

University of Plymouth



Carers' Health & Well-Being Checks - Service Evaluation Study

Interim Report for
Project Implementation and
Sustainability Team

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EXECUTIVE SUMMARY: EMERGING THEMES

The Devon Carers' Health & Well-being Check (H&WBC) is drawn from a 'broad spectrum screening framework'. It is designed for adult carers and is built around a self-help model which encourages carers to express their own issues and concerns with the aim of working with them to plan how to overcome barriers to the steps they decide to take to protect their health. (See Appendix B for a more detailed check description). In advance of the H&WBC appointment, each carer is provided with a preparation booklet which has been designed to help identify the areas on which the carer would like the check itself to focus (DCC/PCT, 2009).

This executive summary provides a condensed record of some early indications suggested by the data collected from carers in the early stages of the development of the delivery of the Carers' Health & Well-being Checks service in Devon, described in more detail in the full text of the interim report which follows. Themes emerging from the research data are considered in relation to the seven primary aims identified by the programme delivery team at the beginning of the project.

Increasing identification of carers

The study data suggest that most success has been achieved in engaging older, retired carers, the majority of whom are caring for a spouse/partner in the H&WBC processes. A high proportion of study participants are already attending regular clinics for medication and monitoring of chronic conditions as well as for periodic recall, for instance for 'flu vaccinations and it appears that these lists are being exploited effectively to identify older carers. Substantial increases may now only be produced by efforts to widen the search to include younger, working adult carers, those looking after relatives not in the same household and children and young people with complex conditions or multiple needs. Drawing on and developing active links with other professionals in, for example, learning disability and mental health teams may pay dividends.

Providing carers with a structured consultation to discuss health and well-being

All project sites have been successful in this area although there is wide variation in the numbers of checks provided at different sites with no straightforward correlation with practice list size. As might be expected with any new project and was clear from the pilot study completed in 2009, time is needed for the establishment of structures and the embedding of procedures in the 'whole team' approach at provider sites which is central to overall implementation success.

Overwhelmingly, carers themselves have been satisfied with the check (84%) and almost all (91%) would recommend to others. Sometimes, the structured approach centring on the booklet seemed to overshadow the real purpose of the check and some reduction in the welter of paperwork would appear to be welcome – both for staff and carers. Some of the weight may not be directly related to the check itself but rather more to the research requirements for both local and national evaluations. Carers appear in these early stages to be almost equally divided between those who value the opportunity for an extensive health check and those who want to focus more closely on their emotional needs and well-being. From these early data, there is some evidence to suggest that nurses are better equipped to identify health problems while health care assistants are more adept at agreeing personal goals and action plans. The programme management team might like to consider whether

there are any ways in which both these areas of strength in different staff can be adapted and melded to best advantage.

Asked about possible improvements, carers almost invariably wanted to add more elements to the check, especially in relation to further biochemical tests such as bone density, blood, urine, kidney and liver functioning.

One important non-medical area of particular strain revealed by this sample is the financial strain imposed by caring which appears to be much higher here than would be expected in the general population and providers might like to consider whether this should be a priority area for at least some discussion with every health check recipient.

Increasing recognition and support for carers in GP surgeries

One carer in a participating surgery after the check did note that *'the doctor seems to be more helpful to the carer now as well as the person you are looking after'* and carers frequently felt that there was a 'safety net' on which they could call at particular times of need or as a starting point – without bothering the doctor – in their search for information and advice. It is a recurring theme from all the data that carers value the GP surgery as the trusted central contact point for all their enquiries.

It is disappointing to note therefore that when asked about their registration status, a significant number of carers do not know. It would appear that some of the administration and clerical systems in relation to the carers' register in GP surgeries are still in an early stage of development or it could be that carers do not feel any direct benefit from entry onto the register and therefore disregard its importance.

Offering choices which improve carers' control

None of the carers responding to the research questionnaires reported being offered any choice in provider or venue although one check did take place at home rather than in a surgery. It could be that carers have already made their choice by approaching a particular provider but given that the majority undertaking a check have been invited by their GP surgery and that the number of participating pharmacies is still very small, it is not possible to ascertain what part choice is playing in the process to date. In addition, it should be noted that payment for providers is directly linked to delivery of each check and there may be a pecuniary driver for providers to retain each carer identified rather than offering delivery through a competing service.

A rather different picture has emerged in relation to BME carers who are being offered 'clinic style' appointments in their own community centre settings as a result of preferences expressed through the programme's management committees and groups.

Complex care teams, learning disability and mental health teams have been primed to signpost carers to the H&WB checks programme and are about to come on stream along with arrangements for workplace checks. The impact that the availability of this range of different routes into the service has on carer choice and up-take will be tracked in the forthcoming months.

Facilitating links to preventive or early intervention services through membership of third sector organisations

Just over half of the carers responding to the local evaluation study were linked to a range of support services and nearly two-thirds reported actively using organisations including Devon Carers' Link, local carers' or condition-specific support groups and community transport services.

Promoting links to carers' assessment through complex care teams, mental health and learning disability teams

As already indicated, these additional providers are in the process of joining the study and the impact of their participation will be reviewed in the final evaluation report in 2011. However, it should be noted that the H&WBC booklet has been designed to include some specific elements, for example a section addressing work, education & leisure to link directly with Devon's carers' assessment processes. In fact, this is one section of the booklet that the current population of respondents found least helpful. Given that most are older carers who are not working or retired their lack of enthusiasm for work or education is not a surprising finding and it will be interesting to track responses if a wider range of younger carers is identified in the next phase of the project development.

Narrowing inequalities by focussing on areas of geographic and social isolation and disadvantage

The response to the preferences of BME carers has begun to address some of the aspirations underlying this project aim and further data will be gathered over the coming months for report in May 2011.

1.0 BACKGROUND

1.1 Rationale

The background to the programme and the evaluation study lies in a range of government initiatives set out in Green and White Papers such as *Every Child Matters* (HMSO, 2003), *Putting People First* (DH, 2007), *Independent Living* (ODI, 2008), *The Case for Change* (DH, 2008a) and *Carers at the Heart of 21st Century Families and Communities* (DH, 2008b) all of which emphasise the move towards a single community-based support system focused on the health and well-being of the local population. The Carers' Strategy (DH, 2008b) is an integral part of this central government agenda, which sets out a vision that by 2018, carers will be universally recognised and valued as expert care partners and will have access to:

- integrated and personalised services to support them in their caring role
- a life of their own alongside their caring role
- support to stay mentally and physically well
- services in which they are treated with recognition, dignity and respect

Carers UK, working on behalf of carers has highlighted a number of primary concerns for services including:

- Public health planning that explicitly addresses the prevention of ill-health amongst carers
- An active role for GPs in promoting the health of carers, eg. annual health checks
- Use of Carers' Assessments to address carers' health issues as a matter of course
- Promotion of a wider range of sources of information for carers

Against this background, the Department of Health has provided special funding to test different ways of offering health and well-being or lifestyle checks in a number of 'demonstrator sites' in England, of which Devon is one. The hypothesis to be tested through the demonstrator sites has several elements:

- That checks will give carers and health professionals an opportunity to detect and deal with, at an early stage, any emerging health problems a carer may have;
- That checks will contribute to better outcomes for carers including those who have recently stopped caring due to bereavement ;
- That early interventions to support carers will result in effective use of resources and possible savings:
 - by avoiding or minimising more intensive/expensive interventions
 - by avoiding or minimising the call on alternative support where a carer is unable to continue caring for health reasons.

1.2 Aim

A new programme has been designed in Devon to test specific Carers' Health & Well-being Checks (H&WBC) as part of the implementation of the government's national Carers' Strategy. The programme is funded by Department of Health to

deliver 3000 checks over two years from October 2009. The programme aims to maximise the physical and mental health and well-being of carers by:

- Increasing identification of carers;
- Providing carers with a structured consultation in which to consider their own health and broader well-being;
- Increasing recognition and support for carers in GP surgeries;
- Offering choices which improve carers control;
- Facilitating links to preventive or early intervention services through membership of third sector organisations, e.g. Devon Carers' Link
- Promoting links to carers' assessment through complex care teams, mental health and learning disability teams
- Narrowing inequalities by focussing on areas of geographic and social isolation and disadvantage.

The NHS Devon Carers' Health & Well-being Check (H&WBC) is drawn from a 'broad spectrum screening framework' and is capable of being conducted by staff at or above the level of health care assistant (HCA). The H&WBC is available to all carers aged 18 years and over who are registered at self-identified, participating GP surgeries. The H&WBC protocol is built around a self-help model which encourages carers to express their own issues and concerns with the aim of working with them to plan how to overcome barriers to the steps they decide to take to protect their health. In advance of the H&WBC appointment, each carer is provided with a preparation booklet designed to help identify the areas on which the carer would like the check itself to focus. (See Appendix B; DCC/PCT, 2009).

To increase accessibility and control for carers checks are being delivered at pharmacies and facilitated through the new NHS/Devon County Council partnership arrangements for learning disability, mental health and complex care teams as well as taking place in GP surgeries. Each location is designated as a 'provider site' for the purposes of this report.

2.0 STUDY DESIGN AND INSTRUMENTS

The local evaluation study draws strongly on a previous evaluation project - GP Carers' Project – commissioned in 2008 from RE:search South-West at the University of Plymouth by Westbank, to track the needs of carers to identify the key elements of four pilot schemes, based in GP surgeries, that best support carers in their care-giving role (Donnellan, 2009). These pilot schemes were funded through the Department of Health's Participation of Older Persons Projects and each provided a chosen GP surgery with a part-time carers' advice and support worker. In addition, four surgeries also offered an additional service specifically for carers, namely health checks, counselling and occupational health assessments. This year-long project reported in May 2009 and the executive summary for the evaluation is attached at Appendix A.

The local evaluation of the Health & Well-being Checks study aims to build some of the evidence for 'what works' in identifying and supporting carers in Devon to

maintain their own health, psychological and social functioning within their caring role. There are two strands to the evaluation study:

(i) **Process:** How well are the systems for identifying carers, providing health checks and meeting carers' needs working?

(ii) **Outcomes:** What types of carers are presenting for health checks? Does this vary across provider 'type' and access route e.g. GP, pharmacy, complex care team? What carer needs are uncovered? What are the benefits of the health check system from carer, GP and provider perspectives?

Following the inaugural H&WBC in November 2009, the project management team experienced difficulties in the recruitment of a sufficient number of provider sites to meet early targets. Contracting and training requirements for delivery staff, together with delays in confirmation of national evaluation team (NET) requirements, further frustrated commencement of checks and the local evaluation study was only able to commence data collections in late January 2010.

There has been a staged programme of recruitment in which providers have joined in four phases: November 2009; January 2010; April/May 2010; & July 2010. The range and distribution of providers engaged in the project to date is summarised in Table 1 below. It should be noted that the workplace checks and clinics for black, minority ethnic (BME) groups are being undertaken at various locations across the county in partnership with St. John Ambulance. As the main contact points are in Exeter, these providers are recorded in this table as part of the Eastern region.

Table 1: Schedule of programme provider types (as at 27/08/10)

Programme Provider Types	North	South	East	Totals
GP Surgery	9	8	18	35
Pharmacy	1	1	8	10
Complex Care Team	1		1	2
Workplace Checks Provider			1	1
BME Clinics – Hikmat/Sahara			1	1
Totals	11	9	29	49

2.1 Carer Involvement

Drawing on established best practice guidance, the research protocol includes arrangements for direct carer contribution to the study design, tools and piloting through a Carers' Participation Group comprising 8 members drawn from participating GP surgeries and carers' support groups in Devon. A specific budget has been allocated for remuneration for attendance at meetings, as well as travel, carer costs and expenses. Three of six planned meetings have taken place and members have reviewed progress and themes emerging from the study.

2.2. Participants

The study is using a mix of standardised and validated forms, locally generated questionnaires and semi-structured interviews to gather both quantitative and qualitative data. There are three categories of participants:

- Carers consenting to join the study aged 18 years or over
- Health & Well-being Check (H&WBC) providers
- Participating GP surgeries

2.3 Carers

Data collection is designed to address both carers' health status and satisfaction with services offered/received. An initial research pack handed to carers on completion of their H&WBC contains two questionnaires for those choosing to respond:

- Background Information Form to gather benchmark and demographic data. This also includes a modified version of the Carer Strain Index (CSI), a validated 13-item questionnaire;
- The General Health Questionnaire (GHQ28) - a validated and widely used instrument – asking seven questions in each of four domains: physical health; anxiety/depression; social functioning; and mental health;

The pack also contains a reply slip for those who wish to identify themselves to the research team to take part in a subsequent satisfaction survey by telephone interview or follow-up postal questionnaire.

The research questionnaires are completely anonymous and do not ask for any personal details that would identify a participant. The forms have an anonymous research reference number to track only the provider site from which responses have been generated. However, in accordance with NHS ethics approval, the GHQ28 bears a unique identification number in addition to the site code so that should any particular response show 'above threshold' scores, the check provider (not the research team) will be able to make contact with an individual participant in order to agree the best action in the light of the risks identified by the GHQ28.

BME groups

A primary outcome for the demonstrator site project is to improve the engagement in health checks of carers drawn from black and minority ethnic (BME) backgrounds and most particularly those whose first language is not English.

The Hikmat and Sahara Projects in Exeter are designated as a 'provider site' where H&WBCs will be offered to BME carers in partnership with St. John Ambulance. Arrangements have been agreed for the translation of the research study's invitation letter, information sheet and GHQ28 into four languages (Arabic, Bengali, Mandarin and Urdu) to facilitate participation in the research by those whose first language is not English. Those choosing to do so will be offered the opportunity to complete the initial background questionnaire at the time of their H&WBC appointment with the support of a community mentor. BME participants will be invited to take part in a focus group meeting to gather individual experiences and perceptions of the H&WBC. Focus groups will take place in familiar surroundings at a known community centre with translation and support from a community mentor provided through the Hikmat and Sahara Projects. Checks for carers from BME groups commenced in June/July 2010. Responses to initial background questionnaires are not therefore available for inclusion in this report but the first focus group took place in July 2010 and is reported in Section 5.

Young carers

The interim report relates only to checks provided to adult carers aged 18 or over. However, the evaluation project will be extended to include data collection from young carers aged 14 – 18 years, who will take part in a separate Health & Well-being Conference Day which the programme team will deliver in Exeter in October 2010. Co-ordinated through established young carers' projects across Devon, young carers will be invited to participate in six health and well-being zones at the conference and to provide an evaluation of their experiences both before and after attendance. This extension of the programme is the subject of on-going planning, including ethical approval and will be reported in the final study report in May 2011.

2.4 Check Providers – Monthly Reports

All provider sites – GP surgeries, pharmacies, Hikmat Centre, complex care teams etc - are asked to complete a monthly activity report form relating to that specific site and returned electronically to the evaluation team, detailing cumulative numerical totals for groups and types of carers to whom a check has been delivered each month. No personal information is included.

2.5 Participating GP Surgeries – Global Monitoring

GP surgeries only are asked to complete and return electronically a global monitoring form up-dating the research study with numbers and gender/age demographics of all carers registered at their practice. Cumulative numerical totals for groups and types of carers are reported and no personal information is included.

3.0 DATA COLLECTION

3.1 Provider Sites

Of the total provider sites identified as above, active participants in the research study included in this report are summarised in Table 2.

Table 2: Provider site activity (as at 30/06/10)

Provider Type	Active Sites	Sites Returning Research Reports	
		Monthly Activity Form	Global Monitoring Form
GP Practice	26	12	11
Pharmacy	3	3	n/a
Totals	29	15	11

Less than half (44%) of the GP practices actively delivering checks have provided the research team with monthly activity reports in relation to the volume of appointments made/refused/delivered and a slightly smaller proportion of participating GP surgeries (41%) have been able to provide a breakdown of the overall activity and characteristics of patients included in their carers' register (global monitoring form) in terms of the relationship, age and gender of carers and care recipients.

These differences are surprising and further efforts will be made to better understand the disparities in reporting standards. On preliminary investigation, the surgeries which have responded with detailed data appear to be larger, with a list size in excess of 8500, with perhaps a larger or more flexible workforce, or are those surgeries that have had previous experience from involvement with the pilot project in 2008/9.

3.2 Carers' Questionnaires

Providers distributed 577 'research packs' to carers completing a H&WBC at 26 GP surgeries and 3 pharmacies during the period January to June 2010. As at 30th June 2010, 207 initial background questionnaires have been completed and returned in batches averaging 48 per month. (See Table 3).

However, it may be worth noting that receipts in June 2010 were reduced by nearly one-third (31%). At this time, in response to requests from providers for simplification of the processes, revised paperwork was introduced at provider sites, involving new procedures for delivery staff and an additional form which attempts to synchronise the management data for the programme and national evaluation team requirements. This was completed by carers as part of their appointment time, which was extended by 10 minutes to include the additional task. It may be that these changes affected either the distribution of packs by providers or the readiness of carers to undertake 'yet another questionnaire'. Carers' comments about improvements to the process have included:

“Possibly not so many different forms as I have got to the point where we have had some forms more than once now and I feel I probably may not bother”.

“Repetitive paperwork – just not necessary”.

Responses since June have returned to the previous average numbers. The overall response rate to date is 36% as set out in Table 3.

Table 3: Participant response rates - carers

	Packs distributed	Responses Received	Response Rate
Initial Research Pack:			
Initial Questionnaire including Carer Strain Index (CSI)	577	207	36%
General Health Questionnaire (GHQ)	577	198	34%
Satisfaction Survey:			
Satisfaction Questionnaire	237	146	62%
Telephone Interviews		51	22%
TOTALS		197	88%

3.3 Initial Background Information Questionnaire

The report is based on an analysis of responses from the first 100 participants in the research study. The geographical spread of provider sites and types across Devon from which this sample has been generated is illustrated at Table 4.

Table 4: Geographical distribution of carer responses (n=100)

Geographical Area	Carer Responses %	
	GP Surgery	Pharmacies
North	25%	0
East	53%	6%
South	16%	0
TOTALS	94%	6%

Carers – General characteristics

The Programme Implementation and Sustainability Team have collected global management information in relation to a range of general demographic characteristics of all carers who undertake a H&WBC and these were made available to the research team in September 2010. Although some criteria have been defined using different *ranges* (e.g. age), a comparison of the general demographics illustrated below reveals a strong correlation between the whole population and study sample across all criteria with the exception of age of carer. The study sample at this early stage is skewed towards older carers with a higher proportion of study respondents aged 65 – 74 years than in the whole programme population

Table 5: Comparison of demographics – All carers and study sample

Characteristic		All Carers <i>Whole Programme Population</i>	Study Sample
Gender of carer	Female	71%	72%
	Male	28%	28%
Age of carer	18 - 64	49%	37%
	65 - 74	26%	36%
	75 - 84	20%	20%
	85+	6%	7%
Care recipient - Type	Child	12%	11%
	Parent	19%	21%
	Spouse/Partner	64%	64%
Care recipient - Age	0 - 64	26%	26%
	65+	74%	74%

Turning to the study sample, all except four carers described themselves as the main carer and the vast majority (90%) are living in the same household as the care recipient. This is a much higher proportion than has been found in either local (77%) or national (48%) surveys of carers (NHSIC, 2010; GfKNOP, 2010) and is one of the factors already known to be associated with higher levels of carer stress (Nolan et al, 1996; Twigg, 1992).

Nearly three-quarters (72%) of this sample of carers are female and two-thirds are aged 65 years or over. Over half (57%) have been in their caring role for more than five years and over three-quarters (78%) are spending more than 30 hours each week in their caring role. Further general characteristics of carers responding to the initial background questionnaire are summarised in Table 6, p. 18.

More interesting data begin to emerge when carer characteristics are analysed by gender and these proportions are shown separately in italicized numerals in Tables 6 & 7 for both women and men.

A recent survey of carers known to local authority adult social services departments in England has been carried out by the NHS Information Centre (NHSIC, 2010). Figures extracted from this survey specifically in relation to results reported by Devon authorities are included in the right-hand column of Tables 6 & 7 for comparison against a number of carer and care recipient characteristics found in this study.

Age

This sample comprises a higher proportion of carers (63%) over 65 years compared with 24% found in the latest national population survey of carers (GfKNOP, 2010). There are also differences within the sample in relation to gender and age. Of the women, 35% are under 64 years and 20% over 75 years. The opposite is true for male carers with 22% under 64 years and 45% over 75 years.

Working and time spent caring

The table shows that the majority of male carers (75%) are retired and nearly all (89%) are caring for a spouse/partner. Nearly two thirds (63%) of men are in the first five years of caring whereas 45% of women have been in their caring roles for 10 years or more. Women are also involved in caring for children, grandchildren, parents and parents-in-law to a greater extent (42%). Over half (58%) of the total sample of carers report spending in excess of 50 hours each week caring and there appears to be little gender difference in relation to this descriptor.

Care recipients – general characteristics

The majority of carers (85%) in this sample are caring for one person. Those caring for two or more (15%) have completed questions about recipient characteristics for the person for whom they provide the most care (see Table 7). There is a fair level of congruence across recipient characteristics with the demographics reported in the NHS Information Centre survey (NHSIC, 2010). Care recipients in this study are slightly more likely to be men than women but similar proportions are aged over 65. Nearly all (92%) have physical difficulties frequently in combination with one or more additional problems and 1 in 4 has a diagnosis of dementia, Alzheimer's or Parkinson's disease.

Table 6: Summary characteristics of carers

Carers		Total Sample <i>n=100</i>	Within sample of women <i>n=72</i>	Within sample of men <i>n=28</i>	National Carer Survey Devon sub-set <i>NHSIC 2010</i>
Gender	Female	72%	72	-	-
	Male	28%	-	28	-
Age	20 – 44 years	5%	6%	4%	7%*
	45 – 59 years	17%	21%	7%	44%*
	60 – 64 years	15%	14%	15%	
	65 – 74 years	36%	39%	3%	49%*
	75 – 84 years	20%	19%	26%	
	85 – 89 years	7%	1%	18%	
Relationship to care recipient	Spouse	64%	54%	89%	54%
	Child / Grandchild	11%	14%	4%	6%
	Parent /in law	21%	28%	7%	34%
Length of time in caring role	Less than 2 years	18%	17%	26%	44%
	2 – 5 years	24%	21%	37%	
	6 – 9 years	19%	19%	19%	26%
	10 – 20 years	25%	32%	7%	21%
	20+ years	13%	13%	11%	9%
Hours spent caring per week	0 – 20 hours	13%	10%	18%	16%
	21 – 30 hours	9%	11%	0%	5%
	31 – 50 hours	20%	21%	22%	8%
	51+ hours	58%	58%	59%	59%
Employment status	Unable to work due to caring	15%	18%	7%	13%
	Retired	62%	57%	75%	68%
	Paid work – Full or part time	11%	13%	7%	16%
Surgery visits in last 12 months	Average consultations-GP	3	-	-	-
	Average consultations-Nurse	1	-	-	-
Regular clinics attended	Regular attendance	70%	70%	70%	-
	Blood pressure	28%	31%	58%	-
	Flu vaccination	51%	76%	63%	-
	Asthma/chest conditions	13%	16%	26%	-
	Osteoporosis / Arthritis	10%	14%	16%	-
Perceptions of own health	Self-identified disability	29%	24%	38%	27%
	Good health	41%	38%	50%	48%
	Fairly good health	45%	49%	35%	43%
	Not good health	13%	13%	15%	9%
Carers' Register Registrations	Jan 2010 onwards	26%	-	-	-
	Prior to 2009	34%	-	-	-
	Don't know / No response	40%	-	-	-
Hospital admissions in last 12 months	Carer admitted	5%	27%	19%	-
	Care recipient admitted	24%	27%	19%	-
	Formal respite day or night	13%	13%	11%	-

* GfK NOP (2010 National figures only–not Devon specific. Fully analysed data due in December 2010

It is interesting to note however that while 30% of the female carers are looking after those aged 85 or over, only a small proportion of men (8%) are involved with the oldest care recipients. It has already been noted that men are caring primarily for spouses and it may well be that the older care recipients are more likely to be parents/parents-in-law who are being cared for by female carers in this sample.

Taken together, these data suggest that the current sample is skewed to older, long-term, highly involved and heavily committed carers, primarily in spousal dyads, but this may well be the group that can derive greatest benefit and support from a specific H&WBC service.

Table 7: Summary characteristics of care recipients

Care Recipients		Total Sample n=100	Carer		National Carer Survey Devon sub-set NHSIC 2010 ¹
			Female %	Male %	
Gender	Female	46%	-	-	56%
	Male	53%	-	-	44%
Age	20 – 44 years	4%	6%	0%	17%
	45 – 59 years	12%	11%	15%	
	60 – 64 years	10%	6%	19%	
	65 – 74 years	15%	14%	19%	13%
	75 – 84 years	34%	33%	41%	33%
	85 - 89 years	10%	10%	4%	37%
	90+	15%	20%	4%	
Health * conditions	Physical difficulties	92%	-	-	62%
	Dementia/Alzheimer's/Parkinson's	30%	-	-	25%
	Sensory impairments	25%	-	-	35%
	Learning disabilities	7%	-	-	7%
	Mental health	8%	-	-	8%

*Total >100 due to care recipients reported as having >1 difficulty

¹ National survey of carers known to local authority social services depts. (NHSIC, 2010)

Consultations

Nearly three-quarters of carers (70%) attend a regular clinic and just over one quarter (27%) attend more than one clinic. These data suggest that GP practices are successfully engaged in services linked to the quality outcomes framework (QOF) and carers are well represented by high attendance at these clinics, which clearly provide an excellent sub-set on which to focus the search for other, as yet unidentified, carers.

Just over half (55%) of carers reported that they had consulted their general practitioner (GP) 2 times or less in the twelve months prior to their H&WBC and nearly half (46%) had not seen a nurse at all in the same period. Carers reported an average number of 3 GP consultations and 1 with a practice nurse in the previous 12 months. These are very low levels of consultation when compared with national data from the General Household Survey (GHS) in 2007 when men were making an average of 4 visits and women an average of 5 visits per year to their GP. We

already know that carers are frequently reluctant to identify themselves, and these consultation data may suggest that carers are making the decision to ‘soldier on’ rather more frequently than those who are not in a caring role. With more data, the on-going study will aim to interrogate and elucidate some of the reasons for this finding.

Carers’ Register

When asked, 40% of carers could not say if they were registered as carers with their surgery. One third gave registration dates prior to October 2009 and just one quarter (25%) were more recent recruits who had joined the register in 2010.

These results suggest that current H&WBCs are being delivered to those carers already known to surgeries and in the early stages of development, this may be a helpful strategy to provide staff delivering the checks with an opportunity to rehearse and ‘fine tune’ their approaches with more engaged carers.

The proportion of ‘don’t know’ responses is disappointing and suggests that perhaps administration processes or arrangements to prioritise and promote the importance of carers in participating surgeries are still in the early stages of development.

Perceptions of own health

Asked about their own health, 29% of carers reported having a limiting longstanding condition or disability themselves, very much in line with findings of the general household survey in 2007 which showed that long-standing illness was reported by 32% of the population in the south-west region. When asked to rate their own health over the last 12 months, a contrast with ‘whole population’ figures emerged (see Table 8). However, the ‘not good’ figures are comparable:

Table 8: Carers’ General Health Rating over the previous 12 months

Self-reported health status	Carers as at 30/06/10	General Household Survey 2007	National Carer Survey* Devon sub-set NHSIC 2010
Good	41%	63%	48%
Fairly good	45%	25%	43%
Not good	13%	12%	9%

* National survey of carers known to local authority social services depts (NHSIC, 2010)

Some gender difference emerged with 50% of men rating their health as good compared with only 38% of women. This is a surprising finding given that the male carers are older and reported a higher level of disability although conversely, they did report higher levels of attendance at regular clinics with the exception of ‘flu vaccinations. There is some evidence to suggest that men are more ready than women to seek out the help they feel that they need (Corcoran, 1992, Fitting et al, 1986).

3.4 General Health Questionnaire (GHQ28)

The General Health Questionnaire (GHQ) is divided into four domains:

- Section A: **Physical difficulties**
- Section B: **Anxiety and insomnia**
- Section C: **Social and personal difficulties**
- Section D: **Depression and mental health**

Each domain comprises 7 questions and respondents may choose one from four options, which provide a total score from 0 – 7 in each domain. A high score (4 or more) in any domain is sufficient to trigger a concern in this area of functioning (high risk) (Goldberg, 1978).

Questionnaire responses were collated and scored and an initial analysis of the data was undertaken using SPSS (Statistical Package for Social Sciences), in relation to each of the four sections of the GHQ. A primary analysis of all responses is given in Table 9 below:

Table 9: GHQ28 Responses – All participants

GHQ Domain	Participant Responses %				
	Low risk	Medium risk	High risk		
	Total	Total	Total	Female	Male
A: Physical strain	68%	23%	10%	15%	4%
B: Anxiety & insomnia	77%	7%	15%	20%	8%
C: Social dysfunction	80%	14%	5%	5%	8%
D: Mental health	94%	3%	2%	4%	0%

The table shows that physical strain and insomnia are the domains in which there is the largest proportion of ‘high risk’ participants. The ratio of those scoring high – at or above the level to trigger a concern – in each domain of the GHQ is as follows:

- **A: Physical strain: 1 in 10 scoring high**
For instance, 10% of respondents feeling run down and more ill than usual
- **B: Anxiety and insomnia: 1 in 6 scoring high**
For instance, 15% of respondents felt ‘edgy and bad tempered’ and reported feeling ‘constantly under strain’.
- **C: Social dysfunction: 1 in 20 scoring high**
For example, 5% reported ‘taking longer over things’ and being ‘able to enjoy day to day activities’ much less than usual.
- **D: Mental health: 1 in 50 scoring high**
For example, 1 in 50 feeling ‘worthless’ and ‘finding life entirely hopeless’.

The code numbers of 16 participants have been referred back to the check provider - 9 GP surgeries; 1 pharmacy - as a result of ‘above threshold’ scores for follow-up, in line with ethical approval.

3.5 Carer Strain Index (CSI)

Analysis of responses to the thirteen questions contained in the Carer Strain Index (Sullivan, 2007) has been used to identify those areas which give rise to most stress for carers. The highest score is represented by those selecting ‘regularly’ from the three response options. The ‘primary stressors’ which emerged are set out in order of frequency, expressed as a percentage and as a ratio of the study sample:

- | | |
|---|------------------------------------|
| 1. Changes in the person cared for (39%) | 1 in 3 selected ‘regularly’ |
| 2. Emotional adjustments (37%) | 1 in 4 selected ‘regularly’ |
| 3. Changes in personal plans (35%) | 1 in 3 selected ‘regularly’ |
| 4. Sleep disturbance (32%) | 1 in 3 selected ‘regularly’ |

The areas of least stress are represented by those selecting 'never' from the three response options, again in order of frequency:

- | | |
|---|--------------------------------|
| 1. There have been work adjustments (64%) | 2 in 3 selected 'never' |
| 2. Care-giving is a financial strain (50%) | 1 in 2 selected 'never' |
| 3. Care-giving is inconvenient (46%) | 1 in 2 selected 'never' |
| 4. I feel completely overwhelmed (43%) | 1 in 2 selected 'never' |

Sleep disturbance and changes to personal plans imposed by care-giving affected 87% of carers at least sometimes. 82% of carers also found the emotional demands of caring and changes in the care recipient to be sources of stress at least some of the time and for the majority of this sample - in early retirement and caring for a spouse or partner - these findings are not surprising. Although 43% never felt overwhelmed, it is concerning to note that 1 in 2 of the study sample felt completely overwhelmed at least some of the time.

Again, there are some interesting gender differences. A higher proportion of men than women consistently selected 'never' across all stressors. For example, 50% of men and only 21% of women felt that caring was never a physical strain. Three times as many men (38%) than women (12%) felt that there were never other demands on their time and twice as many men (64%) compared to women (33%) reported that they never felt completely overwhelmed. In this sample, the male carers are almost exclusively caring for their partners and a high proportion are retired. By contrast, the female carers are those caring for a wide range of recipients, many of whom are very old (85+) and female carers are also more likely to be attempting to combine work and caring roles.

Financial strains can be particularly pernicious (Princess Royal Trust, 2010; Vellone, 2007) and when asked to describe their own financial position both within the Carer Strain Index and in the satisfaction survey, 1 in 5 carers felt that they were struggling to get by. Compared with the responses of carers known to councils in Devon (Table 10), there is cause for concern. It may be that carers presenting for a H&WBC are not in receipt of all the benefits that could be available to them. The data clearly suggest that financial information and advice could be a priority focus for the H&WBC appointment.

Table 10: Levels of financial strain

Level of financial strain	Carer Strain Index	Questionnaire response (Own rating)	National Carer Survey Devon sub-set NHSIC 2010*
Never / Comfortable	50%	31%	59%
Sometimes / Managing	30%	42%	34%
Always / Struggling	20%	20%	7%

* National survey of carers known to local authority social services depts (NHSIC, 2010)

Supports, respite and hospital admissions

Taking a break away from caring is an area in which the situation and condition of carer and care recipient are almost inextricably intertwined with one another. Given the levels of strain, disability or long-standing illness and self-reported levels of poor health noted above, it is surprising that only 5% of carers reported needing hospital

care in the last year. By contrast, nearly a quarter of carer recipients had been admitted for at least an overnight stay in the same period. Nearly one-fifth (18%) of carers reported making use of formal day care or night sitting services and a smaller proportion (12%) reported accessing formal respite for at least an overnight stay in the twelve months preceding their H&WBC.

Just over half of carers (54%) reported making use of a variety of formal supports in the six months prior to their H&WBC. Those most frequently mentioned are presented at Table 11.

Table 11: Support services accessed by carers

Services accessed 6 months prior to check	Carers %
Social Services or Care Direct	37%
Devon Carers' Link	27%
Local Support Groups	19%
Benefits Advice	17%
Day Centre	14%
Community Transport Services	13%

Carers were also asked about the Internet and a majority (64%) reported being able to access the internet for themselves at home. Interestingly, there appears to be no correlation with either gender or financial situation but age is a strong limiting factor. Only 16 respondents with access to the internet are aged 75 years or over.

3.6 Satisfaction Survey

The satisfaction survey sample comprises those who, having had their H&WBC, agree to participate in a follow-up survey and identify themselves to the research team. A short telephone interview or postal survey option is available for those who have difficulties with the telephone and/or express this preference when responding to the research invitation. From the total of 237 participants responding to the invitation, 51 (22%) agreed to undertake a telephone interview which are about to commence and 146 (62%) have returned a postal survey. Three-quarters of survey respondents (75%) are female and 25% male.

The satisfaction survey uses a mix of closed, 'tick box' questions, using scales from 1 – 5 to generate quantitative data, as well as providing space for participants to record more qualitative material, expressing individual opinion and open comment.

When asked about their overall opinion of the H&WB Check, 84% were satisfied with the H&WBC and 91% said that they would recommend it to others.

Appointments - Information and logistics

Nearly all H&WBCs (94%) had taken place in a GP surgery, although 5% were in a pharmacy and one had been undertaken at home. None had been offered any choice of venue although by approaching a particular provider for an appointment it may be assumed that the carer had already made this choice.

The majority of carers (80%) felt it was easy to find out about a check with nearly three-quarters provided with information by their surgery. A small minority (9%)

referred to Carers' Link as an information provider. Other sources cited included word of mouth via other carers, the local hospital and carers' support groups. These data suggest that early take up of the H&WBC is most actively pursued by those already well connected to established social networks and support groups.

The vast majority (96%) agreed or strongly agreed that it was easy to book an appointment. Two-thirds had in fact been contacted direct by their GP surgery. A minority (16%) of carers needed to draw on specific additional assistance in order to attend the appointment. Those who needed replacement sitting services at home generally made arrangements with a member of their family rather than employing an additional formal carer. However, several carers did mention time pressures and the necessity for appointments to keep to time, even though they understood that some people may need more than others and scheduling could be difficult:

“Everything beginning at the appointment time... If a carer has had to bring in help it is important for them not to worry that they might be late getting back. But it does work two ways ... the carer must endeavour to be on time too. This can prove difficult if a paid worker is late though.”

“I know it's difficult but I had to wait 30 minutes for my appointment – time I really didn't have to waste. I know it was because the previous person needed more but I was on a time limit too and had to ask the health care assistant to rush my session.”

Duration of checks

Delivery arrangements are based on an initial assumption that each H&WBC will take one hour. Early post-check summary reports show appointments ranging from 30 to 120 minutes, with an average of 66 minutes. There appears to be little variation between providers although the small number of pharmacy-based checks are taking longer but these are still in the very early stages of development

Delivery staff

Carers were full of praise for those who delivered their checks:

“[the nurse] was very helpful and most efficient. She covered every aspect and gave good advice”.

“The nurse who carried out the check was excellent”.

For this initial sample of respondents to the postal survey (n=100), a variety of staff had been involved in the delivery of the H&WBC (Table 12).

Table 12: Check delivery staff – Types and outcomes

Check delivered by	Total Checks Delivered %	% Plans Agreed	% New Condition Identified
Nurse	64%	47%	27%
Health Care Assistant	29%	63%	18%
Pharmacist/Dispenser	5	80%	20%
Advice & Support Worker	1	0	0

These early data seem to suggest varying levels of success in relation to different sections of the check depending on the background/qualification of the person delivering the check. It is perhaps not surprising that nurses appear to uncover a

higher proportion of new conditions. On the other hand, health care assistants appear to be much more successful in making and agreeing concrete plans for action with carers. The numbers of pharmacists and advice and support workers reporting is too low to inform the analysis at this early stage.

Carers themselves noted:

“Should the checks be split into medical things such as blood checks and a more aware person going through the other issues for carers? The nurse going through my check for instance thought it could be done by a health care assistant”

“I think the person doing the check needs to be more tuned in to what being a carer, especially a full-time carer means, that is emotionally and physically. I felt it was very much a physical ‘black and white’ check”

Some also mentioned the weight of paperwork and what appeared at times to be a cumbersome process that staff (and carers) encountered in the course of the check process:

“As it is, the whole scheme is a smokescreen to obtain some sort of funding. The carers are an irrelevant distraction in a bureaucratic exercise”.

“Instead of ticking boxes, it would be nice if I could talk about individual problems. We don’t all fit in the box!”

The extent of this perception will be presented in the final report.

Pre-preparation booklet

A booklet, *‘How to make the most of your health and wellbeing check’* (DCC/PCT, 2009), has been designed specifically for the programme. Nearly all (97%) carers had received the preparation booklet prior to their check. Nearly two-thirds (62%) found it very useful or better in helping them to prepare for their appointment. The vast majority (88%) had completed some questions, with 44% completing all of them before attending for their appointment. Only 25% had attempted the section on personal planning.

When asked about each section in turn, the ‘top three’ sections most frequently considered **‘very helpful’** were:

- Own health (**52%**)
- Check-ups and screening (**45%**)
- Home safety (**41%**)

The three sections considered **‘not helpful’** most often were:

- Questions about alcohol (**25%**)
- Work, education and leisure (**16%**)
- Personal plans (**13%**)

New conditions

Nearly a quarter (23%) of carers reported that a new condition had been identified. This finding is not entirely consistent with the high proportion of the study sample already attending regular clinics for screening and follow-up of specific conditions.

Onward referrals to the GP (50%) or practice nurse (39%) for further tests was the outcome for the majority of these carers although some experienced heightened anxiety in waiting for results from the GP surgery:

“ I wish I had known about these tests before ... 1st March health check; 17th March BP test; 22nd March ECG; 5th April for results ... I feel anxious about the outcome It seems a bit drawn out”.

“It would be nice to know the results of the check samples that were taken but I have never been told the result. I contacted the surgery to ask and was told if anything is not right I will be contacted but a personal answer would go down well and give comfort”

Specific goals and action plans

Just over half (53%) of carers had identified specific individual action plans or goals as a result of the H&WBC. These were many and diverse but are presented in the following four main groups:

- **Medical goals** (35%) for example, GP/nurse referral, exercise, weight loss
- **Support goals** (28%) for example breaks, ‘me time’, support groups
- **Practical goals** (21%) for example finance/benefits advice, Care & Repair, alert cards
- **Training/education goals** (3%) for example Expert Carers’ and St. John training programmes.

Less than half of those who reported agreeing goals (43%) felt that any of these would be easy to achieve and some had already decided to delay or defer attempting them. There is a sense in which goals had been agreed simply to bring an end to the consultation:

“To be quite frank, I found it a waste of time.....All of the plans agreed meant being away from home and having to pay a sitter”.

“For about one week I made the effort to look after myself better, eat more healthily, a bit of exercise but that soon went by the way side. I haven’t the inclination or the time to keep it up”.

Talking and coping strategies

Many carers – both male and female - valued talking and the opportunity for validation of their role by a professional as the most helpful part of their H&WBC. This has been reported as an effective coping strategy in stressful situations in a previous study (Lepore et al, 2000).

“Talking to a nursing professional about some of my needs and receiving positive and sympathetic responses was really good”

“Time out to talk and evaluate my position as a carer. The health check gave me confidence in my own health”

“Time to talk and have a sensible conversation”

Confirmation that there were no areas of concern about their own health seemed to give much valued ‘peace of mind’ to a number of carers

“Reassurance on my health matters – that I am taking care of myself”

“Feeling confident about my own health – time to think – access to advice”

“I felt more confident about my own health, knowing there were no concerns and just the satisfaction of being able to talk to someone about general problems of being a carer....”.

Improvements

Asked about areas for improvement, 29% of carers responded. Comments again referred to the extent to which the check focussed on physical, health-related matters and their preference for a better balance with emotional issues:

“There were one or two issues that didn’t seem to have time to discuss... the tests took up all the time. Perhaps being asked ‘any other questions?’ would have been helpful”.

“[The check] needs to focus on carers’ needs... that is talk to the carer to identify needs...a set of questions which are closed have limited value. Carers have emotional needs as well as the more obvious health issues”.

However, other suggestions for improvements offered by carers focussed on additional health checks such as urine, kidney and liver tests as well as ECG and bone density checks.

Expectations & satisfaction

When asked about their expectations of the H&WBC, over three-quarters (78%) of the carers taking part in the survey agreed or strongly agreed with the statement that the check met their expectations. Some responses suggested that some carers may have unrealistic expectations of what can be achieved through a H&WBC or it may simply be that there is a strong preference for a ‘one stop shop’ where several concerns can be dealt with in one appointment:

“I was expecting the person I saw to have all the answers to my concerns. I was just directed to other people which when you are a carer it’s not always easy to access when you have time constraints”.

“Time to talk about my own health issues and receive checks that I wouldn’t have made time for otherwise. Also meant that several issues could be covered in one appointment”.

However, a large majority (84%) were satisfied with their check although several felt that it might be more relevant to new carers at the time of diagnosis of the condition of the care recipient.

“I was very satisfied with all aspects of my health check”

“I think if you were a new carer it would have been more beneficial because I have been introduced to most of the help you can get after 8 years!”

“This check should be offered at diagnosis to enable carer to fully benefit ... as should all other support”.

The vast majority of carers (85%) felt that staff were well trained and competent:

“I couldn’t have had a better person to carry out my health check”.

Asked if they would recommend the H&WBC to others, 91% of carers either agreed or strongly agreed.

4.0 FOCUS GROUPS – BME CARERS

Although there has been an increased focus on carers in the UK, there is a lack of research looking specifically at black, minority, ethnic groups (BME). The National Strategy for Carers - *Caring about Carers* (DH, 1999), acknowledges that there is insufficient information surrounding BME carers and the H&WBC programme will be looking specifically at the experiences of BME carers in Devon as part of the local evaluation.

A survey in 2007 showed that 10% of carers in England, Scotland and Wales were from BME backgrounds (Yeandle et al, 2007) and compared with other carers, these communities are more likely to:

- report that they struggle to make ends meet;
- be caring for their children, particularly children aged 20-25;
- be caring for someone over the age of 85;
- be caring for someone with a mental health problem;
- say they are using Direct Payment arrangements to pay for services;
- more likely than other carers to say that they are unaware of local services.

4.1 Background information and focus group set-up

The Hikmat Black and Minority Ethnic Centre is a resource based in Exeter which also manages an outreach community mentoring project – the Sahara Project – in North Devon.

The Hikmat Centre is part funded by Devon County Council and has been designated as a provider site working in partnership with St. John Ambulance to deliver the H&WBCs through a named nurse in a 'clinic style' delivery. The local evaluation team is working with the Hikmat Centre and has set up a research reference group comprising community mentors and members of the Hikmat Centre staff including carers, who identified themselves as Chinese, Arabic and Bengali speakers. The group is able to inform the research processes and assist in engaging with BME carers in Devon as part of the evaluation study.

4.2 The focus group

In order to reduce carer burden and to make the evaluation accessible to those BME participants who do not speak English, the satisfaction survey is being carried out via focus groups, with translators who are familiar to the participants in attendance at the focus group sessions. The first focus group took place at the Hikmat Centre in Exeter in July 2010. The Hikmat Centre was considered the most appropriate venue as it was accessible and familiar to all participants. Focus group attendees had all recently had a H&WB check.

Participants had been sent a translated invitation letter and information sheet and were individually invited to take part in the focus group through their community mentors working with Hikmat and Sahara projects. Consent forms, together with background demographic information forms, were completed and signed before the session by focus group participants with the assistance of translators and mentors (See Table 13).

Table 13: Focus group demographics

Focus group characteristics		%
Age	45-64	100
Gender	Male	29
	Female	71
Employment Status	Paid work FT	14
	Paid work PT	14
	Self-employed	29
	Retired	29
	Unemployed	14
Relationship*	Partner/Spouse	14
	Parent	14
	Child/Grandchild (under 20)	14
	Parent & Partner/Spouse	27
	Parent & Child/Grandchild < 20	14
	Parent & Child/Grandchild > 20 & Grandparent	14
Length of time in caring role	1-5	100
Hours spent caring per week	0-10	29
	31-40	29
	41-50	14
	51+	29

*The data is based on 7 carers – information was not obtained from one focus group participant.

*(Does not add up to 100% due to rounding)

The focus group comprised Chinese speakers and consisted of 8 carers - 6 female and 2 male. Two translators were present, who were also carers and also took part in the focus group.

4.3 The check process

The H&WBCs of the focus group participants were carried out in June/July 2010. The majority of carers had their H&WB check at the Hikmat Centre (86%) with the remainder carried out at a GP surgery.

- All checks were completed by the named nurse from St. Johns Ambulance;
- On average the checks took 59 minutes each
- Additional support from an interpreter was needed in 30% of checks

4.4 Benefits

Some participants mentioned they had difficulty in being understood when trying to make a GP appointment so the H&WBC delivered in an already familiar place with established support available if needed was an especially welcome aspect of the service.

All of the participants felt that the check was useful. Participants reported that:

- the booklet was helpful in preparing for the check;

- the booklet helped to ‘keep a check’ on their own problems;
- having the checks in a community centre helped to share similar experiences with others.

“Normally we feel shy to talk about feelings, but in a group you can talk to each other and share experiences”

“It’s nice to know people care and to speak to others with similar experiences and in the same language”

All carers felt that having a H&WBC helped them to recognise themselves and to be recognised as a carer:

“I’m not recognised as a carer. In China you wouldn’t say ‘I’m a carer, you automatically care ‘because you should’...It’s the Chinese family way, our culture’

It is interesting to note that new health conditions were discovered for the majority of this group and this trend will be monitored over the course of the coming months as the numbers of checks delivered increase:

“I’m going for a blood check now because of the health check”

The majority of the group had taken advantage of the ‘Care & Repair’ voucher scheme to review conditions at home which would not have happened without the H&WBC and all participants said that they would recommend the check to another carer.

4.5 Suggested Improvements

All felt that the booklet was helpful although the amount of time and writing needed to complete it was noted. Participants felt that it was essential to have written information translated into their own language and this was much appreciated in relation to the preparation booklets. There was a feeling that more promotion of the availability of the H&WBC through the range of local community groups would raise awareness and encourage others to take advantage of the opportunity to have a check.

All of the female participants expressed a preference to see a female nurse in the first instance and then if required, to be referred to a doctor;

“Easier to ask about female problems”

When asked about specific changes, most suggested further additions including:

- further body / physical checks;
- making the check an annual event;
- condition specific training and education such as lifting and handling training;

Isolation was identified as a specific source of stress and that IT training in their own language to establish, for instance, internet and Skype connections would be helpful in maintaining the informal support network of family and friends overseas.

A rolling programme of further focus groups is planned to take place in Exeter and Barnstaple.

5.0 EMERGING THEMES

It is important to emphasise the small number of respondents (n=100 plus 8 focus group participants) in this interim study sample and the early stages of development of service delivery in those sites that have joined the programme in January, April and June. Comments focus on GP surgeries which have delivered the majority of the checks to date. A number of early indications have emerged which providers may like to consider as the service is further developed and refined.

Time

Although a number of surgeries appear to have been ambivalent about the amount of time necessary to carry out the H&WBC as proposed, the average delivery time of 66 minutes is an encouraging start and it is perhaps worth noting that none of the carers raised time away from caring as a contra-indication to undertaking the H&WBC. Indeed very few have drawn on the additional funding available to provide them with replacement sitting services in order to attend. It is no surprise that carers valued appointments that ran 'on time' and this may in itself be an important influence on their overall experience and any subsequent satisfaction rating.

Promoting and prioritising carers

Carers have reported a lack of presence in the wider community of information about the specific checks. An important element in the slow rate of take up may well be that carers are simply not aware of the opportunity. The GP carers' register is a good indicator of overall engagement with carers and low rates of increase indicate that there is a need to continue to promote the register and the new service both within the surgery and as widely outside it as possible. We know from the pilot project that the promotion of carers within the surgery is best achieved using a 'whole team' approach, involving not only clinical but also clerical and reception staff to identify and encourage carers to come forward for a H&WBC appointment. This might also help to reduce the number of carers who appear doubtful about their registration status.

Identifying carers

The study data suggest that most success has been achieved in engaging older, retired carers in the H&WBC processes. Almost three-quarters of this group already attend at least one clinic for an on-going, chronic condition and these – particularly 'flu vaccination and vascular check clinics – may continue to provide a rich 'hunting ground' for identifying new carers who have so far declined to engage with previous services but for whom a targeted and specific check might be attractive.

Younger, working carers and those looking after recipients other than a spouse/partner are clearly missing at the moment from the data and efforts to widen the search to those caring for other relatives and friends not living in the same house and for children and young people with complex conditions or multiple needs may yield dividends.

Training and developing best practice

As a result of the on-going identification of provider sites continuing to join the programme, as one carer noted, the service is still to a large extent 'in its infancy'. There is much to be gained for staff and service improvement by encouraging links across sites both for mutual support and for sharing best practice in virtual, web-

based networks, groups and meetings. Centrally co-ordinated newsletters, recent communication skills training and quarterly support meetings for delivery staff have all been well attended and are an important element in maintaining commitment amidst a plethora of competing demands for those delivering a new service often in an isolated setting.

Relevance

As one way of improving relevance and satisfaction for carers, it may be advantageous for staff to try to explore carers' expectations in a little more detail at the beginning so that each check can become more focussed on the carers' situation. For instance as suggested by one respondent, where 'tests' – cholesterol, sugars, prostate, blood pressure etc., - are clearly an important element, these could be offered or clarity established around why they will not be part of the process. These 'MOT' style measurements seem to be a part of general expectations of a health check for a number of carers and could improve satisfaction ratings if carried out or at least discussed. For other carers, emotional support is the most important element and a check with this as its primary focus will take a rather different course.

Outcomes and action planning

Talking is likely to be an important part of the check process and keeping track of important points and drawing them together into outcomes that are clearly articulated to each carer may be a new skill that staff delivering the checks will need to acquire. Recent communication skills training has certainly been well received by those who have attended.

Carers frequently mentioned receiving 'good information and advice' as a valued part of their check. Offering as much of a 'one stop shop' as possible in which one appointment can meet several needs for carers seems to be important. Access to a good bank of well-maintained and up to date *local* information, together with a network of named contacts in other services and resources works well. This may be particularly helpful in encouraging carers to make use of the sign-posting which staff feel they are providing and to actively follow up what might be perceived as an informal suggestion.

BME carers

Although based on a very limited number of Chinese-speaking participants in just one focus group to date, a number of different preferences have emerged. Difficulties were reported in engaging with, understanding and being understood at a GP surgery and attempts to make appointments were not assiduously followed up. The focus group participants were unanimous in valuing the check delivery in a familiar community setting, which allowed the process to be part of their established routines and social networks, thus avoiding the stresses which could be associated with any new arrangement. They drew much confidence from having help nearby if needed, particularly in the form of a known and trusted translator as well as support from each other as a group to overcome reticence, to undertake the check and to discuss the outcomes.

It is important to note that for majority of this group, a new condition was identified as a result of the H&WBC and when referred, they had attended hospital and GP surgery appointments for follow-up.

6.0 LIMITATIONS

This is a small empirical study being undertaken in a group of self-identified provider sites in Devon.

Assumptions

A number of assumptions have been made:

- that the sites and participants comprise a representative sample of the whole population;
- that all participating surgeries will achieve identification and registration of carers equivalent to 5% of list size.

Limitations

There are limitations when seeking to generalise any findings to a wider population:

- Sample size is very small
- Participants have identified themselves and may be introducing bias because they possess particular characteristics as people who put themselves forward rather than reflecting the differences across the whole population, including those who do not choose to come forward.
- Low response rate means that even though 577 packs were sent out, the number of responses (207) is too small to be broken down into sub-groups and subjected to meaningful statistical analyses.

Mitigation

Having acknowledged the assumptions made and the limitations imposed by a small, self-selected study sample, we are encouraged to find congruence of our sample externally with national data (NHSIC, 2010; General Household Survey 2000; Health & Wellbeing of Carers Survey, 2002) and internally with the total population of registered carers at all participating surgeries, across a number of important characteristics (See Comparison Table 5) which provides confidence that the study has not identified an aberrant group.

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GP CARERS' PROJECT – FINAL REPORT MAY 2009

EXECUTIVE SUMMARY

The executive summary provides a very condensed record of the principal aspects of the study, its findings, conclusions and recommendations. The full text which follows the summary provides more data and a wider, more comprehensive discussion of the issues which have emerged, set within contemporary research evidence.

SUMMARY INTRODUCTION

The evaluation of the GP Carer's Project was awarded to RE:search South-West at the University of Plymouth on 16th June 2008 by Westbank, in partnership with Devon County Council. Ethical approval for the evaluation study was granted by the NHS Ethics Committee on 19th September 2008. The study was undertaken during the period from end of September 2008 to the end of February 2009.

SUMMARY STUDY DESIGN & METHODS

The study was in two stages, using mixed methods including questionnaires, interviews and focus groups, to gather quantitative and qualitative data from project surgery staff and registered carers as follows:

Stage I (T1)	Data prior to project implementation	Sept/Oct 2008
Stage II (T2)	Data following 6-months' implementation	Feb/March 2009

Data were collected via similar surveys undertaken at the start of project implementation (T1) in October 2008, and repeated six months later (T2) in March 2009 using the following instruments:

- **Surgery staff interviews**, using structured questionnaires.
- **Postal carers' questionnaire packs** as follows:
 - General Health Questionnaire (GHQ)**, a 28-question validated tool
 - Enhanced Carer Strain Index (CSI)**, a 13-question validated questionnaire
 - Monitoring Form** designed to gather demographic data
 - Carers' Satisfaction Survey (CSS)**, a an 8-part locally-designed questionnaire
- **Carer focus groups** using a topic guide prepared in partnership with the evaluation project's Carers' Participation Group.

SUMMARY ACHIEVEMENTS

A more holistic approach

All sites have recognised the importance of taking a more holistic approach and have sought ways to develop a broader support and social focus to the interventions offered to carers, identified and presenting to the GP surgery. A surgery-based champion for carers, the advice and support workers have continually reminded staff throughout the surgery to 'think carer'.

Systems links for carer and cared for

A major achievement of the advice and support workers in all pilot sites has been the establishment of robust 'read coded' systems for the identification and linking of carer and cared for. The needs of carers frequently lie in a 'grey area' where health and social care overlap. Their position is further complicated by the inter-connectedness of the needs of the person they care for and their own needs. Some of the tensions inherent in this close inter-

relationship are exemplified by the comments from the focus group participants who said that they ‘felt invisible’ and just wanted some recognition of their existence, which is facilitated by the electronic ‘tags’ now in use.

A face-to-face ‘listener’.

GPs recognised the need for talking with carers but also acknowledged their limited appointment time for this more supportive intervention. In the focus groups, carers identified the importance of having a named person, such as the A&SW, with whom they could make direct contact, without having to ‘bother’ the GP. A personal contact, as opposed to a telephone call centre, was highly valued by those in the focus groups but did produce some concerns around the personal impact of the work for the A&SWs themselves and projects had begun to put arrangements in place for more support and clinical supervision.

Flexible consultations

All pilot sites had identified the need to provide a range of ways of accessing their services and the importance of offering a choice of times and location to carers, so that sensitivity to the needs of individuals and flexible ways of setting up a specific appointment or consultation was a priority for all A&SWs.

A local information ‘hub’

The importance to carers of one central, easily accessible, ‘hub’ through which they can receive guidance, advice and information about what is available to them in their own locality cannot be over-stated. Carers felt most confidence and trust in services derived from the GP surgery and preferred this, as opposed to social services offices, as the conduit for access to sources of help. A particular strength of the A&SW role based in the GP surgery is the ability to deliver a flow of information and advice at times which are appropriate to individual needs and sufficient for the particular stage in the journey through caring.

Range of services

It was clear from even the few words that each carer used to introduce themselves at the beginning of the focus groups that carers cannot be regarded as an homogenous group. Carers need to be offered a wide range of different services which will not necessarily be taken up by all, but which might be needed by different people at different times. All project sites had established an ‘information bank’ about local resources for carers including those aiming to meet their needs in four specific ways:

- To relieve the pressures of care-giving, e.g. support groups and condition-specific information
- To assist with practical tasks e.g. aids and adaptations, laundry and domestic help
- To provide relief from caring e.g. sitting services, day care or respite
- To help carers get more from the care system eg. advice and information about benefits

Generally, sign-posing involved handing on a leaflet or telephone number to carers. Given more time, there is scope to develop the advocacy role of A&SWs included as one of the initial pilot project objectives.

SUMMARY RECOMMENDATIONS

Future developments to consolidate the services and ensure sustainability of the benefits are set out in the seven recommendations below:

Recommendation 1

Clarification of the role of the Advice and Support Worker, identifying a clear job description, linked to on-going training and support for the role.

Recommendation 2

Identification of a GP lead for carers' issues to develop a strategic 'whole team' approach in the surgery including reception as well as administrative and clinical staff.

Recommendation 3

Continuation of work to increase registrations by drawing on existing clinics, chronic disease registers and public health promotions to identify harder to reach individuals.

Recommendation 4

Prioritisation of carer and their role at an early stage, as part of the diagnosis in a cared-for patient's plan with three primary aims:

- to increase registrations
- to facilitate take-up of advice and information
- to target support services to those identified in the study as most at risk of experiencing damaging levels of stress i.e. women, aged 60 – 65, caring for a partner for 30 hours a week or more

Recommendation 5

Development of training and support for carers, particularly condition-specific information and groups

Recommendation 6

Improving information and communication between carers and the surgery through:

- Website updating to include a specific space for carers;
- Development and co-ordination of specific carer participation groups and forums to actively gather perceptions and views of carers for integration into surgery developments;
- Routine inclusion of carers issues on core group and practice meeting agendas.

Recommendation 7

Sustaining the A&SW posts and services in alternative ways:

- **Integrating the role into the workforce** by sharing the key tasks across a number of existing staff workloads and designing job descriptions to reflect opportunities for personal and professional development in leading and developing carers issues in the team.
- **Building on the success of co-located professionals** by creating a shared, jointly-funded post, for instance within a cluster group to reflect similar arrangements already in place for graduate mental health workers.
- **Adding specific elements of the additional carer checks to existing clinics or public health promotion appointments**

Full report available at

<http://www.plymouth.ac.uk/files/extranet/docs/HSW/GP%20Carers'%20Project%20Final%20Report%20May%202009.pdf>

NHS Devon Carer Health and Wellbeing Checks

Check Description

The Devon health and wellbeing check is a “broad spectrum screening framework” designed for adult carers. It was developed with input from carers and clinical experts using:

- Clinically validated screening tools, for example for depression and alcohol misuse where appropriate;
- Material from Carers UK and other carer sources on concerns for carers such as the demands of the caring role itself;
- DH guidance on the Carer Assessment, which it incorporates;
- The NHS vascular health check, and other measures for risk factors such as obesity where the vascular check is not indicated;
- Public health priority concerns for healthy eating, exercise and smoking;
- Aspects of home warmth and safety;
- A check that the carer has not ignored routine screening (e.g. cervical screening, mammogram), and is attending for dental checks, eye examinations and any other clinics which they should attend.

Carers are encouraged to express their own concerns and worries. It is designed on a self care model. As the provision of the check is based on the assumption that carers often neglect their own health, the methodology of the check promotes self care, hoping to encourage this as a habit, and works with the carer to plan how to overcome barriers to the steps they decide to take to protect their health. However, staff are briefed that if a carer is caring for 30 hours or more, or shows signs of stress, or for some other reason they feel the carers may not follow up on signposting done as a result of the check, they should make referrals rather than simply signposting where this would otherwise be appropriate.

The check design aims to put power and control into the hands of carers before and during the consultation. The check itself is incorporated into a colourful booklet. The protocol for the check requires that this is given to the carer when the check appointment is booked, ideally a week in advance of the check, and the accompanying letter encourages the carer to read it, think about it, and if possible fill it in before the appointment, or at least decide on which areas they would like the appointment to focus.

In order to be as confident as possible that the carer will be able to undertake any actions arising from the check, carer and check provider are encouraged to use SMART planning; for example it is unlikely that the carer will be able to take a walk or simply more time to themselves if there are unaddressed substitute care issues. This approach was also adopted as consistent with public health approaches, and likely to help the carer take the first step in whatever programme they have determined with their check provider will be likely to help them.

For the providers, a comprehensive care pathway has been written to give easy access to services especially those with which they may be less familiar. A list of general information leaflets likely to be needed by carers undertaking the check is also provided.

The check was designed to be able to be conducted by staff at or above the level of Health Care Assistant, which level had been pre-determined by the commissioning lead.

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23/9/10

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