

Carer Health Team – Sussex Community NHS Trust

Service Review – Summer 2015

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Acknowledgements

We would like to acknowledge and thank the following individuals, without whom this research would not have been possible:

All the carers who participated in this research
Wilma Thomas and her team
Di Hughes & Jane Colliss
Ally Katsande, Chris Rainey and colleagues at the Public Health Research Unit
Shauna Torrance
Steph Baxter
Mark Greening
Dawn Bishop

Summary

The Carer Health Team – Sussex Community NHS Trust (CHT) was initially launched in September 2013 to address the needs of adult carers within West Sussex. Since its initiation, the CHT has taken on 1050 referrals, 841 of which have now been seen through to completion. Although initially tasked with improving the general resilience and emotional and physical wellbeing of carers over a four to six week period, the CHT has offered prolonged support to some of the most vulnerable individuals within West Sussex and may very well be responsible for the prevention of many a breakdown or crisis. They have also been responsible for increasing confidence and improving the quality of life of over 1000 carers within West Sussex, while potentially saving local health care services in excess of £2 million per year.

This having been said, the service has not been without its faults, particularly when considering the gathering and analysis of both demographic and outcome data. There have also been a number of issues surrounding the clarity of provision which have been highlighted, both by service users and stakeholders. This notwithstanding, the team have shown great compassion and flexibility and must be commended for their efforts, with the recommendation that the service be both continued and expanded, albeit in a potentially revised form.

Key points

- The CHT is providing an invaluable service, without which many carers may reach breaking point
- Based on current referral rates, the CHT is potentially saving local health services over £2 million per annum
- The service is currently receiving more than twice the anticipated/contracted referrals of a monthly basis
- It is clear that the team are well respected and appreciated and should be commended for their flexibility and partnership working – their carer-centred approach is greatly valued by all, as is their holistic approach
- It is entirely possible that the CHT service has prevented significant decline and helped to prevent injury or crisis in many cases
- Referrals appear to be relatively evenly distributed across the three CCG regions, with the majority of referrals coming through statutory care providers

Background

In 2014 the Carers Trust (Carers UK, 2014) estimated that there were around 6.5 million carers in the UK. This exceeds the 5.4 million counted in the 2011 census (Office for National Statistics, 2011), and would appear to suggest an increase in the number of individuals who identify themselves as carers. A carer is defined as follows:

“A carer is anyone who cares, unpaid, for a friend or family member who due to illness, disability, a mental health problem or an addiction cannot cope without their support.

Anyone can become a carer; carers come from all walks of life, all cultures and can be of any age. Many feel they are doing what anyone else would in the same situation; looking after their mother, son, or best friend and just getting on with it.

Carers don't choose to become carers: it just happens and they have to get on with it; if they did not do it, who would and what would happen to the person they care for?” (The Carers Trust, 2012)

Caring can be a positive role and bring about many rewards. However, there is strong evidence to suggest that this role can also have a detrimental impact on the individual engaged in this role, with a significant proportion of carers reporting that the role has indeed had a negative impact on their health and that their role leaves them feeling stressed and unable to achieve a good night's sleep (Carers UK, 2014). One of the key strategic aims in the West Sussex Interagency Carers Strategy (Pillow, 2010) was to ensure better support to carers from the NHS, with the overarching local vision that carers would be supported to stay mentally and physically well and to be treated with dignity. This strategy is supported by the three local clinical commissioning groups; Coastal West Sussex, Horsham and Mid-Sussex and Crawley.

Over the past fifteen years there has been a significant shift both nationally and locally in acknowledging the role that carers play and recognising their valuable contribution to society. In 2012 the UK government made £400 million available nationally to primary care trusts (PCTs) specifically to develop services to support carers. This was followed in 2014 by the Carers Strategy: Second National Action Plan (Lamb, 2014), which set out the following

four key outcome areas for carers that build on the legislative frameworks, progress and developments from previous strategies:

- Identification and recognition
- Realising and releasing potential
- A life alongside caring
- Supporting carers to stay healthy

The Carer Commissioning Team, which forms part of Integrated Adult Care Commissioning and Public Health, holds both West Sussex County Council (WSCC) and local clinical commissioning groups' (CCGs) financial allocations within its pooled financial arrangements for carers. A decision was taken to commission delivery of a new specialist team of health clinicians, the Carer Health Team – Sussex Community NHS Trust (CHT), who would engage directly with carers and the people they care for. The service was commissioned in September 2013 and initially scheduled to run for 18 months with the primary aim of improving the health and wellbeing of both the carer and care recipient, by providing clinical interventions, advice and support. Following an interim evaluation in November 2014, the service was extended and became “business as usual”. The team work proactively and in partnership with the carer and statutory and third sector organisations, drawing on the team’s professional knowledge and expertise, to provide training, advice and signposting. The service is unique in that it is clinician-led and focused on the carers’ individual needs, and identifies them as “expert partners in care”.

The service operates from 900 to 1700 during the week, with the flexibility to deliver the service outside of standard working hours, where required. However, no limit is placed on the amount of time each carer may receive outside of the standard hours. It is available to all carers aged 18 years and over and has teams based in both the Coastal and Northern CCG regions of West Sussex. Young carers lie outside the remit of this service. The CHT is tasked with ensuring that carers gain additional knowledge regarding the care recipient’s condition and likely care pathway, so that both are able to achieve the best possible quality of life, relief from symptoms, and are offered flexible and proactive choices and advanced care planning to assist them with the management and care of the patient. The service was commissioned to provide a variety of interventions to deliver a number of outcomes, including:

- Improved resilience and physical and emotional wellbeing of the carer, as measured using the Warwick-Edinburgh Mental Well-being Scale (WEMWBS; see appendix 1) and measures of self-rated physical health
- Increased knowledge and ability to support the care recipients
- Identification of undiagnosed acute and/or chronic conditions in both the carer and care recipient
- Reduction in unscheduled care and emergency admissions
- Improved nutrition and hydration
- Improved medicines management

The team are also expected to ensure that the carers are registered with their GP and Carers Support West Sussex, and to provide individualised health and wellbeing plans and goals for

each service-user. A clear illustration of the purpose of the CHT can be found in the case studies in appendix 7.

What Is The Carer Health Team?

The primary focus of the Carer Health Team is to deliver a service working directly with carers in conjunction with the person who is being cared for (patient). The team works proactively with the carer to ensure that they are considering their own health and wellbeing.

They offer each carer personalised advice, support, strategies and clinical interventions on maintaining their own health & wellbeing.

They also work to support carers through also providing input on the health needs of the cared for person, ensuring that they have additional knowledge about the cared for's condition and likely care pathway, so that both the carer and cared for person achieve the best possible quality of life, relief from symptoms, and flexible proactive choices and advanced care planning about the management of the condition and caring situation.

They work in partnership with the carer, drawing on the team's professional knowledge and expertise, providing training and advice, signposting.

They work with other statutory multi-disciplinary services e.g. Proactive Care or the Prevention Assessment. Partnership working and collaboration with other key third sector carer focused services is also critical to ensure that carers receive seamless support. These include Carers Support West Sussex, Crossroads Care South Central & partner agencies.

The approach of this service is unique in that it focused on the carer's individual needs and working in partnership as an 'expert partner in care'.

(K. Howard, 2012)

Since the CHT became operational there have been changes in government and new legislative developments for carers. There continues to be a strategic focus on supporting carers to stay healthy (Lamb, 2014) and there is also greater recognition of carers by the NHS. This is supported by the recent publication of the NHS Commitment to Carers 2014 and NHS Five Year Forward Plan:

"For the first time, carers will be recognised in the law in the same way as those they care for."

According to the 2011 census, there are just over 800,000 people living in West Sussex, of whom nearly 85,000 identify themselves as carers (10.5% (Office for National Statistics, 2011)). Since its inception in 2013, the CHT has accepted 1050 referrals from across the county (1.2%). This compares with around 13,500 carers registered with Carer Support West Sussex (16%, local data).

At the time of completing this evaluation a new local strategic document and commissioning framework is being progressed with key stakeholders; the West Sussex Joint Commitment to Carers.

Aim

This report presents an evaluation of the CHT. The aim of this evaluation was to review the service delivery compared with the initial specification, and to identify any risks or benefits to the care or care recipient as a result of this service. A brief analysis of financial benefits and projected savings is also presented.

Methodology

This is a mixed-methods approach, including both qualitative and quantitative approaches. In addition to the collection and analysis of demographic and service-use data, semi-structured questionnaires and focus groups have been employed to establish both client and stakeholder opinion of the service provided by the CHT.

Results

Quantitative data

A total of 1050 referrals have been accepted by the CHT since its inception in September 2013. This represents 0.13% of the total population of West Sussex (n = 806,892; based on 2011 census data), and 1.2% of the individuals who have identified themselves as carers (n = 84,395). Of this number 841 cases are closed and 209 open and on-going cases. Over the entire client base, staff have made 1549 client visits and spent 5979 hours working with carers, ranging from 0 to 168 hours on individual cases (mean = 7 hours). Of these hours, 964 (16.1%) occurred outside of the standard office hours (0900 – 1700, Monday to Friday). Although not all clients required out of hours care, those that did (n = 189 (17.3%)) received an average of 5 hours (range 1 to 25 hours). Demographic data can be found in the table below:

Table 1: Demographic data

Gender	
Male (%)	309
Female (%)	741
Age	
Mean age (years)	68
Age range (years)	18 – 114
Missing cases	78 (7%)
Ethnicity	
White English / Welsh / Scottish / N Irish / British	893
Any other white background	13
White & Black Caribbean	1
Any other mixed / multiple ethnic background	8
Indian	3
Pakistani	1
Any other Asian background	3
White Gypsy or Irish Traveller	1
White Irish	1
Bangladeshi	2
Any other ethnic group	4
Missing cases	120 (11.4%)
Housing tenure	
Home owner	619
Council rented	85

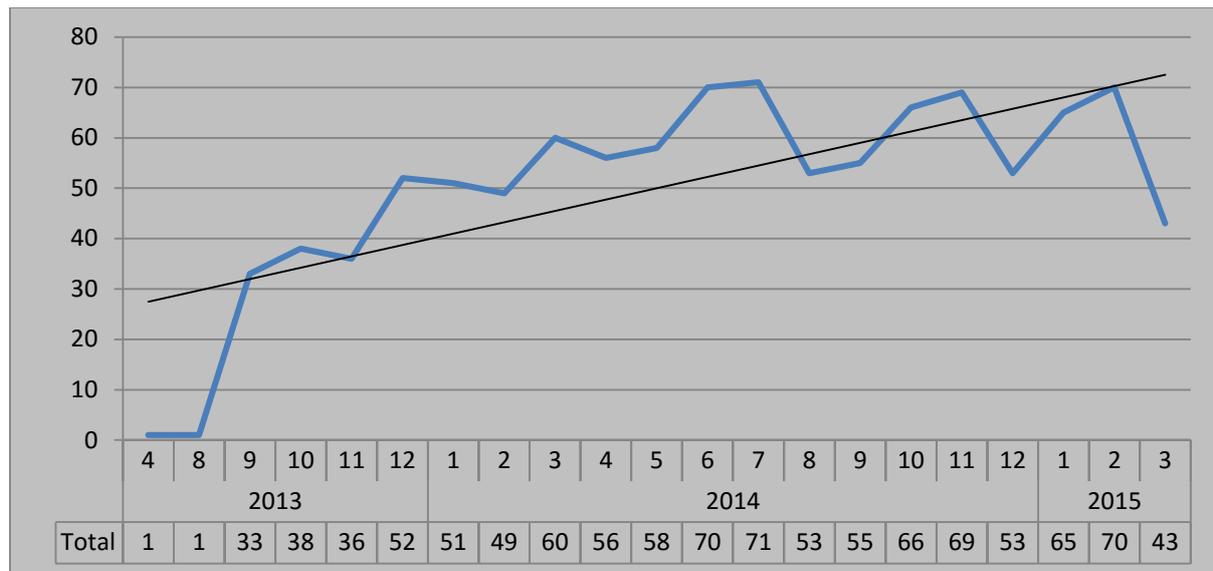
Private rental	56
Homeless	1
Other	8
Not living with cared for	3
Not stated	180
<i>Missing cases</i>	<i>98 (9.3%)</i>
Economic status	
Employed F/T	42
Employed P/T	40
Unpaid/Voluntary	18
Retired	640
Unable to work	147
Unemployed	11
F/T Parent	1
Student	1
Not Stated	97
<i>Missing cases</i>	<i>53 (5%)</i>

As the table shows, the majority of carers are retired female home owners of white ethnic origin, with a mean age of 68 years.

Demand for the CHT service:

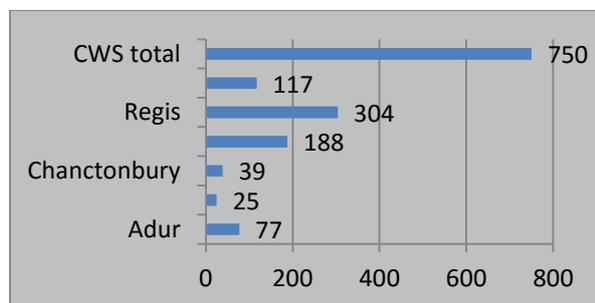
Referral data are shown in the figure 1 (full data are not available for March 2015). Aside from an overall increase in referrals across the months since the inception of the CHT, there appear to be no clear patterns to these referrals. However, the trend line does appear to indicate a continued increase in demand for the CHT, which is perhaps to be expected bearing in mind the CHT currently serves less than 2% of the local carer population according to 2011 census data, or around 7% of those registered with Carers Support West Sussex. Mean time between referral and first contact is four days; however, this has ranged from contact on day of referral to a wait in excess of four weeks for some clients (max = 53 days). Clients who were assessed by a member of the team waited an average of 17 days from their initial referral to be assessed. The time to assessment ranged from 0 to 348 days. This will be addressed in the discussion section.

Figure 1: Month-by-month referrals to the CHT



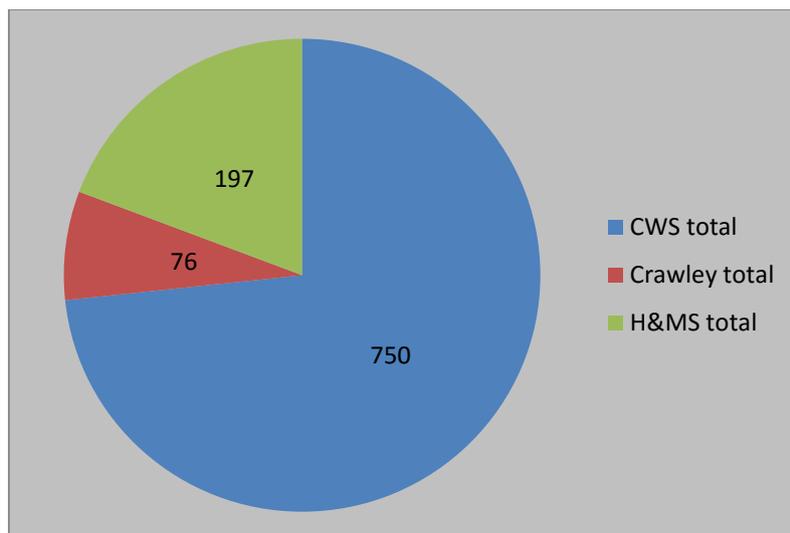
Referral sources:

Of the 1050 referrals to date, 689 came from the southern region of West Sussex and 361 from the north. In terms of referrals by Clinical Commissioning Group (CCG), data were available for 1023 cases. Overall, 750 referrals came from the Coastal West Sussex (CWS) CCG region, 76 from Crawley and 197 from Horsham and Mid-Sussex (H&M-S). Full CCG data can be found in figures 2, 3 and 4.



Figures 2 & 3 (above left and above): CWS and H&M-S referrals – breakdown by locality

Figure 4: Total referrals from each CCG region



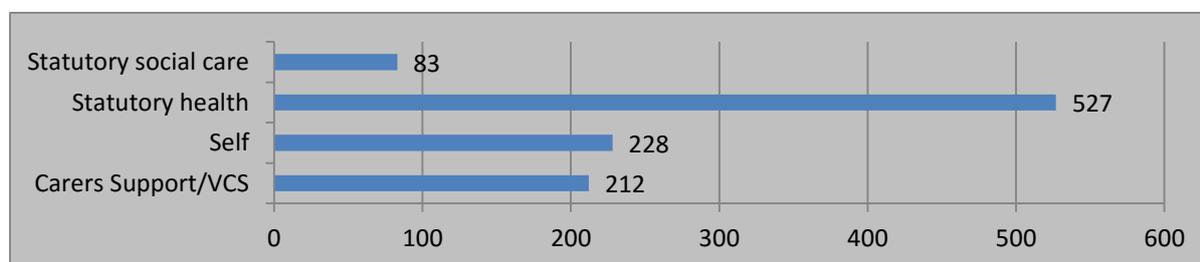
From this data it can be seen that the vast majority (73%) of referrals are currently taken from patients residing within the CWS CCG region (based on 2011 census data). However, CWS is also the largest of the three CCGs within West Sussex so, in terms of percentage of the population, CWS are referring in a similar proportion of its carers to the CHT (see table 2).

Table 2: Population and carer distribution across West Sussex by CCG *data are missing for 27 cases

CCG	Population	Carers	% of pop	CHT referrals	% of carers
CWS	478,950	52,516	11.0%	750	1.4%
H&MS	221,345	21,977	9.9%	197	0.9%
Crawley	106,597	9902	9.3%	76	0.8%
Total	806,892	84,395	10.5%	1023*	1.2%

In terms of specific referral sources, the vast majority of cases have been referred to the service from statutory health services and providers. Full data are shown below:

Figure 5: Sources of referrals to the Carers Health Team



The mean age of those referred from statutory health (72) was around ten years older than those who self-referred in to the service, which may suggest a more pro-active approach among the younger carers. Referral source was not influenced by gender or ethnicity

In terms of onward referral to GP and/or Carers' Support, data can be found in table 3. It can be seen that around half of the carers were already known to their GP upon referral to the CHT. This supports the finding that the majority of referrals have come in via statutory health services.

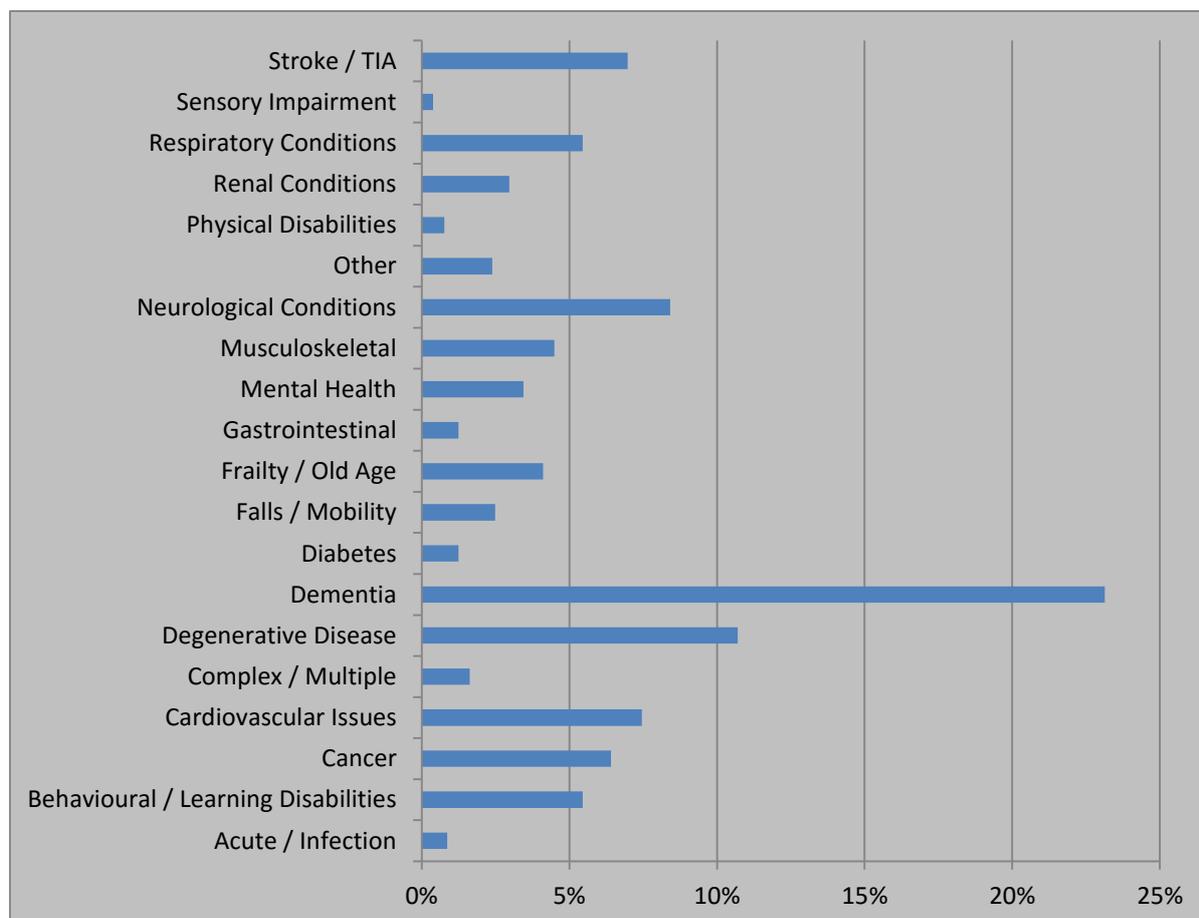
Table 3: Number of carers referred on to GP and/or Carers' Support

Onward referral	GP	Carer's Support
Yes	176	174
No	180	180
Patient refused	30	30
Already known	545 (51.9%)	533 (50.8%)
Missing cases	119 (11.3%)	133 (12.7%)

Primary condition of care recipients:

Data for this variable are available for 1046 of the 1050 clients recorded on the CHT database. By far the most prevalent condition among those being cared for is dementia, followed by degenerative and neurological conditions (see figure 6). Bearing in mind the demographic profile of the study population, this is perhaps to be expected.

Figure 6: Distribution of primary condition of individual being cared for



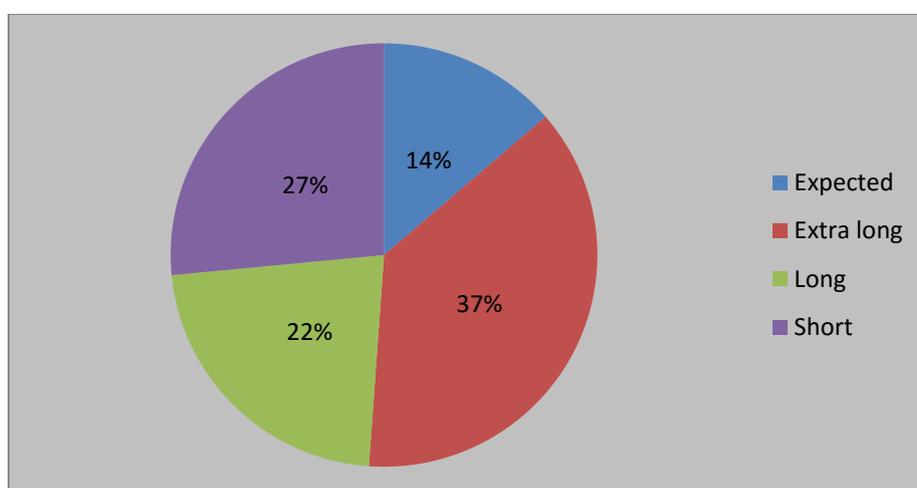
Analysis of closed cases

Data for these analyses are based on the 841 closed cases.

Length of intervention:

Length of intervention has been measured as the time from initial referral to the closure of the case. Although initially commissioned to provide interventions lasting from four to six weeks (28 – 42 days), the CHT has shown great flexibility with the range of services provided to, and length of time spent with its' clients. Most interventions included at least one face-to-face visit and, on average, lasted for just over ten weeks (71 days), ranging from no actual intervention to over 16 months (501 days). Only 14% of the closed cases received the anticipated four to six week intervention; around a quarter received a shorter intervention, with the remaining 60% (n = 503) receiving far greater input than expected (see figure 7).

Figure 7: Level of intervention received by carers



(Expected = 28 – 42 days; Extra-long = > 70 days; Long = 43 – 69; Short = < 28 days)

A subgroup analysis was conducted to explore if there were any potential reasons for the differences in length of intervention. There were no significant differences found across the majority of factors; however, those receiving the expected level of intervention showed the best response in terms of a reduction in the hours spent in the caring role. Also, and perhaps unsurprisingly due to the reduced length of intervention (mean = 12 days), those who only received a short intervention were less likely to be referred on to either Carers Support West Sussex or their own GP.

Time spent in caring role:

Table 4: Time spent in caring role

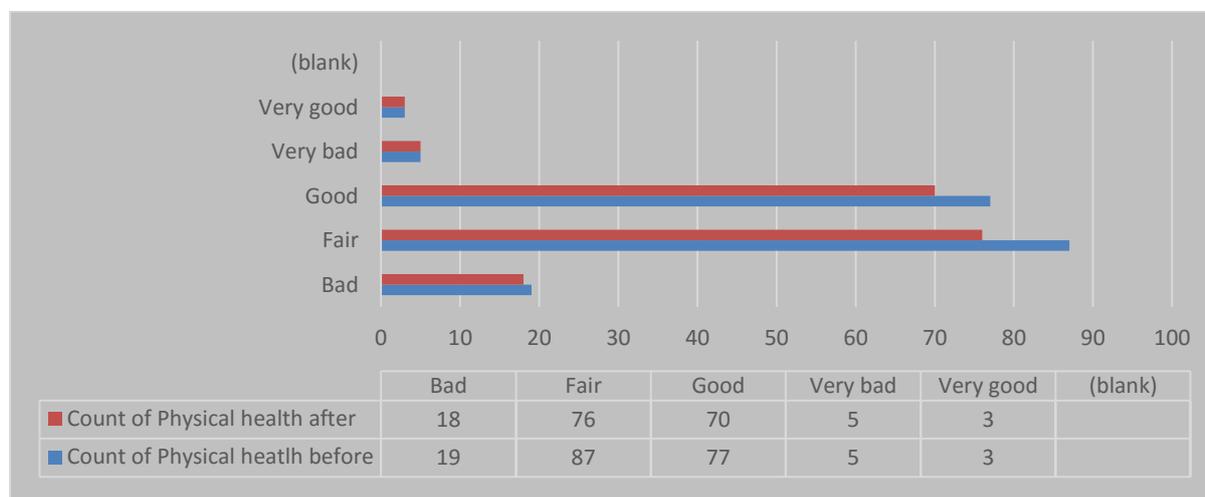
Time spent in caring role (hours)	Weekly	Daily
Mean before intervention	133	19
Min	0	0
Max	168	24
Missing cases	105 (12.5%)	
Mean after intervention	113	16
Min	0	0
Max	168	24
Missing cases	114 (13.6%)	
Mean difference	-20	-3
Min	-168	-24
Max	133	19

Overall, the intervention appears to have been successful in reducing the amount of time individuals are spending in a caring role.

Self-reported health status:

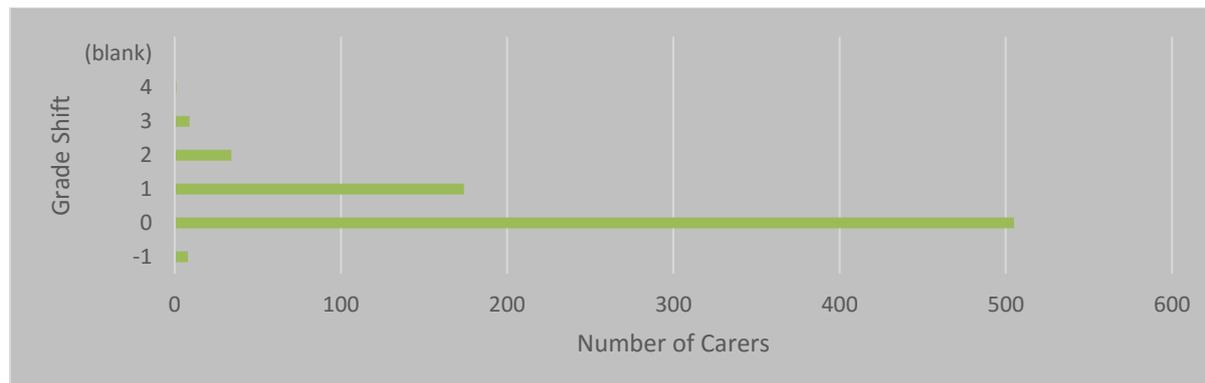
The data for self-reported physical health status are displayed in figure 8.

Figure 8: Self-reported health status (please note these rankings are not paired)



From the graph above it would appear that there has been little overall change in self-rated physical health following intervention. This assumption is reinforced when the individual differences between scores are compared and “grade shifts” are plotted (see figure 9). This graph shows the changes in self-rated health category. A plus 1 grade shift represents an improvement by one category. The majority of clients’ physical health remained the same.

Figure 9: Change in self-reported physical health following intervention by the CHT



WEMWBS:

As previously noted, the WEMWBS gives a measure of emotional wellbeing, with a higher score indicating a greater sense of wellbeing. Although there is a large amount of data missing for this variable, the results suggest that this intervention is having a positive impact on the carers engaging with the service (see table 5). This effect remains unchanged when only cases with both before and after scores are included. This will be considered in greater depth within the discussion.

Table 5: WEMWBS scores

WEMWBS scores	
Mean before	22
Min	5
Max	35
<i>Missing cases</i>	<i>262 (31.2%)</i>
Mean after	25
Min	0
Max	35
<i>Missing</i>	<i>292 (34.7%)</i>
Mean difference	4
Range	-18 to 22

Neither physical nor emotional wellbeing were influenced by, nor did they influence the length of the intervention.

Qualitative data

A total of 787 carers who had used the CHT service were invited to participate in this part of the evaluation, as well as a range of stakeholders. A total of 154 semi-structured questionnaires were returned from carers (see appendix 2); however only 131 (17%) are included in this analysis as the remainder were clearly not referring to the CHT in their responses. Instead, the carers were clearly commenting on their experiences with other services, such as CSWS or Proactive Care. Twenty-five questionnaires were received from key stakeholders (see appendix 3), including GPs and CSWS; however two of these were discounted because the respondent stated that they had not heard of or used the service. In addition, five carers who had returned the survey attended focus groups, which were employed to collect data pertaining to overall client and stakeholder satisfaction and feedback regarding the CHT (see appendix 4). In addition, all CHT staff were asked to participate in a focus group (see appendix 5). Carers were also asked to consider how they would rate a number of personal outcomes, the reason for their choice and then consider specific questions about the team, their views on their own health and the health of the person they were caring for.

Data from both the surveys and focus groups were collated and analysed. When considering the main reasons for referral into the CHT and outcomes and benefits gained, a number of key themes emerged from the data, including “advice and networking”, “access to services”, “health and wellbeing of the carer”, and “health and wellbeing of the care recipient” (see appendix 6 for raw data).

Advice & networking:

Carers discussed the need to have advice, information and opportunities linked in with other networks, including statutory health and social care services, third sector providers of carer services and other areas including welfare, benefits and condition specific information. Knowledge that they were getting all the help and support they needed and were entitled to, was considered to be of great benefit, particularly to those who were new to the caring role. This may be unsurprising when taking into consideration both historic and recent changes to care provision and what individuals are expected to provide for themselves. Many may feel reluctant to approach services or to apply for help if they believe this will involve disclosure of their assets. Indeed, it is entirely possible that many may expect to end up paying out more for their or their partner’s care if they ask for any help, even if they are entitled to it.

Carers also reflected a need for help and support to discuss the options available to and for the care recipient. Many participants felt that this was the first time they had viewed themselves as a carer, as focus had previously always been on the care recipient, rather than them. The knowledge that there was professional support available both at the present time and in the future was highly valued by all of the carers. Comments also suggested the need for greater provision in terms of discharge planning following both brief and lengthy hospital stays:

“It was good to have someone to contact who would visit the home and understood what we were going through. They could advise us about the system and help us to navigate it”

"My father came to live with us very suddenly after being discharged from hospital. It was a time of great worry, stress and adjustment. Advice and support from the team eased this adjustment both practically and emotionally"

"My husband does not willingly accept outside help. I have access to more experienced help and information which has informed my choices and reinforced my confidence to make decisions that affect both of us"

When considering the reason for initial referral in to the service, around one quarter of participants stated that advice and networking was the primary reason. However, this was not identified as strongly by respondents when questioned regarding outcomes and/or benefits.

Access to services:

Access to a range of services was considered important and many highlighted a number of challenges associated with this prior to their engagement with the CHT. Emphasis was placed on assistance for and with the care recipient, including services to assist with personal care, attendance at specific activities or receiving equipment to help with activities around the home. For many, financial issues posed a barrier to services and they found the assistance they received to apply for benefits, including carer and attendance allowance, to be highly beneficial. Importance was also placed on having the opportunity to consider the legal aspects of financial management, such as the implications of, and how to apply for enduring power of attorney.

Accessibility of carer-specific services was also improved following involvement with the CHT. These services included the provision of respite care and carer wellbeing payments, follow up support, and the provision of Carers Emergency Alert cards. Also of note was an improvement in access to other third sector and voluntary organisations, which also provide support to carers, such as the Red Cross. The carers also reported that the team played a key role in gaining the involvement of other health professionals, including specialist clinicians and hospital staff, GPs, and the initiation of medication reviews and discharge planning. However, a small number of participants reported that they had received no further contact or support and that no other services were forthcoming.

"I felt at breaking point, unable to think let alone plan ahead. I am now familiar with services available, getting help and can plan a bit better"

"I was exhausted and falling apart due to caring for my husband. Things have improved recently; I have been able to get more respite care"

"I know the team is doing great work, but I am not sure how much they have helped me personally"

"My husband is trialling a MindMe device, a Keysafe has been fitted and I have been informed of the groups I can attend should I need to. This has given me peace of mind"

Health & wellbeing of the carer:

A significant number of the participants reported that they had not considered their own health needs prior to engaging with the CHT. This finding was particularly prevalent among those aged over 65 years and those who were physically frail and those with multiple health issues themselves. It is also reinforced by the quantitative finding that self-referrals were most common among the younger carers. The complexity of the carer-care recipient dyad

was apparent in many cases. Particularly problematic issues included lack of sleep, manual handling and recent hospitalisation and major surgery. Many felt that the pressure of caring was overwhelming. Following intervention, many participants recognised the importance of prioritising their own health needs and asking for help to address their own needs. One major benefit appeared to be gaining/re-gaining the ability to think about contingency planning if they were to become significantly unwell and/or no longer able to provide care. Many had not previously considered this.

There was little evidence to suggest any significant improvements in physical health. However, nearly a quarter of respondents described an improvement in their own resilience and ability to cope with their caring role as a result of their involvement with the CHT. Significant emphasis was placed on the overwhelming pressure of caring and the impact on emotional wellbeing. Many reported that this pressure was lessened as a result of the intervention. Many also reported feeling more confident and assertive, and better equipped to deal with the challenging behaviour of the care recipient. Participants consistently attributed this to the intervention:

"Made me realise that I must take time out to maintain my own health and emotional wellbeing and not feel guilty for doing so"

"During my contact with the team I increased the amount of physical exercise I was taking, I also became more organised about monitoring my blood pressure and blood sugar levels"

"By looking after myself I am in a better position to cope without resentment or destructive feelings"

"They gave me the confidence to carry on"

"I was falling apart both physically and mentally and have now returned to my normal down to earth approach"

"I am getting too old and tired and just not coping well"

Health and wellbeing of the care recipient:

There was significant feedback from the carers regarding the complexity and number of physical conditions present in the care recipient. Care recipients with multiple, chronic long-term conditions including osteoporosis, cancer, degenerative and cardiovascular conditions were noted to be receiving high levels of informal support. There were an equally large proportion of responses given on the range of mental health conditions, including dementia, eating disorders and other functional mental health issues. Many participants felt that the CHT had helped them to understand the challenging behaviours of the care recipient, particularly those with dementia. Advice on safe handling, skin care, continence management, mobility and falls prevention was also considered useful and helpful. There was little evidence pertaining to any improvements in the overall wellbeing of the care recipient:

"It has made my wife less anxious regarding her own health"

"Arranged for re-admission to the hospital as a drip was required, well done!"

"I was struggling to care for my 22-stone husband; he could not walk and had leaking legs [sic]"

Operational and organisational feedback

When carers were asked to consider how the service worked and any potential areas for change and/or improvement, three key themes emerged. These were staff, service and systems and processes.

Staff:

Just over a fifth of participants cited the team members as the primary reason for the success of the CHT service. They considered them to be professional, supportive and approachable. Participants were particularly appreciative of the manner in which the staff treated them, specifically as an individual, rather than just a carer:

"The team members I spoke with were very friendly, informative and reassuring"

"I could not fault the team at all"

"I felt that my needs as a carer were recognised"

There was no negative feedback received regarding the CHT staff.

Service:

The carer-centred approach adopted by the CHT was greatly valued by the carers, as was the acknowledgement that they, too, have specific needs, in addition to those of the care recipient. Many carers also stressed the importance of being listened to and heard. Many also valued the option to be seen in their own homes:

"Overall the service was extremely good"

"I can off-load my worries and they listen to my needs"

"All aspects of the service have worked well. It must be even more essential when carers themselves are elderly and caring for their partners"

"Having someone to come and see me in my home environment has really helped"

In terms of areas requiring improvement, a few participants highlighted the impact of other services or gap in services, including length and number of visits, the lack of written information or care plan, and the impact of capacity issues and waiting list with other services:

"It's just another service a busy carer has to deal with"

"The team were great but I am still waiting for [other service] and have no other options to support me"

Systems & processes:

Around half of all participants made reference to systems and processes, placing positive emphasis on having a point of contact either for future needs or in an emergency. Regular contact with a specific, named member of the CHT was also identified as a key benefit of this service. Many participants felt that these benefits had given them the confidence to continue in their caring role, particularly as they now had access to support and back-up. The assistance that the CHT were able to provide for the care recipient, along with the

coordination of referrals and other activities were positively received and highly valued as a result.

"Seeing a health professional is helpful as my GP doesn't recognise my caring role"

"We are a couple that have no close family to help out. Knowing that we can call on the team for their support gives great peace of mind"

"You need someone in the system to help understand your way around the system"

When asked to comment on what was not working so well, the majority of comments related to external influences and structures pertaining to other services not directly related to the CHT.

The number of professionals and services that the carers were in contact with was extensive and many expressed the challenges of "juggling" these, while not really understanding what one service did and another did not. Examples of this include confusion about the range of services that had "carer" in the name, waiting lists for other services, lack of partnership working between hospital and community care, gaps in provision and areas of cross-over and duplication between services:

"I am confused as there are lots of different services with "carer" in the title!"

"I badly need a company to wash clinical laundry and there is no one to help"

Organisational stakeholder feedback

Specific work was undertaken with key stakeholders, including the CHT staff and external stakeholders, to establish the interfaces and pathways between services. Professionals from a range of statutory, private and third sector organisations were invited to participate and asked to complete semi-structured questionnaires (see appendix 3), to understand the frequency and main reasons for referral into the CHT. Participants were asked to consider how they or their team interacted with the service, what worked well and where they felt improvements could be made. The following organisations took part in this study:

- Carers Support West Sussex
- Wellbeing hubs
- Proactive care
- Older people's mental health
- Prevention Assessment teams
- Community Team for People with Learning Difficulty
- Care management
- Other specialist services

A carer-centred service:

Several participants highlighted the number of other services, which focus solely on the care recipient and the impact of this on the carer, and many emphasised the importance of having a clinical team focusing entirely on the needs of the carer, and taking a more holistic approach to the carer-care recipient situation. This was particularly noted where carers were not engaging with their GP or any other conventional health service, because this increased the risk of an acute or unplanned health episode. This may consequently leave

the care recipient requiring additional assistance. Participants felt that working with carers to focus on their own health could encourage them to prioritise their own health needs:

"I have referred two clients within the last day. They both put their spouses' health needs before their own and one of the clients had not seen the GP in three years"

"A great asset to the county's resources in supporting carers. Many carers neglect their own health needs so a dedicated team to focus on carers and visit them at home is excellent"

"I am able to refer carers with health problems, which may help reduce admissions"

Interactions & partnerships:

A high proportion of participants outlined their main involvement with the CHT as the initial referral process and engaging with carers who need support:

"They are a partner organisation and we refer to the team frequently"

"A valuable resource to refer carers to when they are experiencing carer health-related stress"

"They pick up referrals very quickly and look at the carer's role holistically. They are a great team to work with"

There was evidence of referrals from the CHT to other teams and working in partnership with these teams. Around one quarter of participants highlighted the need for feedback from the CHT to the original referrer, as this was currently considered to be lacking. However, it is worth bearing in mind that this comment is not believed to be unique to the CHT.

Overall, views on the service interactions and the partnership approach from the team were very positive, with many acknowledging the importance of joint working to ensure carers did not fall through gaps in the system. A small number of participants expressed some ambiguity in their understanding of the CHT's purpose and remit. Some explained that they would signpost all carers to the team, others mentioned needing the team's assistance in dealing with urgent and critical situations:

"I think that they are a very useful service for carers who have health problems. I would just like to be clearer about their criteria"

"It would be helpful to be sent feedback from every referral. This could be by forwarding a copy of what they are already typing up"

"I have not experienced any problems with any aspect of the CHT. Their team approach and professional work is great"

Good partnership working was a key theme for many participants, and included joint carer activities, staff induction and the provision of points of clinical advice for both clinical and non-clinical staff. It was felt that this type of partnership working would lead to better outcomes for the carers:

"We work in partnership to get good outcomes for the carer"

"Flexible and professional staff whose sole focus is carers and they are good at partnership working"

"We work in partnership in a complimentary way – we provide practical and emotional support, they can address clinical issues"

Concerns were raised regarding team capacity to meet the growing demands on the service, particularly as the caseload and referral rates were significantly higher than anticipated when the service was first commissioned. This concern was also voiced by members of the CHT staff. Multi-disciplinary working was evident and stakeholders outlined a range of levels of intervention from the CHT. This included one-off advice, attendance at multi-disciplinary team (MDT) meetings and staff meetings. The team also undertook home visits as part of the assessment process for other services, citing examples from CSWS and Proactive Care, and provided clinical interventions for complex needs:

"We refer a lot of carers of proactive care patients to the CHT. They are happy to add to or complete contingency plans and if they have concerns over a particular carer and patient they are happy to attend the MDT to discuss"

"The CHT is very accessible and I always feel I can call/e-mail and discuss patients. If the cared-for patient dies the team are quick to respond. I feel the carers are in safe hands and will feel supported in every sense"

"It is an integral part of proactive care to be able to support the carers so they can look after the patient and keep them at home"

The interactions with the CHT and other services also highlighted that they were viewed as the clinical "eyes on the ground". There was an emerging theme of increased confidence from stakeholders in referring to and interacting with an NHS service; however, the potential reasons for this were not explored. This was reinforced by a number of respondents who commented on the ability of health colleagues to act as an advocate for the carers' situation to other health colleagues:

"Gives weight when NHS staff talk to other NHS staff"

"They action our referrals in a very timely manner. They are our clinical eyes on the ground and we have a very good and professional relationship with the team"

"As many carers have health conditions themselves, this service is essential, but needs to be linked with GP practices"

There was evidence of requests for the team to engage with the Proactive Care teams to undertake carer-specific work as part of a wider clinical approach. Feedback from this indicated a degree of ambiguity surrounding the roles and profiles of different services in their provision of support to the carers.

Service:

Feedback was received regarding the variety of skills within the team and overall job satisfaction. The ability to offer a holistic approach to support carers was greatly valued. A range of interventions were described, including e-mail, text messaging and both telephone and face-to-face visits. Clinical tasks undertaken by the team included advising the carers on INR monitoring and catheter care. They have also liaised with local pharmacists to initiate the provision of both the carer and care-recipients' medications in blister packs, which are simpler to use and ensure greater compliance with medication. Participants commented that this reduced the workload of GP surgeries, pharmacies and phlebotomy teams. The CHT's links with other health, social care and third sector organisations were believed to have a positive impact in coordinating and facilitating services to support the carer-care recipient dyad. In particular, the multiple locations of the team across West

Sussex have enhanced their ability to build up local links and networks. In addition to their carer-centred approach, the CHT staff routinely undertake risk assessments to ensure there are no safeguarding issues arising from the caring situation.

Future developments:

Staff and stakeholders were asked to consider future options to improve the service. Although there were a tiny minority of contradictions, the overall feeling was that the service should be expanded and enhanced, with a view to co-locating the service with other carer commissioned services, with one point of contact for all carers. Other suggestions included a development of the service to include other disciplines and skills training, such as mindfulness and relaxation techniques.

Carer & stakeholder satisfaction:

The vast majority of carers who completed the survey indicated that they would recommend the CHT (see figure 10):

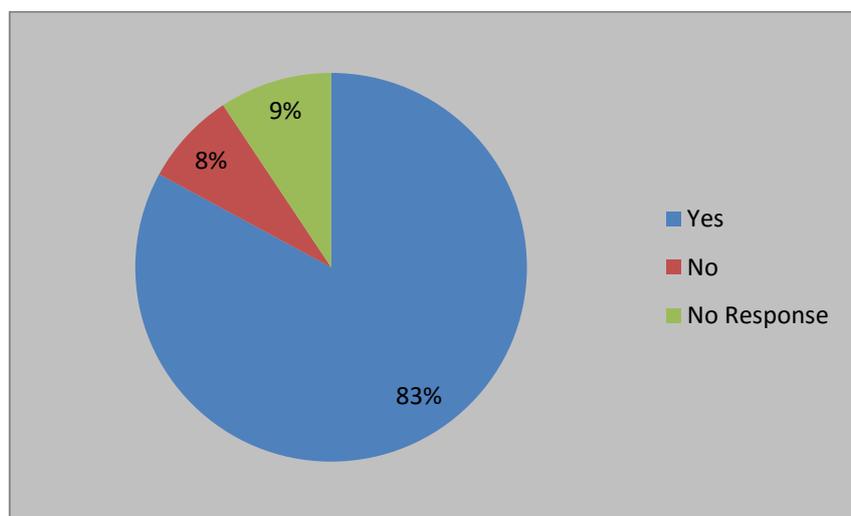
"I was able to talk freely about my needs as a carer and felt they were addressed"

"One of the few professionals who look at the whole picture and take the family into account"

"It helps the carer and carers need as much help as they can get"

"Because they are there for you"

Figure 10: Percentage of carers who would recommend the CHT



The following comments were made by those who stated that they would not recommend the CHT service:

"I am not aware of them having done anything"

"It is just another service you have to fit in"

"No help was given"

The team was also highly valued by key stakeholders, all of whom said they would recommend the service:

"I feel carers are safe in their hands"

"Only clinical team I know of that really looks at the needs of the carer"

"They provide one to one support for the carer and help them to prioritise their own health and wellbeing"

"Fantastic professional resource"

"I haven't referred to them but will take the time to find out more about the team as support to carers is a priority"

Economic evaluation

The economic contribution made to society by carers is well documented, and it has been suggested that each carer contributes well over £15,000 to society per year (Bruckner & Yeandle, 2007, Carers UK, 2014, Lamb, 2014). Based on the number of carers identified by the 2011 census (Office for National Statistics, 2011), this could equate to a contribution of nearly £13 billion in West Sussex alone. Reports such as these highlight the need for both social care and health commissioners to ensure that locally focused proactive and personalised support is made available to all carers.

Financial savings associated with the CHT have been calculated on the basis of improvements to both mental and physical wellbeing of the carer. Projections have been based on CHT activity data, along with a number of existing research sources (Barnet et al., 2012, Buckley, 2014, Clifford et al., 2011, Clifford et al., 2014). This research, along with data regarding various health costs, has enabled the identification of an average estimated unit cost to health organisations of managing the mental and physical health problems of carers. This includes a number of deductions to the gross values, in line with the work of Clifford et al. (2014):

- Deadweight – this deduction of 7% acknowledges that the realisation of a proportion of positive outcomes may have occurred without the support of the CHT and that some gain very limited benefit
- Alternate attribution – this deduction of 45% acknowledges that varying levels of support from elsewhere may be responsible for the positive outcome achieved

To calculate the net financial savings, the cost of the CHT is deducted from any gross savings identified. Savings have been modelled based on the expected prevalence of mental and physical health issues among the carers. It is worth bearing in mind that all costs associated with mental and physical ill health are based on research rather than actual data. It is also worth noting that the financial savings projected here are associated solely with health organisations and it is entirely possible that some benefit to social care will also be realised. Social care costs and benefits have deliberately been excluded to ensure there is no risk of duplication of the social care saving attributable to the carers using both the CHT and CSWS.

Physical health:

Based on the research outlined above, the likely prevalence of any long-term medical condition ranges from 20% to 28% (Barnett et al., 2012, Office for National Statistics, 2011). This gives the following projected financial savings per annum:

- £543 to £761 per carer
- £365,063 to £511,088 for CHT, based on an average of 56 referrals per month
- £7,359,381 to £10,303,133 if the CHT were able to reach all 13,547 registered with CSWS
- £45,847,415 to £64,186,381 if the CHT were able to reach all 84,395 carers in West Sussex

Mental health:

Based on the research outlined above, the likely prevalence of any mental health condition ranges from 39% to 82% (Buckley, 2014, Carers UK, 2014). This gives the following projected financial savings per annum:

- £1,165 to £2,449 per carer
- £782,697 to £1,645,670 for CHT, based on an average of 56 referrals per month
- £15,778,559 to £33,175,433 if the CHT were able to reach all 13,547 registered with CSWS
- £98,297,152 to £206,676,063 if the CHT were able to reach all 84,395 carers in West Sussex

It is therefore possible to estimate that, if all of the carers currently residing in West Sussex were to be assisted by the CHT, there is the potential to effect savings of up to £271 million per year. If all of those registered with CSWS were to be assisted by the CHT, there is the potential to effect savings of up to £ 43.5 million. Based on the current average referral rate of 56 new cases per month, the CHT may potentially save local health services up to £2.1 million per year. Bearing in mind the findings pertaining to self-reported physical health, this is entirely feasible.

Discussion

Overall, this study has shown that the CHT has been well received by stakeholders and service-users alike. However, in terms of the main outcome measures (physical and emotional wellbeing), the CHT appears to have facilitated a maintenance of the equilibrium, or only marginal improvement, rather than causing significant improvements. It is worth stressing the importance of this, however, as a removal of the service could prove to be significantly detrimental to the health and wellbeing of the carers. It is entirely possible that, rather than conferring significant improvements to wellbeing, the CHT service has prevented significant decline and helped to prevent injury or crisis in many cases. What is clear is how highly respected and appreciated the CHT staff are and their professional and flexible approach seems highly valued by all.

Before any discussion regarding the findings of this study can be entered into, it is vital, first, to consider any potential flaws in the methodology and quality of the data and its collection. With regard to the quantitative data, there has, to date, been a lack of rigour in the collection of this, leading to significant gaps not only in basic demographic information, but also in the two key outcomes measures, namely physical and emotional health and wellbeing. In terms of missing demographic data, of greatest concern may be the lack of ethnic data. This makes it impossible to assess the accessibility and equality of the service

across ethnic groups. There have also been a number of inaccuracies, particularly with referral and assessment dates, identified within the dataset, which may, ultimately impact on the findings of this study. It is also worth bearing in mind that, as the CHT is currently only utilised by around 2% of the carers in West Sussex, this data may not be representative of the entire caring population. As such, caution should be employed when interpreting the findings presented herein.

In addition, limited time may have hindered the design and conduct of the study. More specifically, it is not clear why the WEMWBS scale (appendix 1) was chosen as an outcome measure, or indeed if it is appropriate for this particular demographic group. For example, the CHT staff may have felt uncomfortable asking elderly patients to rate the phrase "I've been feeling optimistic about the future", particularly in cases where there are caring for an individual with an untreatable or degenerative condition. This may, to some degree, explain the volume of data missing for this variable. It is also not clear that all important and appropriate outcomes were identified prior to data collection. As such, key information and findings may have been missed. There were also changes made to the data collection process midway through the first 18 months of services provision. It is unclear what impact any changes or lack of consistency may have had on the final dataset.

Service utilisation

In terms of service-use and demand, it is clear that the service is currently over-subscribed. While initially commissioned to handle around 26 referrals per month, the current average rate of referrals is 56 per month (range 33 to 71). However, it is worth noting that only 14% of the referred carers received the anticipated intervention (28 to 42 days). This equates to an average of eight referrals per month. This suggests that the intervention(s) provided by the CHT may not be appropriate for a significant majority of their referrals. Of the remaining referrals, just under a third received a shorter than expected intervention, and the remaining a longer than expected intervention. This, along with feedback from some of the key stakeholders, suggests a lack of clarity around the remit of the team. However, it is worth bearing in mind that many of the cases where an extended intervention is offered, there may be safeguarding issues and the overall complexity of their situation may be far greater than other carer-care recipient dyads. It is also worth addressing the manner in which the length of intervention has been measured. This currently includes the time from first referral to initial contact, rather than simply the amount of time each clinician spends on each case. This may have resulted in an inflated view on intervention length in some cases.

With these findings in mind, it may be appropriate to consider the implementation of a triage process, which may impart necessary information and signposting to those only requiring brief intervention, or forward referral to more appropriate services for those likely to require in excess of the six week intervention initially specified. Aside from ensuring that the carers receive the support they require and that the CHT receive less inappropriate referrals, this could go a long way to minimising service duplication and overlap. For example, Proactive Care have a key role to play in working with both carers and care recipients to reduce the risk of unplanned acute hospital admissions. At the other end of the service spectrum, for those carers requiring a non-clinical approach, CSWS play a pivotal role. A careful balance needs to be maintained between both of these, and indeed all other

services tasked with supporting carers to ensure carers continue to receive a holistic approach, while making the most effective use of clinical time.

This having been said, there are currently 84,395 self-reported carers residing within West Sussex, 13,547 of whom are registered with CSWS. As such, the CHT is or has been in contact with only 16% of registered carers. This reinforces the need for greater provision. However, it is understood that this may not be feasible in current form. It is also understood that nearly all overt marketing and promotion activity has been suspended to allow for the care of existing clients to continue without detriment to their health and wellbeing. It may be that a triaging system would allow for wider provision of the service, where appropriate.

Referral route and reason

When considering the initial route and reasons for referral, it is worth considering that, while around a quarter of participants stated that advice and networking was their primary reasons, this was not supported by the reported outcomes. This suggested an element of disparity between carers' expectations and the actual service provided by the CHT. This notion is supported by the lack of clarity surrounding the role and remit of the CHT.

The service is currently free/open access and carers can make contact with the CHT through a number of routes. However, just over half of all the referrals are made to the CHT through statutory health providers. Although it has been suggested that self-referrals be excluded, this is not recommended as it would severely discriminate against those who do not regularly access conventional healthcare, more specifically those from ethnic and minority groups. Although from the available data it is not clear how well represented these groups are by the CHT, the data we do have suggests a potential service gap among these groups, which is likely to perpetuate health inequalities between social and ethnic groups.

In terms of location of the carers who have been referred into the CHT, although there appear to be a greater proportion of referrals from the CWS region of West Sussex, this reflects the size of the region itself, which is significantly larger than the other two CCG regions. This is also reflected by the distribution of CHT staff between the two geographical bases.

Outcome measures

As already alluded to above, the suitability of the main outcome measures have been called into question. These are expected to measure the impact of the CHT on both the physical and emotional wellbeing. Physical health has been gauged using the same self-reported measure used in the 2011 census (Office for National Statistics, 2011), and emotional wellbeing has been measured using the WEMWBS scale (appendix 1). Although the qualitative component of this study has suggested that the CHT has had a significant, positive impact on the health and wellbeing of the carers, the quantitative outcome measures suggest only minimal change at best, with most participants maintaining their levels of physical and emotional health. This disparity is likely due to the inappropriate choice of outcome measures, a suggestion which is reinforced by the significant gaps in data

collected for these measures. It may also be worth re-evaluating the choice of outcomes if there are likely to be any changes made to the service specification and/or provision.

In 1989, a multidimensional coping inventory was developed to assess the different ways in which people respond to stress (Carver et al., 1989). This inventory, known as COPE, contains a set of sixty questions, which measure various aspects of an individual's response to assorted stressors. This inventory has been revised and split into a number of different subscales and has also been tailored for specific stressors and/or populations. One such case of this was that created as a result of the EUROFAMCARE project (Balducci et al., 2008), which seeks to assess the negative impact and positive value of caring. This scale comprises just 15 items, and is split in to three component subscales: negative impact, positive value, and quality of support (see appendix 8). It may well be that this scale will prove to be more relevant and appropriate to the target population, thereby enabling more complete and accurate data collection and, subsequently, a clearer illustration of the efficacy of the CHT.

Other outcomes under investigation included an increase in knowledge regarding the caring role, benefits and entitlements and networking opportunities. Also of interest was the detection of previously undiagnosed medical conditions in the carer. While the qualitative data support the finding that the CHT intervention will lead to an increase in knowledge, there was very little to support the notion that the service would assist in the identification of previously undiagnosed medical conditions. However, this may be a function of the group demographic profile. As noted above, the majority of the carers accessing the CHT were women, aged in their mid to late sixties.

Economic evaluation

Based on current investment and the calculations outlined above, the CHT clearly has the potential to save local health services a significant amount in terms of physical and mental health costs. However, it is worth re-emphasising that the service is currently only reaching 1.2% of the local caring population and, based on the current service model, would require an additional investment in excess of £30 million per annum to cover all of the carers in West Sussex. However, to reach all carers who are currently in touch with CSWS, would only require a £5 million investment. When combined with the projected net savings of up to £43.5 million, there is a compelling argument for the extension of the CHT service. This is further reinforced by the finding that almost no decline was reported in the health of those carers using the service.

Strategic context

Both carers and stakeholders described the value and importance of having a service that is carer-focused, with particular attention paid to the benefit of focusing on the health and wellbeing of the carer, rather than just the care recipient. This is a reasonably novel approach, as most traditional services tend to place all the attention on the care recipient. From a legislative standpoint, the CHT is ideally placed with the commencement of the Care Act (2014), to deliver on the key principles surrounding wellbeing, equal rights of both members of the carer-care recipient dyad to the provision of personalised services to enable the pursuance of life opportunities.

The CHT is also well placed strategically to continue to deliver key NHS and social care objectives, which will enable carers to stay healthy, and work proactively to minimise crisis intervention through resilience-building and harm reduction. Without this type of intervention, the carer may ultimately reach “breaking point”. The service may also meet Better Care Fund requirements by supporting a reduction in unplanned hospital admissions or permanent admissions. In terms of the Adult Care Social Outcomes Framework (ASCOF), the CHT may help to address measure 1A: Social Care Related Quality of Life. The CHT also works operationally with other health teams to raise carer awareness and ensure that their needs are taken into account by the local health economy at every opportunity. With regard to the Public Health Outcomes Framework, the CHT has the potential to play a pivotal role for many in terms of increasing health life expectancy and reducing the differences in life expectancy and healthy life expectancy between communities.

Overall findings

Prior to drawing any firm conclusions there are a number of factors which should be taken into account. Firstly, and perhaps most importantly, it is very easy to assume that a lack of evidence automatically equates to a lack of effect. However, this is not always the case. As discussed above, it may well be that inappropriate outcome measures were selected at the instigation of this project. As such, it is worth considering that this may be the cause of any equivocal results reported here. Indeed, it is entirely possible that, had the WEMWBS been replaced with a more suitable measure, the results may have shown dramatic improvements in emotional wellbeing over the course of the intervention.

Secondly, although no significant improvements were noted in the physical and emotional wellbeing of the carers, the service does not appear to have caused any harm. This is an often underestimated property of many interventions and, bearing in mind that, by maintaining an equilibrium, many carers may have avoided a significant episode of ill-health, breakdown or crisis, cannot be over-rated. With this in mind, it is worth considering that, in addition to the outcome measures, the actual outcomes which were selected for this study may not have been entirely appropriate.

Conclusions

Prior to any consideration of the service itself, the most important conclusion to draw is that the team have demonstrated excellent partnership and matrix-team working to ensure the best outcomes for the carers. However, confusion over role clarity and overlap with other services may need to be addressed on a wider scale, and this discussion should include all services concerned with the wellbeing of both carers and care recipients. While this discussion may result in changes to the CHT service, the overall care and wellbeing of the carers is paramount and may be better served by the CHT focussing on a smaller sub-set of the carer population, rather than attempting to address all issues for all carers.

This need for clarity is highlighted by the recent commissioning of the Admiral Nurses. This service covers Horsham and Mid-Sussex and works specifically with the carers of dementia patients. It is not yet known what level of impact this is ultimately likely to have on the CHT service. However, it may be that teams, such as the Admiral Nurses, may reduce the CHT workload by addressing certain sub-groups of carers and care recipients. It may also be that

the introduction of a triaging system may ensure that only those who would benefit from the four to six week service commissioned from the CHT are referred in. This, again would ensure that the staff and services are utilised to their optimum potential.

Ahead of making any final conclusions, it is important to address any shortcomings discovered by this evaluation. Undoubtedly the collection and input of data from this service has fallen short of expected levels. As such, the drawing of any conclusions is not a straightforward process. However, both case studies, satisfaction surveys and qualitative research has lent strong support to the success and need to ensure a continuation of this service. It is also clear that, since its inception in 2013, the CHT has developed and grown beyond the scope of the initial service specification, both in terms of flexibility, provision and strategic position within the community. With this in mind, one can only conclude that the CHT is providing an invaluable service, without which many carers may reach breaking point.

References

- BALDUCCI, C., MNICH, E., MCKEE, K., LAMURA, G., BECKMANN, A., KREVERS, B., WOJSZEL, Z. B., NOLAN, M., PROUSKAS, C., BIEN, B. & OBERG, B. 2008. Negative Impact and Positive Value in Caregiving: Validation of the COPE Index in a Six-Country Sample of Carers. *The Gerontologist*, 48, 276 - 286.
- BARNETT, K., MWECER, S., NORBURY, M., WATT, B., WKYE, S. & GUTHRIE, B. 2012. Epidemiology of multimorbidity and implications for health care, research, and medical education: a cross-sectional study. *Lancet*, 380, 37 - 43.
- BUCKLEY, P. 2014. Stress-related and Psychological Disorders in Great Britain 2014. London: Health & Safety Executive.
- BUCKNER, L. & YEANDLE, S. 2007. Valuing Carers - calculating the value of unpaid care. London: Carers UK
- CARERS UK. 2014. State of Caring 2014. London: Carers UK.
- THE CARERS TRUST. 2012. *What is a carer?* [Online]. Available: <https://www.carers.org/what-carer> [Accessed 19th June 2015 2015].
- CARVER, C., SCHEIER, M. & WEINTRAUB, J. 1989. Assessing coping strategies: A theoretically based approach. *Journal of Personality and Social Psychology*, 56, 267 - 283.
- CLIFFORD, J., THOEBALD, C. & MASON, S. 2011. The Princess Royal Trust for Carers: Social Impact Evaluation using Social Return on Investment. London: The Princess Royal Trust for Carers.
- CLIFFORD, J., WARD, K. & CORAM, R. 2014. Carers Support Centre, Bristol and South Gloucestershire: Summary Social Impact Evaluation of the Carers Health Project. Bristol & Milton Keynes: Baker Tilly Corporate Finance LLP Carers Support Centre.
- HOWARD, K. 2012. Carer Wellbeing Clinicians Initiative: Service Brief. Chichester, West Sussex: West Sussex County Council.
- LAMB, N. 2014. Carers Strategy: Second National Action Plan 2014 - 2016. *In*: HEALTH, D. O. (ed.). London: HM Government.
- MUSGROVE, J. 2014. Report for West Sussex County Council Health and Social Care Commissioners on Direct Access Carer Support 2013 - 2014. Carers Support West Sussex.
- PILLOW, J. 2010. West Sussex Interagency Carers Strategy: 2010 - 2015. *In*: SERVICES, A. (ed.). Chichester: West Sussex County Council.
- OFFICE FOR NATIONAL STATISTICS. 2011. 2011 Census: Aggregate data (England and Wales). UK Data Service Census Support.

Appendix 1: WEMWBS

The Warwick-Edinburgh Mental Well-being Scale (WEMWBS)

Below are some statements about feelings and thoughts.

Please tick the box that best describes your experience of each over the last 2 weeks STATEMENTS	None of the time	Rarely	Some of the time	Often	All of the time
I've been feeling optimistic about the future	1	2	3	4	5
I've been feeling useful	1	2	3	4	5
I've been feeling relaxed	1	2	3	4	5
I've been feeling interested in other people	1	2	3	4	5
I've had energy to spare	1	2	3	4	5
I've been dealing with problems well	1	2	3	4	5
I've been thinking clearly	1	2	3	4	5
I've been feeling good about myself	1	2	3	4	5
I've been feeling close to other people	1	2	3	4	5
I've been feeling confident	1	2	3	4	5

I've been able to make up my own mind about things	1	2	3	4	5
I've been feeling loved	1	2	3	4	5
I've been interested in new things	1	2	3	4	5
I've been feeling cheerful	1	2	3	4	5

Appendix 2: Semi-structured questionnaire - carer

HAVE YOUR SAY

CARERS HEALTH TEAM EVALUATION

Questionnaire to carers

We are sending you this questionnaire because you have received support from the Carers Health Team – Sussex Community NHS Trust. To improve and develop our services we want to seek your views on the care and support you may have received and may still be receiving from this team.

If you feel able to help, please complete the questionnaire but if you choose not to complete and return this questionnaire this will not affect the services you receive.

Your feedback will be used by Sussex Community NHS Trust and the Carer Commissioning Team at West Sussex County Council, to develop this service for the future. Your answers will be treated as confidential and will not be passed on to anyone providing a service to you. You will not be personally identified and your answers will not affect the service you receive.

If you have any questions about the survey or need any help to complete it please contact:

Any questions about the actual service you are receiving should be directed to the staff responsible at the Carers Health Team, South 01243 623521 or North 01403 227000 ext. 7613/7686

Once you have completed this questionnaire, please return it in the pre-paid envelope provided by 6 March 2015.

Your views are important and we thank you for taking the time to complete this questionnaire.

www.westsussex.gov.uk

1. Support from the Carers Health Team

(A) Briefly describe the reason/reasons for your referral to the Carers Health Team.

(B) Has the Carer Health Team helped you with any of the following?
(Please circle the appropriate response)

(B1) Reason for the referral strongly disagree | disagree | neither | agree | strongly agree

(B2) Access to other services strongly disagree | disagree | neither | agree | strongly agree

(B3) Increase in knowledge strongly disagree | disagree | neither | agree | strongly agree

(B4) Reduction in stress strongly disagree | disagree | neither | agree | strongly agree

(B5) Improving physical health strongly disagree | disagree | neither | agree | strongly agree

(B6) Improving mental health strongly disagree | disagree | neither | agree | strongly agree

(B7) Increasing confidence strongly disagree | disagree | neither | agree | strongly agree

(B8) Advice/input on the strongly disagree | disagree | neither | agree | strongly agree

person you are caring for

(B9) Please tell us briefly about the reason for your choice.

(B10) Has anything else changed as a result of the support you have received from the Carers Health Team? Please describe:

(C) Please describe in your own words how the Carers Health Team has had an impact on you in relation to:

(C1) Your own health:

(C2) Your ability to care for the person you look after:

(C3) The health and well-being of the person you care for:

(D) In terms of the overall service provided to you by the Carers Health Team:

(D1) What in particular do you think has worked well, and why?

(D2) What in particular may have not worked so well, and why?

(E) Please circle the statement you agree most with and give a brief reason.

(E1) I would recommend the Carer Health Team because ...

(E2) I would not recommend the Carer Health Team because ...

(E3) ... please give the reason:

2. About you

1. **What is your age in years: Are you: Male Female**
2. **Ethnicity** (please circle one of the categories):
3. **First 4 digits of your POST CODE:**
4. **Do you live with the person you care for?** Yes No
5. **What is your marital status?** Single Married Living with partner Widowed Divorced or separated Civil partnership
6. **What is your economic status?** Employed full-time Employed part-time Unpaid/voluntary Retired Unable to work Unemployed
7. **How long have you cared for the person you care for?** (years/months)
8. **How many hours per week do you care for this person?**
9. **Do you consider yourself to have a disability or long term illness?** Yes No Prefer not to say
10. **If yes please state what your disability is by ticking all that apply.**

Thank you for helping us by completing this questionnaire. Please return it in the pre-paid envelope provided.

White English • Welsh • Scottish • Northern Irish • British

White Irish

White Gypsy or Irish Traveller

Any other White background

White and Black Caribbean

White and Black African

White and Asian

Any other Mixed • Multiple ethnic background

Indian

Pakistani

Bangladeshi

Chinese

Any other Asian background

African

Caribbean

Any other Black • African • Caribbean

Arab

Any other ethnic group

Prefer not to say

Physical impairment Sensory impairment Mental health issue

Learning disability Long term illness Other

If you would be interested in attending a small discussion group planned during February to talk about this topic in more detail let us know by providing a name and contact number below.

Would you like to be involved in a small discussion group ? Yes No

If Yes, please give your name: and your phone number:

Your response will be treated as confidential, your details will be separated from the main questionnaire and will not be passed to anyone providing a service to you. When we report our results you will not be personally identified.

Appendix 3: Semi-structured questionnaire - stakeholder

CARERS HEALTH TEAM – EVALUATION

Questionnaire to Stakeholders

The Carer Commissioning Team, part of the Health and Social Care Commissioning Directorate of West Sussex County Council commission a range of services for carers to access. These are funded by both West Sussex County Council & Clinical Commissioning Groups.

An evaluation of one of these services, the Carers Health Team – Sussex Community NHS Trust, is underway. The aim of this piece of work is to see how far this service has improved the health and well-being of the carers who access it and what impact the service has on the wider health and social care system, including the work of the main organisations and people who work closely with the team.

The results of the evaluation will be disseminated to stakeholders and will form the basis of follow up work to determine the future development service.

We would like to hear your views and welcome your input by completing this short questionnaire. Please answer the questions most relevant to your role.

1. Are you responding on behalf of:

(a) An organisation?

(Please state the name of the organisation).....

(b) Service area?

(Please state the service area you work in).....

(c) Your service location?

(Using the Clinical Commissioning Group geographical boundaries please circle the location that your team is based in)

Coastal CCG

Horsham & Mid Sussex

Crawley CCG

2. a) Have you signposted or referred to the Carer Health Team? Yes/No

b) Please describe your role and involvement with the Carers Health Team

.....
.....

3. What elements of the Carers Health Team work well?

Please give your reasons

.....
.....
.....
.....

4. What elements of the Carers Health Team do not work so well?

Please give your reasons

.....
.....

.....
.....
5. Describe how the Carer Health Team fits/interacts with your team or service.
.....
.....
.....

6. How would you like to see the service developed in the future?
.....
.....
.....

7. Please circle the statement you agree most with and give a brief reason.
a) I would recommend the Carer Health Team because
b) I would not recommend the Carer Health Team because
Reason.....
.....
.....

8. There may be other comments which are important to you in addition to those already covered. Please add any further information below.
.....
.....
.....
.....

Thank you for completing this questionnaire. Please return to..... (email address).

Appendix 4: Focus group briefing notes – carers

Carer Focus Group Briefing Notes

Introductions

Context of work

Briefing on Carer Commissioning Team, joint health & social care including examples of some of the services we commission e.g. CSWS, Alert Card, Break Services and then Carer Health Team.

Boundaries & Ground Rules

People will not be personally identifiable nor will any comments affect their service. Information will be written into a report using headings or themes. People only need share what they feel comfortable with.

Overview

Provide a brief overview of why we are evaluating CHT, new service, wanting to look at how it is working, areas that carers value and areas that may need developing. Give a brief list

Themes

Some of the themes that have come through from the completed surveys are:

- 1) **Advice & Networking** – important role of this team in delivering this e.g. carer services, health information, information on conditions.
- 2) **Access to services** – supporting carers and their cared for to access other services e.g. physio, carer break services, referral to a health specialist, assistance to apply for benefits.
- 3) **Health & Wellbeing** of the carer – importance of having a professional that focuses on the carer, gives peace of mind, contact in emergency, helps the carer to stay well, manual handling, managing stress.
- 4) **Health & Wellbeing of the cared for** – input on a particular condition, dementia, multiple health conditions, medication reviews.

Discuss the above: – what is important to this group?

- ask the group to rate the above individually from 1 to (with 1 being the top priority).

Explore:

- What things work well?
- What things don't work so well?
- Who were they in contact with before CHT?
- Who are they know in contact with after? (we would be expecting an increase in services, CSWS etc..)
- The service has nurses and OT's – should it have any other professionals in it?
- Service hours – discuss
- Visits at home, appointments in an agreed place of your choice, clinics at a venue near you?
- Should it be for a time limited period? Or a service you can make contact with in the future?
- Best way to provide information to given- verbally, written into a personal document.
- What does staying healthy and well look like to you?
- Where would you go to find out information about looking after someone?

Appendix 5: Focus group briefing notes – CHT staff

Staff Carer Group Briefing Notes

Introductions

Overview

Provide a brief overview of why we are evaluating CHT, new service, wanting to look at how it is working. A range of different approaches are being used to gather feedback on the service. Explain when the report will be available, what will happen with it and how the team will be involved in the process.

Boundaries & Ground Rules

People will not be personally identifiable. Information will be written into a report using headings or themes. People only need share what they feel comfortable with and if necessary a telephone interview can be set up to ensure people have their say.

Topics To Cover

Who is the service for?

What does the service do now?

Discuss the current team structure and roles.

Are there key partnerships or roles with other services?

What things work well?

Discuss the progress and development of the service over the past 18months.

What things don't work so well?

Are there any barriers?

Explore views on having a clinical team focusing on nurses.

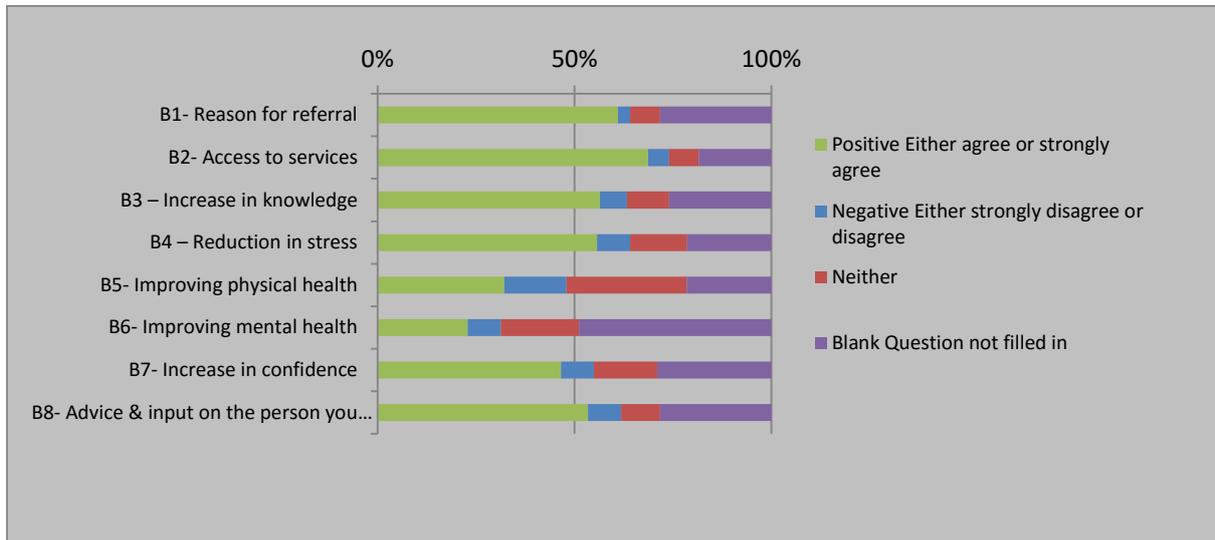
Discuss service hours and duration of interventions.

Discuss ideas for how the service should be developed in the future.

Are there any other issues or feedback?

Appendix 6: Raw qualitative data

Question (B) Has the Carer Health Team helped you with any of the following?



Appendix 7: – Case studies

Mr S.

Introduction:

Mr S was referred to CHT in August 2014. His wife had various health issues including dementia, osteoporosis, hypertension, Raynard's syndrome, asthma, Odema, AF and Cardiac Failure. However, it was the symptoms and behaviour cause as a result of Alzheimer's dementia which was having the greatest impact upon their lives.

The referral came from the Proactive team who recognised that Mr S was finding it increasingly hard to cope with the caring role and felt that a face to face assessment from CHT focussing upon Mr S's needs was necessary to help to prevent a carer crisis.

Mr and Mrs S lived in their own home where they had been for the past 18years. The house is in a semi-rural location but situated right next to a road.

Mr and Mrs S have two grown-up children who do not live close enough to offer regular support. They have a dog called Gabby.

Assessment:

Mr S :

PMH: CKD stage 3 and Gout. Hypertension.

Emotionally: Mr S was becoming more anxious about his wife's safety and also experiencing feelings of frustration and of loss due to the effects Mrs S's dementia.

Mr S found it difficult to attend his own medical appointments or make any social arrangements as he could not leave his wife alone at home. He was also very anxious about what would happen in the case of him becoming unwell or unable to care as their children lived so far away.

Mrs S had over 8 different medications on prescription and Mr S was struggling to keep track of them. She was identified as being at risk of falls and Mr S had hurt his back on one occasion trying to stop her from falling in the bathroom.

Carers were coming in 5 mornings per week for half an hour to assist with washing and dressing. In the evenings and at the weekends Mr S helped his wife with her personal care.

Although Mr S was struggling with the housework and shopping, cooking etc he did not feel they could employ a cleaner as it may distress Mrs S. too much.

Despite having lived there for 18 years, Mrs S. no longer recognised their house as her home. On a daily basis, she believed that she was only visiting the house and so, late in the afternoon every day she would start preparing to go "home". This was a difficult and distressing factor for Mr S to manage.

Often she would attempt to leave the house and had sometimes wandered around the nearby properties. Neighbours would return her home or Mr S would find her. On one occasion Mrs S walked further than the local vicinity and been found half a mile up the road.

An identified issue for Mr S is social isolation. Their social network had diminished in recent years due to friends and neighbours moving away or dying. Most recently their next door neighbours had moved to be nearer to their daughter. This was a great loss to Mr S. in terms of freindship and support and also added to his anxiety about his wife wandering as the new neighbours would be strangers to both of them.

Mrs S is extremely dependent upon both Mr S and their dog (Gabby). Whilst Gabby is a positive factor in terms of emotional closeness for Mrs S she does not like leaving the house/going anywhere for any length of time without the dog.

Mrs S. would also get anxious if she felt that she had been left alone. For example, if Mr S went upstairs and she suddenly feels alone she would come looking for him and be tearful and distressed. This was extremely challenging for Mr S as he had no personal space/freedom in or out of the house.

Quality of life goals identified:

Cared for: Keep Mrs S safe and avoid hospital admission

Carer: freedom from anxiety about the future and Mrs S.
Peace of mind and freedom to live own life, have a social life.

Support/ Needs identified and action taken:

General back care advice given to Mr S. and information on falls prevention re-iterated.

Referral to Crossroads for ERCS and the carers alert card.

Referral through CSWS for a care-line alarm (useful for falls intervention) a key safe and a GPS tracker for Mrs S. which meant Mr S didn't have to worry quite so much if she did wander.

Whilst being useful in themselves these interventions were vital as offering Mr S some peace of mind about the emergency and safety factors identified in assessment (emergency plan, falls, wandering)

We contacted the pharmacy and got Mrs S's medication in blister packs.

Occupation/social interaction for Mrs S – this was a difficult one due to Mrs S dependency on home/dog and husband. However, I liaised with the proactive care team to get day-care arranged. With a very slow introduction including a home visit from one of the day-centre workers Mrs S did start attending for one day per week. This also gave Mr S some "free" time which provided a much needed respite from caring.

All of the above interventions were implemented within a few weeks of my first visit. Mr S. reported feeling reassured and more relaxed due to the few hours of respite per week. He was more aware of other support services out in the local area and felt he knew who to contact in the case of an emergency. The case was closed.

In February of this year Mr S. was re-referred to CHT for some follow-up emotional support. Mrs S. had been wandering more on the road and knocking on neighbour's windows etc. The new next door neighbours were understanding but it was very distressing for them and Mr S was again worried about her safety. He was not managing anymore due to the progression of the Alzheimer's disease and the length of time he had now been caring. The proactive team felt that it was time for Mrs S. to go into residential care.

As the proactive team felt that a therapeutic relationship and rapport had already been established with CHT worker they re-referred for support at this time. On my first visit Mr S was very upset: tearful, feeling guilty and very low in mood.

Over two visits and a couple of phone calls over the next few weeks: We reflected together on all the aspects of the caring role that he had managed to carry out for so long, keeping Mrs S. at home. We discussed how the risks were now too great and that the care and safety needs meant that a residential setting would provide optimum care.

We made lists of jobs that Mr S wanted to focus upon (DIY, garden, decorating). Information was provided on Silver-line and "Contact the elderly" (A once months meet up for single elderly people) Mr S. joined a local social and lunch club.

Mr S. visited Mrs S regularly in the residential home and Gabby had been allowed to visit too. Due to Mrs S's extreme wandering risk, Deprivation of Liberty safeguards have had to be put into place. Mrs S has settled amazingly well in the home and is generally calm and even smiling and relaxed on Mr S's visits. He reports an improvement in his own feelings of personal wellbeing.

Case closed – April 2015.

Mrs R

Introduction:

Mrs R self-referred herself having met me when I attended a Carers Support Group to promote the CHT. She was looking for more support in her role as a carer along with managing her own health.

Mrs R cares for her 76 year old husband. He is a retired Church minister who suffers from Parkinson's disease, and is in the early stages of Parkinson's related dementia. Mr R also has urinary incontinence and sometimes faecal incontinence. They live in their own 2 storey home and have 2 supportive daughters living in West |Sussex.

At the time of my assessment no care agencies were providing assistance and they had savings over £23,500, the SS threshold. Mr R was in receipt of full attendance allowance but, despite Mrs R being exhausted and suffering from a bad back, he not wish any of this money to be spent on his care. He believed SS should do so. However, Mrs R does have assistance from a weekly cleaner.

Mrs R was 72 and in was poor health. In 1997 she was diagnosed with a benign brain tumour. No treatment was given and it was not growing. However, she takes epilem following 1 seizure she had as a consequence of the tumour. Mrs R had previously had both hips replaced, 10 & 11 years ago. Unfortunately her right hip was once again causing her a lot of pain and affecting her mobility. She was also suffering from bad back ache for which she needed to take Ibuprofen for analgesia.

Assessment and agreed interventions:

Mrs R was spending a lot of money on incontinence pads. Mr R uses 2 – 6 / day ----
Provided with one call number so as to self-refer to community nurses if Mr R starts to uses more than 4 pads in 24 hours.

Mr R sometimes spills urine from bottle when in bed or in chair. This results in a lot of extra work for Mrs R ---- I applied for funding from the CHT for 4 bed sheets and 2 Chair sheets that Mrs R can then ordered from Age UK

Mrs R was taking a lot of Mr Rs weight when supporting him as he mobilises. He does not use the zimmer frame supplied. As she is twisting her spine when doing this it is aggravating her back and hip pain---I educated Mr R about the need for him to use a zimmer frame, rather than put his weight on his wife.

Mrs R was doing all her husband's personal care. She was exhausted with this but he would not spend their savings on funding help.

Mrs R goes to choir once per week and would like a carer to visit for 1 hour whilst she is out to shower Mr R, get him ready for bed, and hopefully actually put him to bed. This results in her having respite. I submitted an application to CSSWS wellbeing fund for £300 to help

fund approx. 20 weeks of carers visits (if £15/ hour). The plan was also that this might help him to accept daily care in the near future as in receipt of full attendance allowance.

If Mr R falls has no means of getting help. Referred for trial of careline

Access only to house by Mrs R Referred for a key box to be arranged

For all the following I referred to the OT for assessment:
Mr R struggles to: get out of the car and mobilise outdoors.

Only have one perching stool. Need one upstairs and downstairs.

Have a wet room in-situ. However, Mr R does not like using this as feels insecure on stool provided in such a big space and fears he might fall off. Might benefit from different seating

Mrs R struggles to move her husband in bed and sit him up in bed to eat or pass urine. He can only void sitting on edge of the bed. Is prepared to trial a hospital bed.

On discharge:

Mrs R is feeling much better and stated that the evening of respite when a carer visits so she can go out and Mr R is showered is a 'real lifeline'. She has also bought herself a bike as a means to get daily exercise and a break from caring. Mr R is also stating to accept the idea of having a daily carer in the near future and accepting that the Attendance allowance can be used towards this. Both Mr and Mrs R are finding the hospital bed has made both their lives much easier. They have also found the other interventions from the OT very helpful, including the suggestion of an electric motor that can be attached to Mr Rs wheelchair when outdoors. Mrs R is not so exhausted and has increased knowledge and ability to maintain her own health alongside the caring role.

Mrs G

Introduction:

Mrs G is an 86 year old lady. She is the main carer for her husband, who is 89. She was referred to the CHT by a physio on the Community rehab team. The referral requested Mrs G wanted some advice and support concerning caring for her husband.

Mr G had an aortic valve replacement in March. He had also recently been diagnosed with vascular dementia. He mobilises around the home with a zimmer frame, but no longer goes out. He had also lost interest in doing much, apart from watching TV. This was really annoying Mrs G.

Mrs G assists her husband to have a shower twice weekly. She also lays out his clothes so he remembers to change them. Mrs G also dispenses all medication, does all the household chores and paperwork.

Mrs G has her own health issues. She has bronchiectasis, glaucoma, swollen ankle, arthritic hand, and bowel problems. She recently had a Colongram to investigate her bowels and was awaiting the outcome on my initial visit.

Assessment & carer outcomes:

- a) Very concerned about her husband's declining physical and mental health.
- b) Gets very breathless when bending to dry her husband's legs following his shower.
- c) Exhausted in the evening due to her caring role.
- d) It takes quite a lot of time to dispense both their medication and remember to order new supplies.
- e) Worried about Mr G when she leaves the home to go shopping.
- f) Finds it difficult managing the washing when Mr G has episodes of dribbling incontinence. They had tried continence pads but Mr G hated wearing them, so refused.
- g) Mrs G does not have much information in how to communicate with someone in the early stages of dementia.
- h) They do not have much 'spare money'. However, they are receiving all relevant entitlements.
- i) Concerned who would care for her husband if she was rushed into hospital and her sons were not able to help immediately.

Quality of life outcomes for the carer:

- Maintaining health and well-being - not being so exhausted and breathless.
- Peace of mind - being aware of the services and help available in the future and being reassured her husband can call for help if she is out.
- Positive relationship with person cared for - increased knowledge and skills in communication with someone suffering from dementia.
- Freedom from financial hardship - ability to access funding from CSS to help with her on-going wellbeing

Quality of life for the cared for person:

- Personal safety and security -able to call for assistance if his wife is out

- Personal cleanliness and comfortable to manage dribbling incontinence
- Meaningful independence and mobility – increasing Mrs G's skills in being able to support and motivate him
- Meaningful activity/ stimulation – increasing wife's knowledge in how to engage her husband in meaningful activities. Getting him interested in jigsaw puzzles, painting and his enjoyment of history again
- Maintain dignity and morale – containing the dribbling incontinence and Mrs G being more supportive in her ability to help Mr G with his memory loss

Plan/interventions:

1. Provided a lot of reassuring information as to how various services can help them as both their health continues to decline.
2. Referred to crossroads care for an emergency care plan, carers alert card and weekly respite of 2 x 2 hour sessions. I also arranged that whilst the carer was visiting she would shower Mr G.
3. Registered Mrs G with Carers Support. I also requested that their dementia support worker make telephone contact with Mrs G, then keeps in regular contact to provide on-going support.
4. Completed a Carers Support Dementia Wellbeing application for funding to help provide the crossroads care at £20/ week.
5. Organised both Mr and Mrs G's medication to be placed in blister packs from their local pharmacy.
6. Referred for assistive technology, via Carers Support, for a Care line and key box to be installed.
7. Provided information so they could purchase all-in-one continence pants that Age UK provide.
8. Gave Mrs G information sheets, provided by Dementia UK, on Improving the Quality of Life and Communication with someone with dementia.
9. Provided both of them with 'Message in bottles'

Outcomes:

On discharge from CHT Mrs G was more positive about the future. Her husband was much less low in mood and also seemed to have 're-engaged with life'. He was also managing to shower himself without any assistance and mobilising without the zimmer frame. They therefore chose not to have Crossroads care respite visits, despite receiving funds from CSS. I therefore liaised with CSS that Mrs G could use some of the funds provided towards washable continence pants for her husband instead.

Mrs G states she has much more energy now that her husband's condition and outlook has improved, blister packs commenced, and continence pants being used. She also feels less tied to the home now care line is in situ. She feels particularly empowered to have more insight and skills in supporting her husband's struggle with dementia, getting much less irritated with him.

Both feel reassured to know help is available in the future if they need it.

Mr M

Introduction:

Mr M was referred to our team by Carer Support as he is the main carer for his father and no other agencies involved at present

Mr M has been the main carer for his father for last few years. He has recently had a hip replacement. Mr M is in very poor health himself with prostate problems and hernias and is under a London hospital for investigations and currently off sick from work as in too much pain.

Mr M is suffering from low mood and very anxious and stressed as fear of losing his job too.

Assessment/carers outcomes:

No contingency plans in place

Father discharged to stay with ex-wife, not ideal, no OT assessment completed

Financial worries, father not contributing to house hold

Mr M very stressed, low mood, in constant pain

QOL carer – Avoiding carer crisis by accessing services, looking after mental health and better pain management

QOL cared for- Avoiding hospital admissions by engaging with community rehab team

Plans/interventions:

Registered for Crossroads emergency respite care

Applied well-being fund to fund Careline

Referred to Community rehab team for assessment of both homes.

Advised to see GP re low mood and pain

Refer himself back to Time to talk

Outcomes:

Community rehab team assessed both houses and supplied equipment

Mr M managing pain better, has changed jobs, less stressed, worried.

His father returned home but stays some days with ex-wife which gives Mr M a break too.

Appendix 8: COPE Index

	Always	Often	Some- times	Never	N/A
Do you feel you cope well as a caregiver?	④	③	②	①	
Do you find caregiving too demanding?	①	②	③	④	
Does caregiving cause difficulties in your relationships with friends?	①	②	③	④	⑧
Does caregiving have a negative effect on your physical health?	①	②	③	④	
Does caregiving cause difficulties in your relationship with your family?	①	②	③	④	⑧
Does caregiving cause you financial difficulties?	①	②	③	④	
Do you feel trapped in your role as a caregiver?	①	②	③	④	
Do you feel well supported by your friends and / or neighbours?	④	③	②	①	⑧
Do you find caring worthwhile?	④	③	②	①	
Do you feel well supported by your family?	④	③	②	①	⑧
Do you have a good relationship with the person you care for?	④	③	②	①	
Do you feel well supported by health and social services?	④	③	②	①	⑧
Do you feel that anyone appreciates you as a caregiver?	④	③	②	①	
Does caregiving have a negative effect on your emotional wellbeing?	①	②	③	④	
Overall, do you feel well supported in your role of caregiver?	④	③	②	①	

Negative impact of caregiving
Positive value of caregiving
Quality of support