



University of Plymouth

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



EXECUTIVE SUMMARY
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EXECUTIVE SUMMARY

Programme background

The Carers Strategy Demonstrator Sites (CSDS) project is a Department of Health initiative to explore new approaches to offering support to informal, family carers through three types of intervention:

- Health and well-being checks
- Innovations in approaches to breaks and respite
- Enhanced NHS support .

In 2009, as one of 25 successful bidding teams in England, a partnership between NHS Devon (formerly Devon Primary Care Trust) and Devon County Council, was awarded funding as part of the CSDS initiative to design, develop and deliver 3000 new health & well-being (H&WB) checks to carers in Devon over a two-year period, commencing in October 2009.

Programme protocol

A key design innovation for the H&WB check was its foundation on a self-help model which encouraged carers to express their own issues and concerns. This allowed those delivering the check to work with them, during an hour long consultation, to plan how to overcome barriers to the steps they decided to take to protect their health.

For adults, in advance of the H&WB check appointment, each carer was provided with a preparation booklet, *'How to get the most out of your health & well-being check'* designed specifically to help identify the areas on which the carer would like the check itself to focus. . In addition, for adult carers, the Devon H&WB check protocol was specifically arranged to include a statutory Carer Assessment and a Vascular Risk Assessment for those aged 40 – 74 years.

Programme delivery

Four work streams were established to deliver the programme as follows:

- adult carers aged 18 years and over
- working carers
- black and minority ethnic group (BME) carers
- young carers under 18 years

Adult carers including working carers

H&WB checks were delivered to adult carers through a number of provider type choices: Participating GP practices x 35; participating pharmacies x5; a complex care team; and alternative clinics offered by a St. John Ambulance nurse and a peripatetic nurse, targeting working carers delivering workplace and community-based checks at clinic appointments arranged in libraries, community hospitals, memory cafes and a parent carer conference

Black and minority ethnic group (BME) carers

In addition to checks available at participating GP practices, Hikmat Outreach Service (Hikmat) worked in partnership with St. John Ambulance to deliver checks to

BME carers in community resource centres drawing on existing Hikmat project support workers active in Exeter and North Devon to identify, prepare and support carers, mainly from Asian and Chinese backgrounds to undertake a H&WB check.

Young carers

Checks in GP practices and pharmacies were not available for young people under the age of 18 years. Two 'Health & Well-being Activity Days' designed in collaboration with young carers and support workers took place in Exeter and Newton Abbot, supported and delivered by Devon Young Carers' Consortium and Young Devon, for young carers identified and supported through these existing project networks. All young carers in their locality project groups had the opportunity to visit each of six 'activity zones' in rotation, during the day. Zone activities were of approximately 45-minutes duration each focussing on the key issues identified by young carers in consultation events as follows:

1. Healthy lifestyle, fitness and food
2. Dealing with bullying and improving self-esteem
3. Relaxation and controlling stress
4. Diagnoses, medications & information
5. Leisure activities & accessing funding
6. Addictions: drugs, alcohol, smoking & caffeine

In addition, two GPs were available throughout each event for individual appointments and consultations, either pre-booked or arranged during the course of the day.

LOCAL EVALUATION STUDY

A local evaluation study was undertaken by University of Plymouth to explore the individual experiences of carers and their perceptions of the effectiveness of the H&WB check programme in supporting them to maintain their own health, psychological and social functioning alongside their caring role.

Participants and recruitment

Adult carers including working carers

All adult carer participants were invited to complete: (1) an initial postal survey gathering background information which was followed up for those identifying themselves to the evaluation team by (2) a more in-depth satisfaction survey using a semi-structured questionnaire incorporating both closed and open questions as prompts for participants to express their own views, opinions and perceptions. A second satisfaction survey (3), focussing on changes in status, health, well-being and assessments of satisfaction was conducted with those identifying themselves who received a second, follow-up H&WB check, one year after their first appointment. It should be noted that eligibility for this second follow-up check was limited to the small number of carers who were seen for their first check in the first two quarters of the programme delivery between October 2009 and March 2010).

BME Carers

In order to gather the more in-depth information requested in the satisfaction surveys, those for whom English was not a first language and BME participants

identified via Hikmat, were invited to take part in one of five focus groups at which interpreters were present and where participants were supported by familiar project workers if they so wished.

Young carers

Young carers attending one of two 'activity days' completed semi-structured questionnaires during the course of each event, with support from familiar project team leaders where this was required or requested.

SUMMARY OF KEY FINDINGS

BME Carers

Just under one-third of this group was registered as a carer with their GP practice compared to nearly three-quarters of all other adult carers in the study. There appeared to be little difference between samples in the average number of visits made in the previous twelve months either to the GP or to the practice nurse although a smaller proportion of the BME sample (42%) attended a regular clinic compared to 60% in the whole study population. Over two-thirds of the consultations with BME carers included a vascular check compared to only 39% in the total study sample.

BME carers were more likely than others to rate their general health as 'good'. However, a higher proportion (21%) had been admitted to hospital in the 12 months prior to their check compared to only 9% in the whole survey population.

BME carers were ambivalent about asking for help from their GP practices particularly when they had been rebuffed in the past. They identified difficulties with language and felt that GPs in particular made assumptions and expected that those accompanying someone to an appointment would automatically act as translator, which was sometimes not appropriate. Some worried about parting with personal information and the project support workers felt that expectations were particularly low amongst members of BME communities as a result of the often negative experiences for many of any engagement with authority figures. There was however high regard for doctors and there was a sense in which the focus group participants considered that a GP consultation was only warranted for an acute illness or crisis and that preventative work or 'small worries' were not appropriate to be taken into the surgery.

Establishing the requisite trust for a check to take place was a key element of the sometimes constant support offered to some carers by the Hikmat project support workers. Most focus group participants appeared to be reinforced in their belief that they should rely on their family and friends from their own community for help and support in caring, which approach fitted more closely with their strongly-held cultural values. They spoke of 'shame' if they needed to turn to those outside or government agencies for help.

Focus group participants considered that the venue, 'clinic style' delivery, check duration and type of person who delivered the check were all key elements of its success. For many, coming forward for a H&WB check was a 'step into the unknown' and the fact that it would take place in familiar and trusted surroundings in

which there was immediate access to social and emotional support was a prime consideration in their decision to participate.

There was unanimous agreement that having the preparation booklet translated into their own language and an appointment lasting a full hour, 'dedicated to them' to go through anything of concern gave them 'peace of mind'. Having a personal invitation to the check was also important in helping carers to accept help, to focus on their own needs without feeling guilty or that they were being a burden to others.

BME carers have identified a range of specific needs in terms of information and advice and the relationships established with project support workers in their communities puts these workers in the best position to act as a knowledgeable and trusted conduit to address the gaps in accessibility to services that have been identified.

The evaluation has highlighted the need for a regular health check for BME carers delivered outside their GP practice to provide reassurance about their general health but more importantly to act as a filter or gateway to encourage those BME carers who are identified as 'at risk' in any area to contact their GP before a crisis or emergency is encountered to help reduce the number of emergency hospital admissions already noted.

Young Carers

From the enthusiasm with which young carers were observed to engage with most sessions and from the exceptionally high number of responses to the evaluation questionnaires, the activity days were clearly an enjoyable and worthwhile experience for those young carers who attended. The evaluation has shown that the framework for an activity day based around areas of concern identified by young carers themselves worked well and the events provided opportunities to combine enjoyment and meeting others in similar positions, helping some young carers to realise that although they felt sad and lonely at times, they were not alone and that others have similar problems.

In this sample, most young carers were female (71%). Most participants (63%) were looking after their mothers and 35% reported being the main carer. The majority did find things to like about themselves much of the time and over half (55%) felt that their experiences as a carer made them better able to cope with life's problems. On the other hand, 78% felt that they couldn't cope with the demands made of them at least 'some of the time' and one third reported that they frequently had to do upsetting things. Those aged 11 – 13 years were more likely to be involved in personal care tasks such as helping the person cared for to dress or undress (50%); have a wash (56%) or take a bath (44%). Those aged 13 – 15 years reported the highest levels of stress and the majority giving cause for concern (70%) were female.

The high level of caring carried out, particularly by girls and by those aged 11 – 13 years has been highlighted and the outcomes from the H&WB activity day may be a helpful catalyst to target this age group particularly to ensure that they are not overburdened and that they have choices so that their caring role is a comfortable one in

which the tasks they take on do not mean they are 'having to do upsetting things a lot of the time'.

It appears that most stress is likely to be experienced by young carers aged 13 – 15 years. These adolescent years present a challenge for many young people and gaining independence from parents is a normal part of development in this life stage which can be made more problematic for those drawn back to family by caring responsibilities. Peer group acceptance is a key support during what is often a turbulent time and the H&WB activity days provided a real opportunity to lessen the feelings of sadness and isolation expressed by these young carers in their questionnaire responses.

The low levels of knowledge reported as they entered each activity zone suggests that information is either not available or is not reaching these young carers in quite the way that is needed. Although there is a vast amount of written information in leaflets from an array of organisations and of course via the Internet, the H&WB activity days offered young carers the opportunity to discuss, to ask questions and get answers from specialists in areas that were either of direct benefit or were causing them anxiety and concern. This appeared to be especially so with those who had expert knowledge about access to funding for activities and breaks and more obviously with the GP, pharmacist and drugs worker all of whom were available to the young carers almost uniquely in a relaxed and informal setting which encouraged open questioning and dialogue not only about their own health but importantly about the diagnosis, medication and prognosis of those they are caring for.

Adult Carers including Working Carers

The evaluation has shown that the vast majority of carers have enjoyed and valued the opportunity to receive an extended consultation, offering them time to talk and consider their own health alongside important related issues in their personal, social and emotional well-being from which two key outcomes readily emerged:

- **Over a quarter of carers (28%) had a new health condition identified as a result of the H&WB check**
- **Just over half (53%) of carers reported a health-related goal as the outcome of primary importance to them.**

The self-help model on which the programme was based has much to recommend it and the booklet '*Getting the most out of your health & well-being check*' was very well-received with a range of suggested changes and improvements offered by carers and delivery staff.

During the consultation, over half (55%) of carers agreed goals or targets for action as part of their individual self-care plan represented in three broad areas as follows:

Health-related goals	43%
Practical activities	38%
Social-emotional issues	20%

One in six (17%) carers identified access to information and advice as an important check benefit, not only now but to provide confidence and security that help would be readily available in the event of future difficulties and challenges. The ‘future proofing’ of worries was something that many carers referred to at all stages of the study and the H&WB check clearly provided them with a single contact point, to a named professional, able to stand outside their family situations, with whom they felt ready to discuss issues to gain a balanced perspective and take control of the choices available to them.

Male carers used the opportunity offered by a H&WB check to seek out advice (42%), to set and act on goals (36%), focussing on their physical health needs (55%) whilst gathering support for their role (55%). On the other hand, female carers placed greater importance on continuity, being able to re-visit the same member of staff with whom they felt that a relationship of trust and confidence had been established. They were more focused on the importance of their emotional wellbeing (53%) than health needs (43%).

Comparing changes in outcomes between the first and follow-up checks, identified needs had reduced in all the areas agreed for action with the exception of practical support.

Changes in outcomes reported by delivery staff (T1 – T2)

Outcome/Goal/Action to meet identified need	Initial Check T1	Follow-up Check T2	Change
Care Direct	42%	31%	- 11%
GP/nurse referral	23%	14%	- 9%
Carers’ Link	27%	14%	- 13%
Care & Repair	26%	14%	- 12%
Respite & sitting services	13%	3%	- 10%
Healthy lifestyle	22%	3%	- 19%
Practical support	17%	31%	+ 14%
Emotional support	23%	21%	- 2%
Training needs	18%	3%	- 15%
Leisure & social support	12%	7%	- 5%

The downward trend in each area suggests that carers have benefitted from their check and taken action to address at least some of the areas of previous concern. The upward trend in identification of practical support as an increasing need may reflect the greater willingness of staff to engage in more non-clinical discussions with carers coupled with greater knowledge of the range of local resources which may benefit carers and increased confidence in signposting to them. The requirements for emotional and leisure/social support show the least change and greatest stability in demand which is not a surprising finding since changes related to broader lifestyle and well-being may be more long term and require greater time, resources, personal, financial and professional support to achieve them.

Given that carers are unlikely to come forward readily to identify themselves, a personal invitation from a GP practice to each carer as part of a co-ordinated programme to increase registrations is more likely to be successful than reliance on carer self-identification alone. Strategies to seek out unrecognised and new carers have been suggested and a range of factors influencing the level of stress experienced by individual carers has been identified and used to build a 'pen picture' of those carers most at risk from damaging levels of stress as follows:

Primary stressors and those most at risk

Stressor/Risk Factor	Carers most at risk
Gender	<ul style="list-style-type: none"> • Women
Age	<ul style="list-style-type: none"> • 45 - 59 years • 65 – 74 years
Hours spent caring	<ul style="list-style-type: none"> • 51+ hours per week
Employment status	<ul style="list-style-type: none"> • Women who are retired • Men who are unable to work due to caring or ill-health
Condition of care recipient	<ul style="list-style-type: none"> • Mental health conditions • Dementia, including Alzheimer's disease

Some of the particular personal attributes of staff that are key elements in the delivery of an extended, in-depth discussion of both health and well-being issues with carers have been identified. Carers emphasised empathy, listening skills, reliability, trustworthiness and knowledge of local facilities as well as professionalism in their 'person specification' for the delivery of a H&WB check. For the future it will be important to select those staff who have the personal qualities necessary to develop trusting and empathetic relationships with carers as well as those able to develop emotional resilience with which to counter some of the personal impacts of the hour-long consultation.

Carers highlighted the need for on-going support particularly where their agreed goals and on-going action plans included more long-term lifestyle changes. At the same time, staff acknowledged that the pilot programme had allowed little time for follow-up or feedback either of carers themselves or from the services to which they had been signposted or referred. For the future, systems need to be developed to seek feedback and track H&WB check outcomes to maintain satisfaction for carers and delivery staff alike.

For delivery staff, the needs of carers revealed in consultations did not lay entirely within health boundaries. Indeed many goals lay in the 'grey area' in which health and social care overlap so that delivery staff were almost immediately challenged to extend their consultation skills, professional networks, local knowledge and expertise beyond their current comfort zone. At the same time, all practices recognised the need for a 'whole team' approach to developing a H&WB check service beyond the initial pilot programme

Most carers were contacted by their GP practice and received their H&WB check at the surgery and it is clear that carers felt most confidence and trust in services derived from the GP practice as the central 'hub' for information and advice.

However, for a particular group of carers an alternative venue was an important consideration in their participation in the programme. Those seen outside GP practices were more likely to be:

- Female
- Working either part time or full time
- In the age range 25 – 44 years.

It seems imperative to consider ways in which the service can continue to be delivered with more flexible clinic style appointments in alternative venues such as those that have already proved successful for this group including community hospitals, resource centres, memory cafes, libraries, workplaces as well as an adjunct to meetings and conferences aimed at specific groups such as parent carers or as part of condition-specific and support group meetings.

RECOMMENDATIONS

BME Carers

Recommendation 1

To continue to deliver a health check, based on the self-help model in community settings which promote the confidence and trust needed to stimulate carers' interest and active participation in promoting and protecting their own health.

Recommendation 2

To develop the role and remit of a project support worker as a named 'carer champion' linked to known community centres, to act as a central contact point for signposting, information and advice.

Recommendation 3

To build on the existing third sector organisation partnership with St. John Ambulance to meet the needs identified by BME carers for a 'basic body check' on an annual basis.

Young Carers

Recommendation 4

To explore different ways in which young carers can pursue more frequent and informal contact with a range of specialists and health professionals in sessions which can be led by the young carers' concerns so that information is available at the time it is needed both in relation to their own health but importantly in relation to the condition, diagnosis and prognosis of those they are caring for.

Recommendation 5

To consider ways to target young carers aged 11 – 13 years through multi-agency activities to ensure that their roles and tasks are appropriate and that alongside caring they are supported to continue in education to enable them to achieve their full potential.

Recommendation 6

To find ways in which to consolidate and extend the individual contacts and networks made during the H&WB activity days not only through existing young carers' projects

but also using e-mail, text and the internet to offer a choice of communication routes for information sharing and to build a social resource capable of reaching those who may live in more rural, isolated or disadvantaged settings.

Adult Carers including Working Carers

Recommendation 7

To continue to offer H&WB checks based on a self-care model to support informal family care-givers to take control in the promotion and protection of their own health.

Recommendation 8

To continue to base H&WB checks in GP practices, taking a proactive stance to increasing the identification and registration of carers.

Recommendation 9

To develop the skills and competencies of staff so that they are professionally prepared and confident to deliver a service led by carers in each consultation

Recommendation 10

To consider improvements in the way in which carers are consulted and involved in feedback and to develop systems to track H&WB check outcomes and goals.

Recommendation 11

To develop person specifications for lead roles as 'carer champions' alongside more integrated management arrangements so that a wider 'whole team approach' for the delivery of a H&WB check service becomes embedded in GP practices.

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