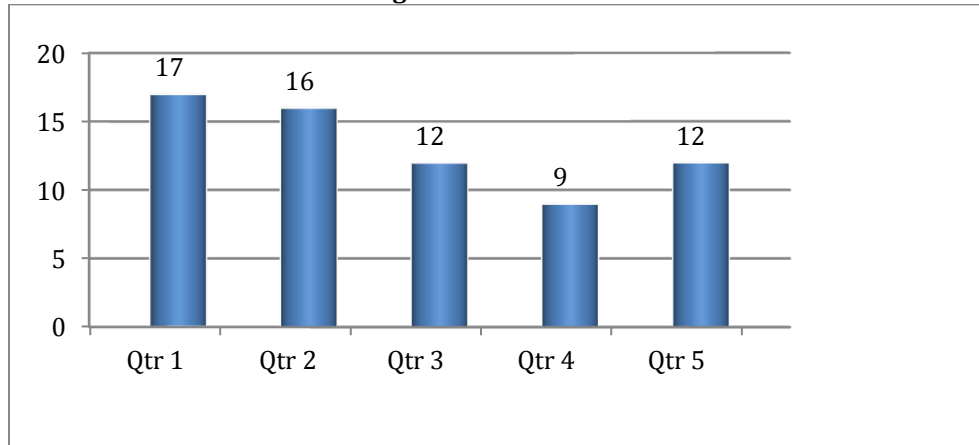


Figure 2: Client Age Distribution

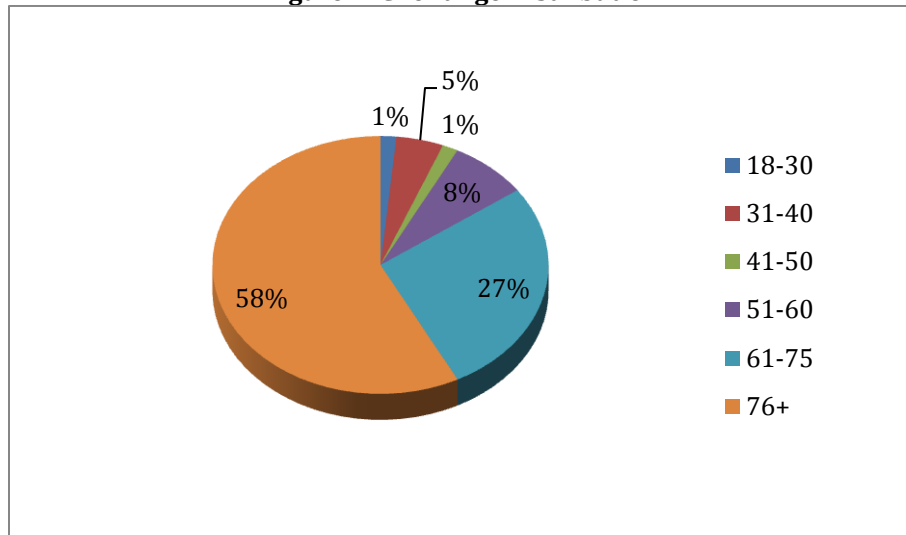
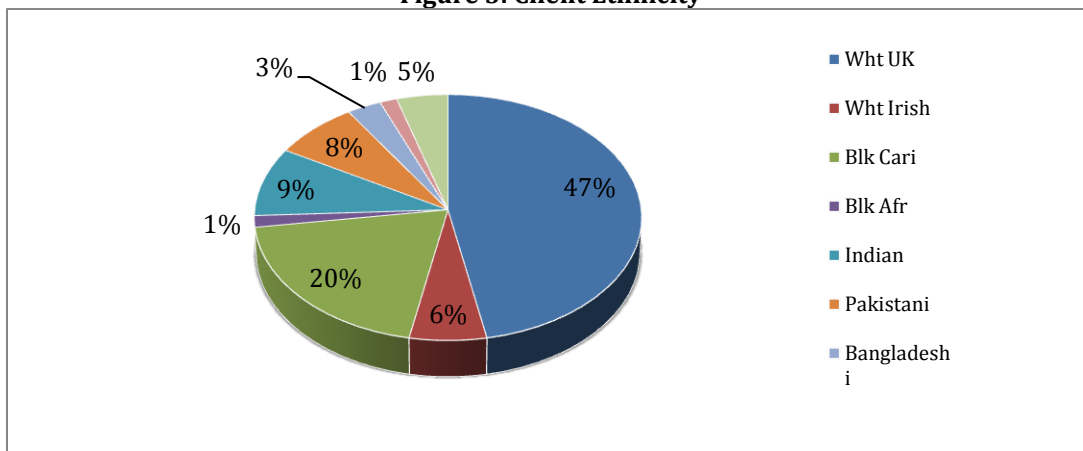


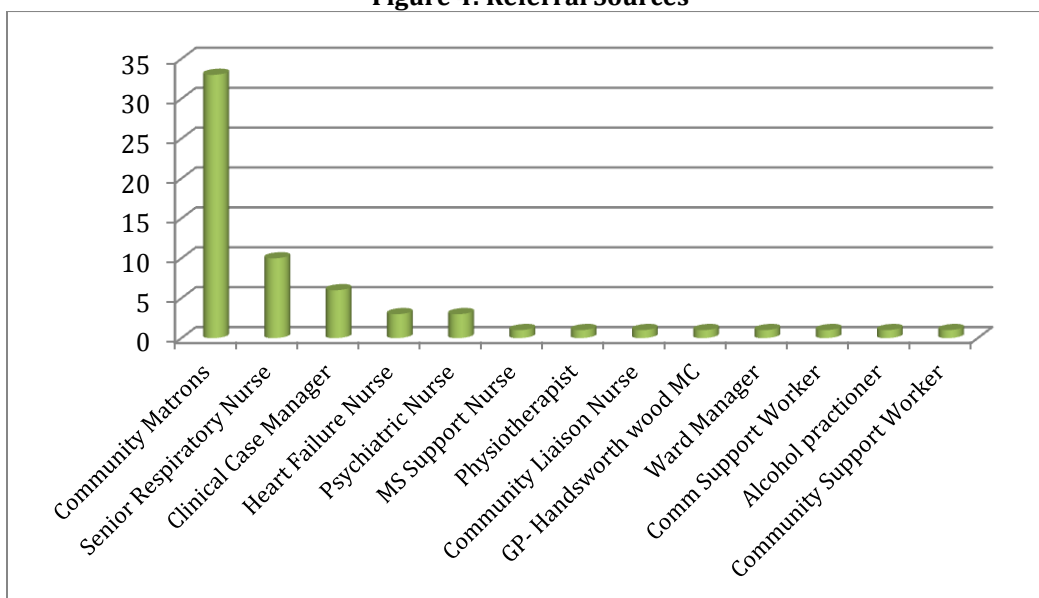
Figure 3: Client Ethnicity



Referrers

Due to slow rate of referrals midway (Jan 2012) through the project the referrers were expanded to include other community healthcare professionals. Previously it was limited to only community matrons and district nurses. This made a considerable difference to the referrals and enabled the project to reach its targets much more quickly. Around 57% of referrals are from community matrons, 15% from the respiratory nurse, 9% from clinical case managers, 4% from the heart failure nurse and the rest from other specialist community and hospital nurses, GP and voluntary organisations.

Figure 4: Referral Sources



Service Activity

A range of direct client activities were delivered; assessments, therapies, teaching sessions, telemonitoring and signposting/referrals. A total of 684 activity events (data for June 2012 not yet available) have been delivered. Around 45% of sessions have been direct therapeutic and self-help teaching sessions, 31% are telemonitoring sessions, 15% are assessments and case discussions and 8.5% are referrals to other Freshwinds and external support services. We estimate that we are on target to deliver the final activity numbers (750) when all the clients complete the programme.

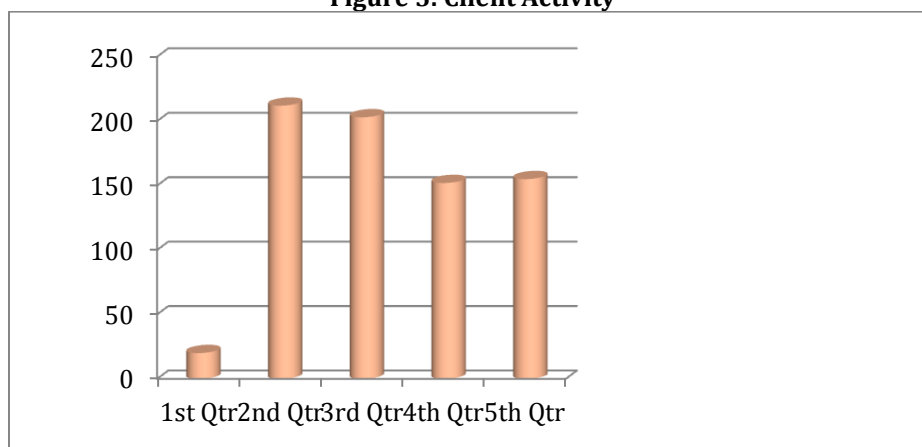
Information and education includes leaflets on, diabetes, cancer support, carer support, age concern and others have been provided. A range of signposting/referrals were made to Freshwinds internal and external agencies. There included support for carers, social isolation, befriending, contacting primary or community health professional for further support, reduce

the risk of falls, financial grants for medical/support equipment, housing issues, benefits advice, winter fuel benefits, meals on wheels and support group.

Table 1: Signposting/referral agencies

CERS+ (emergency carer support)	9
B-sage (older adult support)	6
Falls Prevention	9
FInDA (Advice & Information)	10
Focus Birmingham	1
GP	4
Health Exchange	4
Support Groups	3
Specialist Nurse/Physio/other Allied Health Professionals	7
Stay Warm, Stay Well	2
Other	3
	58

Figure 5: Client Activity



Self-Help Kits

A useful aid for the programme is 'Self-help Kits' which include a range of information resources and tools designed to help clients to learn and implement appropriate self-help skills.

- Self-Management Booklet (NHS Kirklees PCT)
- Pain management Booklet (NHS Kirklees PCT)
- A range of 30 'Self-Help Sheets' which have been developed to assist in teaching self-help techniques.
- Relaxation CD
- Essential oils inhalation sticks

- Mini fans (for anxiety and breathing difficulty)
- Stress Balls
- Windmills (for breathing techniques)
- Acupressure tool

Winter Health Checks

In December -January 2012 we undertook a “Winter Health Check” on all of our clients to ensure that they had adequate support and information on looking after themselves during the cold months. The aim of this was to prevent EHA due to winter causes resulting from colds, coughs, flu, falls, norovirus, hypothermia, seasonal affective disorder and dehydration. In addition the importance to stay active and check smoke alarms was also reinforced. Relevant fact sheets were also made available, such as;

- | | |
|---|-------------------------------|
| • Winter health risks | • Exercising in the winter |
| • Five ways to stay healthy this winter | • Running in the cold |
| • Flu and flu vaccine | • Avoiding winter weight gain |
| • Preventing cold and flu | • Staying warm in winter |
| • 10 myths about flu | • Very cold weather |
| • How to deal with colds and flu | • Keep warm, Keep well |
| • Five ways to stay healthy this winter | • Asthma in the cold |
| • Falls prevention | • Norovirus |
| • How to recognise the Winter Blues | • Carbon monoxide poisoning |
| • Falls Prevention | • Other |



Data Analysis of Emergency Hospital Admissions

For the purposes of reliability EHA data for 38 clients has been collated and the following clients were excluded.

- Clients who declined the service (9)
- Those who died less than 3 months of receiving the service (5)
- Those who are on the service for less than 3 months (15)
- Discharged from the service due to it being inappropriate (1)

Data Collection

Client EHAs for the previous one year is provided by referrers through the referral forms. During the service provision the incidences of EHA is monitored by the team. This data is then re-confirmed with the client during the assessment as well as with any available official documentation. Where an EHA was identified the relevant dates for admission and discharge was recorded and where possible confirmed through hospital discharge papers.

Results

All 38 clients were registered between June 2011 to March 2012. The average age is 72 yrs (range: 27 -87), 29 females and 9 males. 14 (37%) were White British, 9 (24%) Black Caribbean, 4 (11%) Indian, 3 (8%) Pakistani, 3 (8%) White Irish, 1 (3%) Bangladeshi, 1 (3%) Somali, 1 (3%) Mixed and 1 (3%) White European. Primary diagnoses included; COPD (11), heart failure (5), cancer (3), Pulmonary fibrosis/hypertension (3), mental health (2), diabetes (2), and others (alcohol dependency, arthritis, MS, ulcerative colitis and macular degeneration/falls). A total of 127 EHAs (including 8 falls) were recorded from the previous year (range: 1-12). Whilst on the project up to the 30th June a total of 32 EHAs (including 2 falls) (range: 0-5 days/EHA) were recorded, which was a total of 137 hospital days. The most number of EHA were recorded in the period of Oct-Dec 11. Overall there is a positive improvement in the incidence of EHA for 35 (92%) of clients.

Table 2 Number of EHA (n=38)

	EHAs in the Previous Yr	EHA while on the Project
Number of EHA (including falls)	127	32
Avg. no. of EHA (including falls) per client	3.34	0.84

Figure 6a: Number of EHA

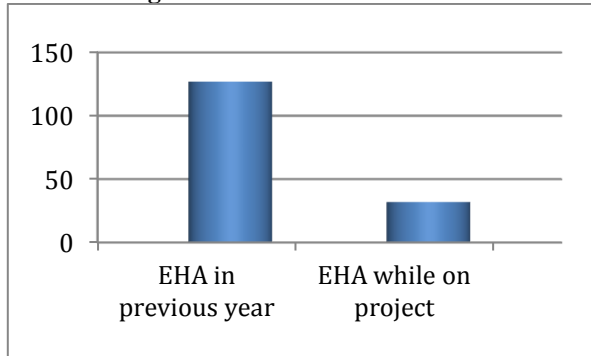


Figure 6b: Average number of EHA per client

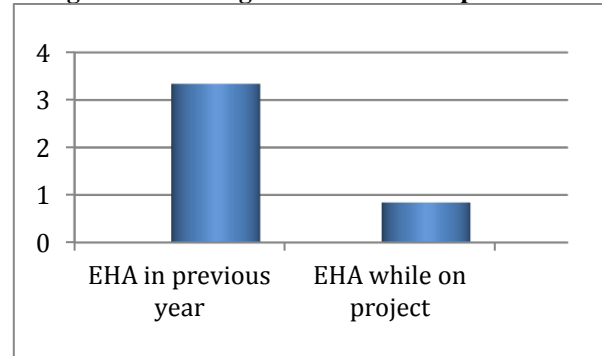
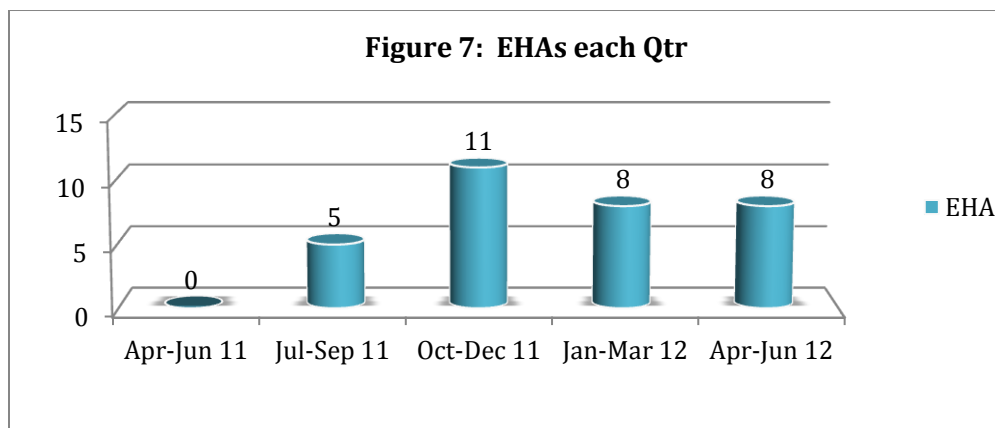


Figure 7: EHAs each Qtr



N= 38 (30 excluded)

Table 3: Individual Client Incidences of all EHA (including falls) (n=38)

Client No.	Length of Service (mths)	EHA: Pre-Project	EHA: During Project	Reduction in EHA (Pre-Post)
1	12	10	3	7
2	12	1	4	-3
3	11	4	0	4
4	11	7	0	7
5	11	3	1	2
6	11	3	0	3
7	11	3	0	3
8	11	1	0	1
9	11	3	1	2
10	11	2	0	2
11	11	12	1	11
12	11	3	0	3
13	11	4	0	4
14	10	1	1	0
15	10	6	3	3
16	10	8	2	6
17	10	3	1	2
18	10	1	1	0
19	9	3	1	2
20	9	1	3	-2
21	8	2	5	-3
22	8	1	0	1
23	7	3	0	3
24	7	3	1	2
25	7	3	0	3
26	7	2	3	-1
27	7	7	0	7
28	7	1	0	1
29	6	1	0	1
30	5	2	0	2
31	5	2	0	2
32	5	2	1	1
33	5	2	0	2
34	5	1	0	1
35	4	10	0	10
36	3	3	0	3
37	3	2	0	2
38	3	1	0	1
Total		127	32	95

Clients who have received minimum 6 months service delivery

In order to account for clients in varying stages of service delivery the table below shows EHA data according to the length of service provision. **A total of 29 clients have received a minimum of 6 months service since the first assessment.** All clients accounted for a total of 102 EHAs in the last 1 year. Whilst on the project 31 EHAs have been recorded for 15 (52%) clients. Average length of hospital stay is 8 days¹, and average age is 66 yrs. There is an overall reduction of 71 EHAs. Overall risk of an EHA has been reduced by 2.4 (69%) See table 4, 5.

Table 4: Analysis of Clients who have received minimum 6 months service

Length of time on Service	12mth	11mth	10mth	9mth	8mth	7mth	6 mth	Total
No. of Clients	2	11	5	2	2	6	1	29
Total No. of EHA Pre Freshwinds (X)	11	45	19	4	3	19	1	102
Total No. of EHA Post Freshwinds (Y)	7	3	8	4	5	4	0	31
Difference in no. EHA (X-Y)	4	42	11	0	-2	15	1	71
% Improvement in EHA	36%	93%	58%	0%	-66%	80%	100%	

N= 29

Table 5: EHA Risk Reduction clients who have received minimum of 6 months service

Length of time on Service	12mth	11mth	10mth	9mth	8mth	7mth	6 mth	Average
Risk of EHA Pre Freshwinds [No of EHA-Pre/no of clients]	5.5	4.1	3.8	2	1.5	3.2	1	3.5
Risk of EHA while on service [No of EHA-Post/no of clients]	3.5	0.3	1.6	2	2.5	0.7	0	1.1
Risk Reduction	2.0	3.8	2.2	0	-1.0	2.5	1	2.4 (69%)

N = 29

Details of individual EHAs indicates that a total of 124 hospital bed days were utilised and the most common reason is breathless and coughing, followed by pain and chest or urinary infections. 3 EHA occurred between 3-15 days of the initial assessment. There was no specific pattern to EHA occurrence although most EHA took place between 60-90 days and 180+ days (9). Further details are in Table 6.

Table 6a: Reasons for EHA

Reason for EHA	
Breathlessness, coughing	12
Pain (abdominal, eye, chest)	8
Chest or urinary Infection	7
Fall	2
Collapsed/Passed out	3
Other	1

¹ Average length of EHA is 12 days (Kings Fund analysis of hospital episode statistics 2009/10).

Table 6b: Individual EHA Admission details (clients with minimum 6 mths service)

EHA No.	Client no.	Bed Days	Reason for Admission
1	1	1	Swelling in his legs, breathlessness. Spent the time in the acute assessment unit. GP unable to give emergency appointment in time.
2		1	Severe chest pain.
3		12	Breathlessness, swelling of legs.
4	2	1	Severe hypertension
5		0	Severe abdominal pain - kidney infection. Given antibiotics and sent home.
6		1	Went to A&E chest light, thinks she has urine infection. Kept overnight they said no infections and sent home.
7		0	Severe abdominal pain. Diagnosed with severe constipation and sent home.
8	3	3	Client "collapsed" at home. Taken in to City Hospital and newly diagnosed with diabetes. (Collapse = fell because legs gave way)
9	4	3	Very breathless breathing very difficult. Investigations didn't show anything specific - query fluid on lungs?
10	5	13	Chest infection
11	6	14	Urinary tract infection
12	7	1	Exacerbation of COPD - kept in overnight for observation - let out the next afternoon.
13		4	Exacerbation of COPD
14		10	Heart failure& Pneumonia
15	8	1	Developed breathlessness, pain and panic - went to hospital (did not ring community matron) - admitted overnight to ward - diagnosed chest infection.
16		1	Developed breathlessness, pain and panic - went to hospital (did not ring community matron) - admitted overnight to ward - diagnosed chest infection.
17	9	10	Chest Infection
18	10	0	Pain in eye - - so went as an emergency to have it investigated at eye hospital
19	11	2	Atrial fibrillation passed out in hospital car on way to routine check up.
20	12	4	Breathing difficulties
21		11	3 hour coughing fit following discharge from Norman power centre with insufficient medicine
22		17	Had a black out caused him to fall and sustained a hip Fracture.
23	13	0	Bad pain in chest & abdomen Tracey given ECG which was clear and discharged the same day.
24		0	Pain in chest, lower back and abdomen. Again had ECG – no change. Discharged same day
25		0	Still experiencing pain following her fall on 7/12. A & E visit again where she was prescribed Ibuprofen for the pain.

26		0	Still experiencing pain in head (across forehead, temples and occipital area) following fall in early December. CT scan found no problem discharged same day.
27		0	Experiencing chest/abdominal pain went to A & E She was given 2x ECG which did not show any problems and she was discharged the same day.
28	14	9	fall at first then UTI
29	15	0	Called ambulance because client was coughing and having difficulty breathing. Diagnosed with chest infection and given antibiotics.
30		4	Chest infection whilst in hospital suffered an angina attack
31		1	Short of breath & sweating
Total		124	



Client Questionnaires Data Analysis

A series of questionnaires have been used for clients as well as their carers. These include;

1. MYMOP (Measure your own outcomes)
2. MHLoC (Multidimensional health Locus of control)
3. AC-QoL (Adult Carer Quality of Life Questionnaire)

The following data tables for EHA clients (including follow-up data where applicable) Accurate as of 02/07/2012.

Table 8. Overall statistics on outcome measure completions to date

	MYMOP	ACQoL	MHLC
Baseline	45	15	36
Follow-up*	14	2	9

Table notes: not all returned outcome measures were completed in full or to necessary validation level (see tables below for further information). Baseline data missing for client 7228, 7341, 7344, 7653, completed "retrospectively" for 7521 so not included in analysis.

**Average (mean) follow-up period = 6.5 months*

1. MYMOP Questionnaire

The MYMOP is a validated well-being questionnaire. The questionnaire asks clients to list the types of symptoms they would like help with. The range of symptoms include, pain, shortness of breath, breathing, heavy legs, fatigue and weakness in legs. Activities include, walking, exertion to answer the phone and speak and reading. Individual baseline and follow up scores are listed in table 7. As this is a seven point score a clinically important minimal change score is between 0.5-1.0. This means that any change below 0.5 is not of any importance to the patient and any change above 1 is significant (appendix 2).

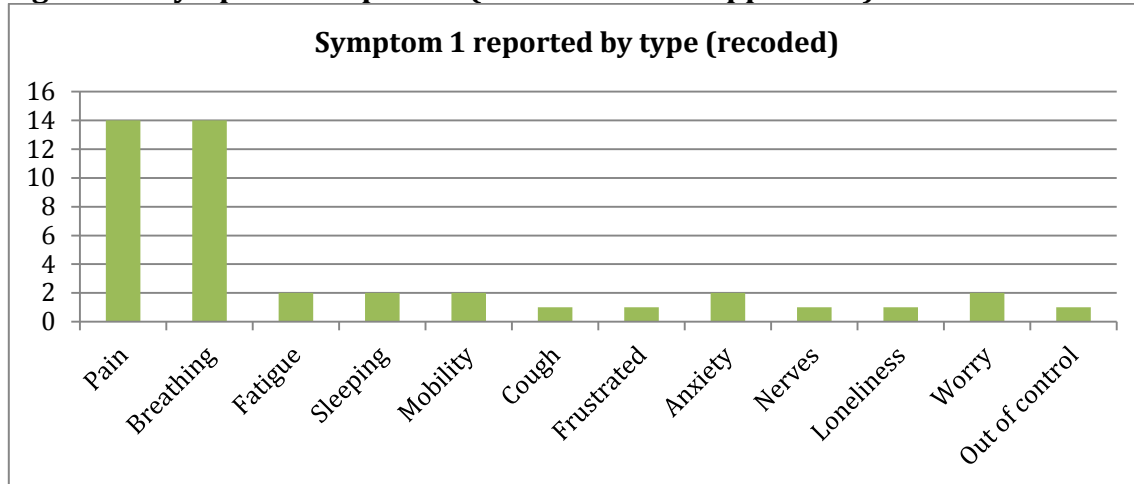
Data indicates that clients have experienced good symptom benefit as well as to their activity level and need for medication. The most common symptom was of pain and breathing difficulties. Majority of clients have had their symptoms for more than 5 years (37%), while 35% have had it between 1-5 yrs. Overall change in MYMOP score is 1.10 which is clinically significant.

Table 9a. Baseline data for MYMOP questionnaire

	Symptom 1 <i>n = 42</i>	Symptom 2 <i>n = 25</i>	Activity <i>n = 38</i>	Wellbeing <i>n = 43</i>	MYMOP profile <i>n = 41</i>
Mean	4.60	5.16	4.95	4.26	4.57
SD	1.45	1.14	1.33	1.48	1.14

Table notes: MYMOP profiles calculated for respondents completing at least Symptom 1 data and Wellbeing data (Profile invalid without these scores)

Figure 7a. Symptom 1 reported (recoded where applicable)

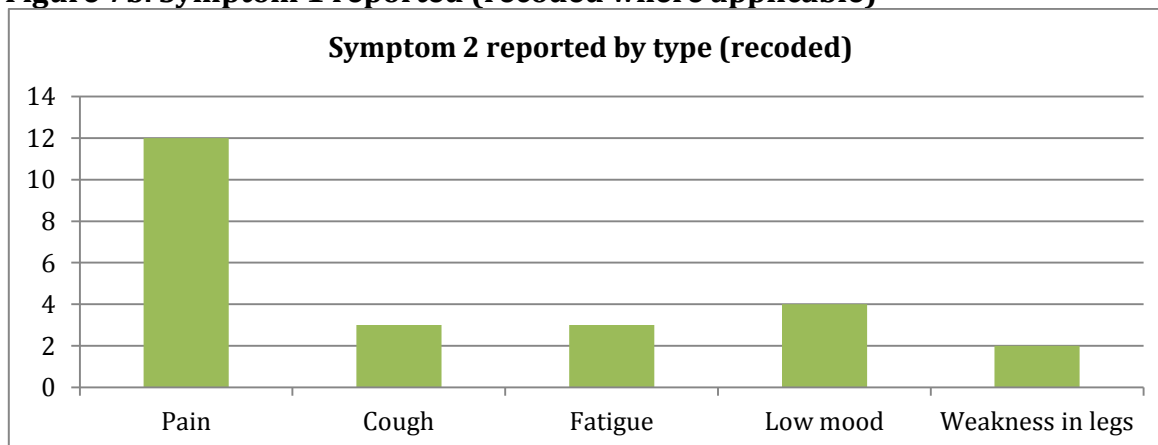


N = 43 (Missing data = 2)

Table 9b. Length of time with symptom 1

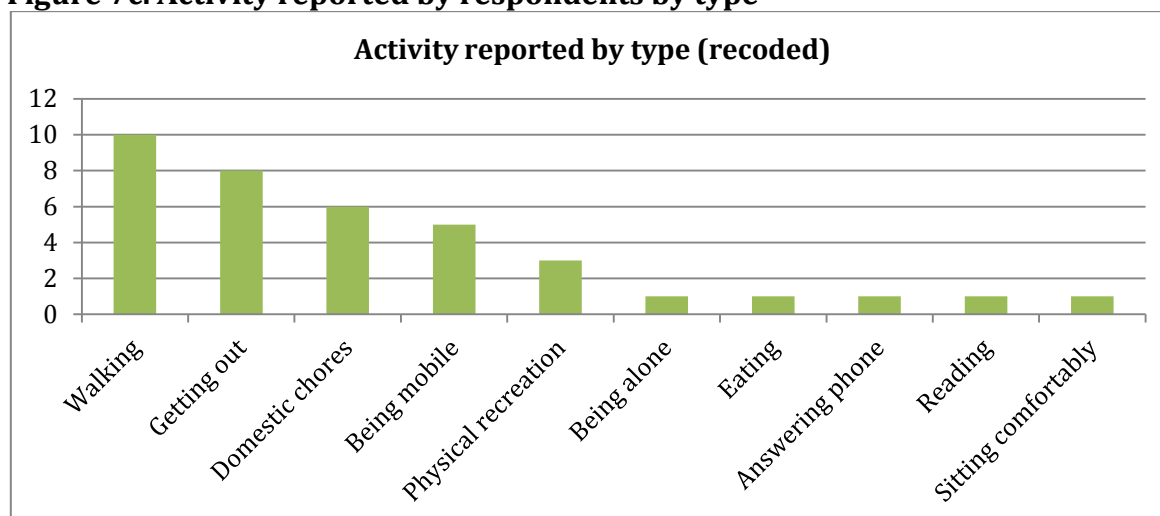
Length of time with Symptom 1	n	%
0-4 weeks	0	0.0%
4-12 weeks	1	2.3%
3 months to 1 year	7	16.3%
1 - 5 years	15	34.9%
Over 5 years	16	37.2%
Missing data	6	9.3%
Total	43	100.0%

Figure 7b. Symptom 1 reported (recoded where applicable)



N = 24 (21 of total sample did not provide data for a second symptom)

Figure 7c. Activity reported by respondents by type



N = 37 (8 did not provide data)

Table 9c. Data for respondents completing Baseline and Follow-Up MYMOP

MYMOP SCORE	Baseline	Follow up	Change in score*	95% Confidence Interval**	
	Mean (SD)	Mean (SD)	Mean (SD)	Low	High
Symptom 1 (n=14)	5.43 (1.16)	4.43 (1.22)	1.00 (1.41)	0.18	1.82
Symptom 2 (n=10)	5.50 (0.85)	3.70 (2.00)	1.80 (2.04)	0.34	3.26
Activity (n=12)	5.25 (1.06)	4.33 (1.07)	0.92 (1.16)	0.18	1.66
Wellbeing (n=15)	4.67 (1.68)	3.80 (1.93)	0.87 (1.46)	0.06	1.67
MYMOP profile (n=14)	5.09 (0.92)	3.98 (1.11)	1.10 (1.19)	0.42	1.79

Table notes: Positive 'change in scores' figures indicate reduction in score from baseline to follow-up

*MYMOP guidance notes suggest change in score is likely to be clinically significant if between 0.5-1.0

<http://sites.pcmd.ac.uk/mymop/index.php?c=faqs>

**Caution should be taken with results given small sample size

Table 9d. Taking medication for this problem

	Yes		No		Data missing	
	n	%	n	%	n	%
Are you taking medication for this problem?	28	62.2	14	31.1	3	6.7

Table 9e. Additional information provided by respondents

	Additional Comments
1	<i>Legs feel good for a day or two. Techniques have really not had an influence on positive thinking. Enjoy time with therapist.</i>
2	<i>I feel better after the 'Pressing' (Bowen Technique) and would like this more often.</i>
3	<i>A little calmer than before, does not get as angry when his wife forgets things.</i>
4	<i>Makes a difference to breathing for 1 or 2 days. Body pains - again feels less achy for a day or two.</i>
5	<i>Service helps in showing me ways of being able to cope with pain.</i>
6	<i>My symptoms are worse at night. Its very hard to walk even short distances, the pain and my breathing are very bad following my massage I feel better for a couple of days, I also feel sleepy. Please could I have more regular treatments? Waiting two months between them is too long.</i>
7	<i>I feel tired all the time following my breakfast and being dressed by the carer I am ready to go back to bed for a few hours. My breathing is bad all the time. This may be due to the smoking (20 cigarettes/day) but I am unable to stop but I will keep trying. I feel the massage isn't helping very much it just helps me stay the same. My right leg keeps swelling up also.</i>
8	<i>(Client) enjoys her treatments.</i>
9	<i>Enjoys the visits and chats feels that she will always be a little nervous as this is her personality. Quite liked both the massage and the relaxation but has to be in the mood for them both, which sometimes she is sometimes not. When she is not in the mood she is anxious to please and tries to go with the flow, sometimes results better than others.</i>
10	<i>Feels she is breathing easier not so stressed and better quality of life. Can take a little weight on legs now, could not take any before.</i>
11	<i>I find the Bowen Therapy very helpful</i>

2. Adult Carers Quality of Life (ACQoL) Data

This is a questionnaire to measure the carers quality of life. It considers various aspects of the carers well being, ranging from their ability to care, personal growth and development, level of satisfaction, financial, stress and choices. At present there are insufficient questionnaires that have been returned to be able to do an analysis.

Table 10. Baseline scores for Adult Carers Quality of Life Questionnaire

	Support for caring	Caring choice	Caring stress	Money matters	Personal growth	Sense of value	Ability to care	Carer satisfaction	Total QoL
	<i>n = 14</i>	<i>n = 14</i>	<i>n = 13</i>	<i>n = 13</i>	<i>n = 13</i>	<i>n = 14</i>	<i>n = 15</i>	<i>n = 14</i>	<i>n = 14</i>
Mean	8.43	9.57	10.85	8.31	9.62	12.07	11.47	12.5	82.5
SD	3.34	3.84	4	5.47	3.93	3.95	2.97	2.31	19.08
No. of Low QoL scores*	5	1	2	4	3	2	0	0	0**

Table notes: Please note that at present only 2 questionnaires have been completed for follow-up, so data cannot be tracked over time accurately.

* Score ranges for subscales (Low QoL = 0-5; Mid QoL = 6-10; High QoL = 11+)

** Total score ranges (0-40 = Low QoL; 41-80 = Mid QoL; High QoL = 81+)

3. Multidimensional Health Locus of Control (MHLC) (Form B)

The measure requires that respondents provide responses to statements regarding health outcomes on a Likert scale between 1 (Slightly disagree) and 6 (Strongly agree). The Multidimensional scale has three subscales: internal, chance, and powerful others where specific statements relate to one of these subscales. Scores for subscales are dependent upon where the individual perceives the control of their health to be, is their health due to their own internal powers, a result of chance, or in the hands of powerful others (i.e. GPs and other health professionals). Each subscale total will range between 6 and 36, where high scores indicate high levels of control attributed to the specific subscale component (internal, chance, powerful other). There is no total MHLC score; all subscales are independent of one another. (Appendix 3).

The MHLC data would seem to show that there is no much difference in the internal locus of control (LOC). In some cases it would seem to be lower. This may be due to the self-selective nature of self-management programmes where individuals who already believe that they are responsible for their own health are more likely to be willing to take part in the programme. This may also be a reason why the rate of clients declining service in the first instance as well as early drop outs is high within this project.

Table 11a. Baseline and follow data for Internal Health Locus of Control (IHLC)

Time data recorded		Internal Health Locus of Control (IHLC) subscale						IHLC Score
		If sick, I have power to make well	I am responsible for health	Whatever goes wrong with my health is my fault	My physical well being depends on taking care of myself	When I am ill, it is due to not taking care of myself	I can stay health by taking care of self	
Baseline (n = 36)	Mean	3.9	4.4	3.3	4.9	3.5	4.4	24.4
	SD	2.1	1.6	1.9	1.4	1.9	1.7	
Follow-up (n = 9)	Mean	4.7	4.2	1.6*	4.4	3.1*	4.1	22.2
	SD	1.7	2.1	1.2	1.8	2.0	2.1	

Table notes: High score indicates high level of internal control affects health outcomes

*Indicates 1 missing value

Table 11b. Baseline and follow data for Chance Health Locus of Control (CHLC)

Time data recorded		Chance Health Locus of Control (CHLC) subscale						CHLC Score
		No matter what I do, I will get sick	Health is influence by accidents	When I am sick I let nature run its course	When I stay healthy I am just lucky	Even when I take care of self I still get sick	When I become ill, its due to fate	
Baseline (n = 36)	Mean	4.3	3.3*	4.2	3.9*	5.3*	4.4*	25.4
	SD	2.0	2.0	1.9	1.9	1.0	1.9	
Follow-up (n = 9)	Mean	4.4	3.4	4.0	4.0*	5.0	3.0	23.9
	SD	2.2	2.2	2.1	2.3	1.5	2.0	

Table notes: High scores indicates high level of chance affects health outcomes

*Indicates 1 missing value

Table 11c. Baseline and follow data for Professional Others Health Locus of Control (PHLC)

Time data recorded		Powerful Others Health Locus of Control (PHLC) subscale						PHLC Score
		See an excellent Doctor will mean less likely to get sick	Maintain health only via HPs	Other people play a big part	HPs keep me healthy	Care I receive from others dictates recovery	Following Doctor's orders will maintain health	
Baseline (n = 36)	Mean	4.4*	3.9	4.6	4.6*	5.0	4.4	26.8
	SD	1.7	1.9	1.7	1.7	1.5	1.8	
Follow-up (n = 9)	Mean	3.7	4.0	4.6*	5.1	5.4	4.4	27.3
	SD	2.2	2.3	2.1	1.7	1.0	1.8	

Table notes: High scores indicate high level of influence from Powerful Others affects health outcomes

*Indicates 1 missing value



Economic Cost Analysis (minimum 6 months service)

On average the cost of one hospital admission has been estimated to be around £2,200-2,500, while the average length of stay per emergency admission is 7.8 days. Literature indicates that for any given episode of care, hospital costs typically decline with length of stay, the highest daily costs is incurred in the early admission period with a gradual reduction towards recovery and discharge. The **national average estimate per bed-day is £255** for the cost of an “excess” bed-day in 2009-10 as used in payment by results (Department of Health, 2011a), which have been adjusted by according to local variations applicable to Sandwell and Birmingham Hospital NHS Trusts (0.9591) relative to the national average (Department of Health, 2011b).

Economic evaluation of whether the project intervention is having an impact on the reduction of EHA and having a cost-benefit is an important outcome. Analysis of the data estimates a cost saving of £103,367 for 29 clients. *It is important to mention that Freshwinds understands that extrapolation of the outcomes from a small sample that may not be representative of the population group and must not be considered to be an absolute result, but can only act as data that contributes to guiding decisions made on the continuation of the project.*

For this purpose the following financial information have been used;

- Average cost of medical emergency medical admission £1,690 (based on short stay £730 no more than 1 night and longer stay £2,650, two nights or more)
- Freshwinds EHA outcomes data for 29 clients totalling 277 mths of service provision.
- Based on project costs of £40,000 p.a. for 50 clients.

Table 7: Cost-Benefit Analysis for clients who have received minimum 6 months service

	EHA	£ Cost per average EHA
Number of EHA 1 yr prior to referral	102	172,380
Number of EHA since referral	31	52,390
Number of EHAs saved	69	(A) 119,990
Cost of delivering a total of 277 mths (6-12mths) of service to 29 clients. $[\frac{40,000}{50 \times 12} \times 277]$		(B) 18,466
Total Financial Cost Savings (A-B)		£101,524

N= 29

Case Studies

Case Study Errol

A 82 year old African gentleman called Errol referred by the community matron in May 2011 to Freshwinds End of Life “Living Choices” project with chronic kidney failure, heart failure and benign prostatic hypertrophy. On assessment it was identified that the client was more suited and subsequently transferred to the EHA project in June 2012. There was a **history of more than 10 EHA** in the previous year usually due to exacerbation of breathlessness and ‘water retention’. Errol does not speak any English and depended on his niece (and carer) to translate for him. Freshwinds alleviated the language barrier by allocating coordination of his care with an Arabic speaking medical staff member to overcome it. From the start the client and his carers were very willing to learn self-help skills. Initially, the client was advised to have homeopathy and bowen technique which helped to reduce his complaints of joint pains. Due to concerns about the amount of oral medications that the client was already taking the carers requested changing homeopathy. Therefore massage was introduced instead. The client’s niece was taught simple massage techniques and she was happy to use it between therapy sessions. Reported benefits of the massage include improved sleep, relaxation. A referral was made to Freshwinds FInDA (advice and advocacy) project for advice on housing issues and possible relocation to a more suitable property which does not require the use of stairs or lifts.

Note: There has been a delay in the delivery of the EHA programme schedule due to prostate surgery. Planned to end in August 2012.

Monitoring: MYMOP questionnaires indicates baseline symptoms as 1) pain and 2) fatigue, walking and well-being was also a problem. Follow-up questionnaires at 6 and 9 mths indicates successive improvements in pain and fatigue, with new symptom of urinary urgency at 6 mths.

EHA: A total of 3 EHA have occurred up to the 31st June 2012 (12 mths).

- The first admission (April 2012) occurred when the GP was unable to offer an emergency appointment when contacted at 10 am for excessive swelling of the feet. After waiting until 4 pm for a call from the GP the carer decided to take the client to A & E. He underwent routine investigations and was kept overnight.
- Second admission (May 2012) for chest pain and breathlessness. Discharged next day. *By this time the client had undergone a prostatectomy and was on warfarin and experiencing urinary incontinence.*
- Third admission (June 2012) due to severe chest pains. Stayed in acute assessment ward and discharged next day.

Case Study Samina

A 38 year old Pakistani lady diagnosed with fibromyalgia and arthritis since 2003 referred in June 2011. **In the past year she has had 6 EHA due to breathlessness and chest pain.** Client was started on a care plan of aromatherapy with some benefit to her low mood, which was added to with EFT relaxation techniques and visualization. It was observed that the Client was struggling considerably with low moods, generalised body and arthritic pains and urinary incontinence. For a short period hypnotherapy was also offered but eventually reverted back to massage as the client felt that even though the effect was short lived she benefited from it. She was also given an ‘Aromastick’ for her to use in the home during her low moods/pain. In order to reduce the social

isolation the client was encouraged to get out of the house, and a Support group and Art therapy centre were identified for her to access and referrals were made to the relevant organisations.

Monitoring: MYMOP questionnaires indicate baseline symptoms as 1) pain and 2) fatigue, and well-being at their worst. Mobility was also a considerable problem. Follow-up questionnaires at 6 months indicate 2-point improvement in pain and fatigue, and 1-point for well-being and mobility. There was a new symptom of back rash at 6 months.

EHA: Since starting on the project (12 months) there has been no EHA.

Case Study David

A 62 year old gentleman diagnosed with COPD, bronchiectasis, gallstones and depression referred in July 2011. He easily becomes breathless even while talking, and complains of poor sleep and upper abdominal pain from the gallstones, which is not adequately controlled by pain killers. **In the past year he has had 8 hospital admissions due to pain and panic attacks.** He is unable to explain the reason for his panic attacks. If he is on his own he is afraid to have a shower as he is frightened of having a panic attack. His wife is at work most of the week.

David was offered a self-help kit and taught to use the windmill breathing technique and stress ball to help bring rhythm into his breathing and reduce stress. He was also shown how to do colour breathing and EFT to improve sleep, control his pain and panic attacks. He was also given a relaxation CD. Throughout the period the breathing techniques were reinforced, and supported by Homeopathy and Bowen technique. By week 12 Client B found that the Bowen emergency asthma move helpful, gall bladder was not as painful and the consultant was pleased with his progress. A winter health check was completed in Dec 2011.

Monitoring: MYMOP questionnaires indicate baseline symptoms as 1) breathing and 2) pain, breathing activity and well-being were all at its worst. Follow-up questionnaire at 6 months indicates 3-point improvement in breathing (both as symptom and activity), 6-point improvement in pain and 4-point improvement in well-being. Changes made includes, starting of exercise which client says he would not have been able to do without the help of the treatments. Comments: *"Feel like a new man since having treatments"*.

EHA: A total of 4 EHA have occurred up to the 31st June 2012 (12 months).

- First admission (Nov 2011) occurred due to pain, breathing and panic. 2 days.
- Second admission (Nov 2011) due to pain, breathing and panic. 2 days.
 - *Break in treatments Dec-Feb due to difficulty contacting client to arrange appointments. Treatments resumed 28th Feb 2012.*
- Third admission (Jan 2012) for chest pain and breathlessness. 5 days.
- Fourth admission (Feb 2012) for chest pain and fever

Discussion & Recommendations

Results for the first year of the project are extremely encouraging. There is a definite reduction in the incidence and risk of EHAs (69%) with an EHA economic cost benefit of £98,144 (excluding qualitative cost benefits). There have been a number of challenges in delivering the project. These are related to the time scales of the project, referrals and personal and health changes for clients that pose either as a barrier or delay which prevents delivery according to the schedule of the care plan. For the purposes of future review the changing circumstances of clients and their ability to commit requires us to consider a shorter 6 mths intervention period, with the option to extend it to 12 months. This will offer flexibility to tailor the programme according to need. We anticipate that the final completion of the project will not be until June 2013 for all clients on the project, but this initial data for EHA is based on a small group of 29 clients but should be considered for its value in outcomes which are significant. We believe that the success of this pilot will continue to be demonstrated for the remainder period of the pilot and thus the impact of the project being expanded across Birmingham is considerable with the potential to hugely influence Birmingham's EHA rates.

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Appendix 1: Datasheet

1st Qtr 01-Apr-11 30-Jun-11	2nd Qtr 01-Jul-11 30-Sep-11	3rd Qtr 01-Oct-11 31-Dec-11	4th Qtr 01-Jan-12 31-Mar-12	5th Qtr 01-Apr-12 30-Jun-12	TOTAL
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Provisional Data

NO. OF CLIENTS SEEN
CLIENTS DISCHARGED
CLIENTS DIED
NEW BENEFICIARIES

7	31	37	48	38	57
1	3	1	4	2	11
		2	2	3	7
17	16	12	9	14	68

AGE (yrs)

18 -30
31- 40
41-50
51-60
61 -75
76+

						%
	1				1	1.5%
	1	1	1		3	4.4%
				1	1	1.5%
	2	2		1	5	7.4%
	2	6	5	1	20	29.4%
	13	8	4	7	38	55.9%
Total	17	16	12	9	68	

CLIENT ETHNICITY

White British
White Irish
White Other
Black Caribbean
Black African
Indian
Pakistani
Bangladeshi
Asian
Mixed
Unknown

						%
5	8	7	5	7	32	47.1%
1	1		2		4	5.9%
1	0				1	1.5%
4	3	3		3	13	19.1%
	1				1	1.5%
1	2		2	1	6	8.8%
2	1	1		1	5	7.4%
1				1	2	2.9%
1					1	1.5%
1					1	1.5%
		1		1	2	2.9%

Total	17	16	12	9	14	68
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SEX

Male	2	8	1	1	5	12	17.6%
Female	15	8	11	8	9	42	61.8%
Total	17	16	12	9	14	68	

VARIOUS CLIENT CONDITIONS & Co-morbidities

						TOTAL	%
Heart Disease	6	6	1	2	3	15	14.6%
Diabetes	9	5	3	1	2	18	17.5%
COPD + Lung diseases	3	7	7	4	6	21	20.4%
Renal disease	1	3	2	1		7	6.8%
Stroke	4	1	1			6	5.8%
Asthma	2	1	1			4	3.9%
Arthritis + Osteo arthritis	3	2	1	2	1	8	7.8%
Cancer	2		1		1	3	2.9%
Parkinson's		2				2	1.9%
Depression		1	1	1	1	3	2.9%
Alcohol Dependency				1			0.0%
Falls					1	1	1.0%
	30	28	18	12	15	103	

CONTACT DETAILS

						TOTAL	%
Assessments	4	32	33	16	20	105	15.4%
Therapy & Teaching Sessions	5	95	85	64	60	309	45.2%
Telemonitoring Sessions	1	55	57	54	45	212	31.0%
Signposting/Referrals	5	15	14	9	15	58	8.5%
Total	15	197	189	143	140	684	

NUMBER OF EHAs (Clients on service from 1 - 12 mths)

Total no. of EHAs in last one year	63	54	34	21	25	197
Total no of Falls recorded in last one year	5	0	2	2	1	10

EHAs recorded in the period	0	7	10	7	9	33
Falls recorded in the period	0	0	1	1	0	2

REASONS FOR EHAs WHILE ON THE PROJECT

Chest infection	2	2	2	2	8	22.9%
Exacerbation of COPD	1	1			2	5.7%
Cardiac cause (Breathlessness/pain)	1	3	1		5	14.3%
Died in hospital	1				1	2.9%
Tight chest/Breathlessness and Pain	1	2	2		5	14.3%
Severe abdominal pain	1		2	3	6	17.1%
Fall or blacked out		1	1		2	5.7%
Pain		2		1	3	8.6%
Other				3	3	8.6%
	0	7	11	8	9	35

REFERRAL SOURCES

Aloma Reid	Psyhiatric Nurse					3	3	4.4%
Anne Tulley	Comm. Matron	1	4	1		2	8	11.8%
Christina Reihill	Snr. Resp Nurse			3	5	2	10	14.7%
Dawn Brookfield	MS Support Nurse					1	1	1.5%
Della Thomas	Physiotherapist					1	1	1.5%
Denise Fitzmaurice	Comm Liaison Nur					1	1	1.5%
Dr McKinnon	GP- Handsworth wood MC				1		1	1.5%
Eloise Phillips	Comm. Matron	4	1			1	6	8.8%

Freshwinds						0	0.0%
Jennifer Weston	Comm. Matron	1	1			2	2.9%
Justine Irish	Ward Manager			1		1	1.5%
Karen Twomey	Comm. Matron	1		1		2	2.9%
Kathryn Harris	Comm. Matron		1			1	1.5%
Lesley Mukwedeya	Clinical Case Manager	2	2	2		6	8.8%
Parminder Purewal	Heart Failure Nurse			1	1	3	4.4%
Pauline Arthurton-Jones	Comm. Matron	3	1			4	5.9%
Samantha Botterill	Comm Support Worker				1	1	1.5%
Samantha Sewell	Comm. Matron		1	3		4	5.9%
Shazana Khan	Comm. Matron		1		1	2	2.9%
Suzanne Powell	Alcohol practioner				1	1	1.5%
Vanessa Foxall	Comm. Matron		1			1	1.5%
Viki Williams	Comm. Matron	1	2			3	4.4%
Vikki Stacey	Comm. Matron	4	1		1	6	8.8%
		17	16	12	9	14	68

GP

2 The Slieve		1			1	1.5%
Apa Zohra Memorial Surgery	1				1	1.5%
Aston Pride Health Centre			1		1	1.5%
Birmingham Heartlands Surgery	1				1	1.5%
Bloomsbury Health Centre	4			2	6	8.8%
Broadway Health Centre		1		1	2	2.9%
Church Road Surgery				1	1	FALSE
Colston Health Centre	2				2	2.9%
Dr ASP Sinha, Handsworth			1		1	1.5%
Dr JK Bansal- Handsworth				2	2	2.9%
Enki Medical Practice	1				1	1.5%
Finch Road HC				1	1	1.5%
Five Ways Health Centre					0	0.0%

Great Barr Surgery		1	1			2	2.9%
Hamstead Road			1	1		2	2.9%
Handsworth Wood Medical Centre	1	1	1	2		5	7.4%
Hockley Medical Practice	1				1	2	2.9%
Holyhead Primary Health Centre	2					2	2.9%
Ladywood Surgery	1					1	1.5%
Laurie Pike Health Centre	1	2	1			4	5.9%
Moor Green Lane Medical Centre	1		1			2	2.9%
Newtown Health Centre			1	2	1	4	5.9%
Orsborn House		2		1		3	4.4%
Shanklin House Surgery	1	1				2	2.9%
Soho Road Primary Care Centre	2	1				3	4.4%
Sparkbrook MC					1	1	1.5%
Springfield Medical Practice		1				1	1.5%
St Clements Surgery	1		2			3	4.4%
St James Medical Centre		1			1	2	2.9%
Summerfield Primary Care Centre	1					1	1.5%
Tower Hill Medical Centre	1	1	3	1	3	9	13.2%
Total	17	16	12	9	14	68	

POST CODE OF CLIENT RESIDENCE	B1		1				1	1.5%
	B5	1					1	1.5%
	B6	1		1	1	1	4	5.9%
	B7		2			1	3	4.4%
	B10	1					1	1.5%
	B11		1			1	2	2.9%
	B13		1				1	1.5%
	B16	2		1		1	4	5.9%
	B17						0	0.0%
	B18	2			1	1	4	5.9%

B19		2		1	3	6	8.8%
B20	3	2	4	3	1	13	19.1%
B21	4	3	1	1	1	10	14.7%
B23			1			1	1.5%
B24	1					1	1.5%
B29	1					1	1.5%
B30			1			1	1.5%
B36		1			1	2	2.9%
B42	1	3	2		3	9	13.2%
B44			1	1		2	2.9%
B70				1		1	1.5%
Total	17	16	12	9	14	68	

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

Appendix 2: MYMOP Questionnaire

SECTION 2: MEASURE YOURSELF MEDICAL OUTCOME PROFILE

Choose one or two symptoms (physical or mental) which bother you the most. Write them on the lines.
Now consider how bad each symptom is, over the last week, and score it by circling your chosen number.

SYMPTOM 1:

	0	1	2	3	4	5	6
	As good as it could be					As bad as it could be	

SYMPTOM 2:

	0	1	2	3	4	5	6
	As good as it could be					As bad as it could be	

Now choose one activity (physical, social or mental) that is important to you, and that your problem makes difficult or prevents you doing. Score how bad it has been in the last week.

ACTIVITY:

	0	1	2	3	4	5	6
	As good as it could be					As bad as it could be	

Lastly how would you rate your general feeling of wellbeing during the last week?

	0	1	2	3	4	5	6
	As good as it could be					As bad as it could be	

How long have you had Symptom 1, either all the time or on and off? Please circle:

0 -4 weeks 4 – 12 weeks 3 months – 1 year 1 – 5 years over 5 years

Are you taking any medication *FOR THIS PROBLEM* ? Please circle: YES / NO

IF YES:

1. Please write in the name of medication, and how much a day/week

2. Is cutting down this medication: Please circle:

Not important a bit important very important not applicable

IF NO:

Is avoiding medication for this problem:

Not important a bit important very important not applicable

Thank you. You have now completed the questionnaire.
Please hand this back to your therapist or to a member of staff on reception.

Appendix 3: Adult Carer Quality of Life Questionnaire (AC-QoL)

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The Adult Carer Quality of Life Questionnaire (AC-QoL) How to Fill in the Questionnaire

This questionnaire asks you about different aspects of your life as a carer. Please think about your experience as a carer within the last two weeks and please tick the box that applies next to each statement. There are no right or wrong answers; we are just interested in what life is like for you as a carer. The questionnaire shouldn't take more than 10 minutes.

Please answer all questions as honestly as you can.

	Never	Some of the time	A lot of the time	Always
Support for Caring				
01. I have a good level of emotional support	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
02. My needs as a carer are considered by professionals	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
03. I am happy with the professional support that is provided to me	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
04. I feel able to get the help and information I need	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
05. I have all the practical support I need	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Caring Choice				
06. I feel that my life is on hold because of caring	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
07. My social life has suffered because of caring	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
08. I feel I have less choice about my future due to caring	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
09. I feel I have no control over my own life	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
10. Caring stops me doing what I want to do	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Caring Stress				
11. I feel depressed due to caring	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
12. I feel worn out as a result of caring	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
13. I am mentally exhausted by caring	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
14. I am physically exhausted by caring	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
15. I feel stressed as a result of caring	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>



Manual for the Adult Carer Quality of Life Questionnaire (AC-QoL)

o9

	Never	Some of the time	A lot of the time	Always
Money Matters				
16. I worry about going into debt	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
17. I feel satisfied with my financial situation	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
18. I am able to save for a rainy day	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
19. I worry about money	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
20. There is enough money in our house to pay for the things we need	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Personal Growth				
21. I have become a more tolerant person through my caring role	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
22. Because of caring, I have learnt a lot about myself	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
23. Because of caring, I feel that I have grown as a person	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
24. I have experienced many positive things through caring	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
25. I feel that I have become a better person by caring	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Sense of Value				
26. I feel valued by the person I am looking after	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
27. The person I look after respects me for what I do	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
28. The person I look after makes me feel good about myself	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
29. I get a lot from the person I am looking after	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
30. I have a good relationship with the person I am caring for	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Ability to Care				
31. I am satisfied with my performance as a carer	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
32. I can take care of the needs of the person I am caring for	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
33. I feel I am able to make the life of the person I am looking after better	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
34. I can manage most situations with the person I care for	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
35. I am able to deal with a difficult situation	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Carer Satisfaction				
36. Caring is important to me	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
37. I resent having to be a carer	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
38. I feel frustrated with the person I am caring for	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
39. I enjoy being a carer	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
40. I am satisfied with my life as a carer	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

1o

Demographic Questions

A Please give your age

B Please indicate your gender (please tick) ☐ Male ☐ Female

C Please indicate your ethnicity (please tick one box)

<input type="checkbox"/> White - British	<input type="checkbox"/> Asian/Asian British - Pakistani
<input type="checkbox"/> White - Irish	<input type="checkbox"/> Asian/Asian British - Bangladeshi
<input type="checkbox"/> White - any other	<input type="checkbox"/> Asian/Asian British - Any other Asian
<input type="checkbox"/> Mixed - White and Black Caribbean	<input type="checkbox"/> Black/Black British - Caribbean
<input type="checkbox"/> Mixed - White and Black African	<input type="checkbox"/> Black/Black British - African
<input type="checkbox"/> Mixed - White and Asian	<input type="checkbox"/> Black/Black British - Any other
<input type="checkbox"/> Mixed - Any other mixed background	<input type="checkbox"/> Chinese
<input type="checkbox"/> Asian/Asian British - Indian	<input type="checkbox"/> Any other ethnic background

D How many hours do you spend caring per week? (please tick)

<input type="checkbox"/> 0-10 hours	<input type="checkbox"/> 11-20 hours	<input type="checkbox"/> 21-30 hours	<input type="checkbox"/> 31-40 hours
<input type="checkbox"/> 41-50 hours	<input type="checkbox"/> 51-60 hours	<input type="checkbox"/> 61-70 hours	<input type="checkbox"/> Greater than 71 hours

E How long have you been a carer for?
..... years



Appendix 4: MHLC Questionnaire

Multidimensional Health Locus of Control (MHLC) Scales

Form B

Instructions: Each item below is a belief statement about your medical condition with which you may agree or disagree. Beside each statement is a scale which ranges from strongly disagree (1) to strongly agree (6). For each item we would like you to circle the number that represents the extent to which you agree or disagree with that statement. The more you agree with a statement, the higher will be the number you circle. The more you disagree with a statement, the lower will be the number you circle. Please make sure that you answer **EVERY ITEM** and that you circle **ONLY ONE** number per item. This is a measure of your personal beliefs; obviously, there are no right or wrong answers.

1=STRONGLY DISAGREE (SD)

2=MODERATELY DISAGREE (MD)

3=SLIGHTLY DISAGREE (D)

4=SLIGHTLY AGREE (A)

5=MODERATELY AGREE (MA)

6=STRONGLY AGREE (SA)

		SD	MD	D	A	MA	SA
1	If I become sick, I have the power to make myself well again.	1	2	3	4	5	6
2	Often I feel that no matter what I do, if I am going to get sick, I will get sick.	1	2	3	4	5	6
3	If I see an excellent doctor regularly, I am less likely to have health problems.	1	2	3	4	5	6
4	It seems that my health is greatly influenced by accidental happenings.	1	2	3	4	5	6
5	I can only maintain my health by consulting health professionals.	1	2	3	4	5	6
6	I am directly responsible for my health.	1	2	3	4	5	6
7	Other people play a big part in whether I stay healthy or become sick.	1	2	3	4	5	6
8	Whatever goes wrong with my health is my own fault.	1	2	3	4	5	6
9	When I am sick, I just have to let nature run its course.	1	2	3	4	5	6
10	Health professionals keep me healthy.	1	2	3	4	5	6
11	When I stay healthy, I'm just plain lucky.	1	2	3	4	5	6
12	My physical well-being depends on how well I take care of myself.	1	2	3	4	5	6
13	When I feel ill, I know it is because I have not been taking care of myself properly.	1	2	3	4	5	6
14	The type of care I receive from other people is what is responsible for how well I recover from an illness.	1	2	3	4	5	6
15	Even when I take care of myself, it's easy to get sick.	1	2	3	4	5	6
16	When I become ill, it's a matter of fate.	1	2	3	4	5	6
17	I can pretty much stay healthy by taking good care of myself.	1	2	3	4	5	6
18	Following doctor's orders to the letter is the best way for me to stay healthy.	1	2	3	4	5	6