- poverty
- perceived wealth
- incompetent caring
- irreligious attitude

The vascular risk assessment of the check was valued because most BME carers do not make medical requests for themselves, only for their dependents. The community setting made it easier to hear bad news about their own health because they could get sympathy and advice immediately. Having a project worker who could translate meant participants attempted to describe complicated symptoms they would not have discussed in a surgery setting.

Once the concept of 'social and educational opportunities' was understood as a possibility in people's lives, SMART planning could start to produce measurable results quickly.

Access to many female carers in BME communities can *only* be achieved by convincing the senior men in the family.

The project encouraged preparatory conversations about emergency care if the carer were to become ill, and about end-of-life care; issues which carers had previously ignored.

Onward referrals to address housing, benefits, alarms, Flexible Breaks, Sitting Services, ESOL and other learning opportunities, fitness, Learning Disability/Mental Health Teams, and other medical conditions have all resulted in positive outcomes.

5.3 Actions taken for sustainability

Opportunities were taken to hold events at venues where longer-term benefits could arise:

- Two of the focus groups were held at Petroc College, in order to familiarise participants with a local learning centre. This proved to be a popular choice and some participants were shown round other facilities at the college during the visit.

- Some project training was conducted at NHS venues. It was intended that not only should the Project Workers become comfortable in health settings, but also that staff at the venues should interact and become familiar with Hikmat workers. This was also successful and popular with everyone involved.

Opportunities for interaction were also capitalised on at information events and the Carers Festival. Good relations are now embedded with Links, PALS, a number of leagues of friends, the Dementia Cafe scheme, and others.

Continuous interaction with Devon Carers Link in North Devon and Exeter areas has resulted in on-going negotiations to develop a more appropriate sitting service for BME carers wishing to access the Take a Break service.

The collaborative working between Hikmat and St John's Ambulance produced a number of unanticipated benefits, with far-reaching results. The nurse who conducted the clinical checks was able to gain experience of working with clients from all the target communities, something they would not be able to acquire through general practice. Where inexperience risked achieving a positive outcome, Project Workers were able to advise and ameliorate. In addition, Hikmat staff benefited from witnessing the nurse demonstrating tight time-keeping and scheduling, accurate record-keeping, and reflective questioning.

A range of practical training for the carers has been developed and delivered from this positive foundation.

Summary

It was common to all the target communities that the concept 'carer' did not exist. Caring is a duty which does not entitle the carer to particular acknowledgement, support or sympathy.

It was also commonly believed that any support received will have to be paid for in some way, for example:

- By reducing benefits
- By withdrawing immigration status
- By paying financially later on
- By paying in a future life
- By bringing shame on the carer/their family because of perceived:

Some people confessed afterwards that they did not tell the whole truth about their problems during the check. They said they will tell a little more each year if the Checks continue.

5 *Partnership Working*

5.1 Statutory Sector

The project received no referrals from GPs or secondary care services. This was anticipated, as productive links between the statutory sector and BME communities are still at an early stage across the county. As mentioned earlier, it would seem that GPs are not identifying BME carers. It may be that there is confusion between 'caring' for someone and 'interpreting' for them.

Early in the Project Hikmat started contacting participating surgeries to check the availability of Language Line. However, as so many were unsure if they would be continuing, this was discontinued.

Three referrals were received from the BME Mental Health Community Development Workers.

All onward referrals were followed up and dealt with promptly.

5.2 Private and Community Sectors

Three referrals were received from Rejuve-Nation. All completed their checks.

An awareness session conducted jointly with the Mosque generated three participants who all completed checks.

A partnership arrangement with a pharmacy became problematic and was abandoned. Issues included:

- Receiving a short Check (40 minutes)
- A carer was refused a diabetes check because she was "not old enough"
- Checks cannot be conducted between 11.00am and 4.00pm
- A carer was told she was not a carer because she did not live with the person for whom she was caring

Some work was necessary with one of the Imams, who was concerned that receiving support for 'caring' may be Haram (anti-islamic).

Many report difficulties in trying to make an appointment, particularly over the phone where language difficulties often become insurmountable.

A number of conditions were identified and referrals for treatment were made. In cases where the participant was not registered with a GP, this was followed up by registering them first, or the person was referred direct to a local hospital.

It was reported that having a nurse in uniform did a much to allay anxieties.

Participants were clear that having been prepared about what to expect in the clinical checks made them a lot less anxious and more co-operative. They also appreciated the support of having a project worker there, waiting outside if not in the room with them. Some said they do not go to their GP in case it is bad news, as there is no-one to talk to when they come out.

A further benefit observed is that the St John Ambulance nurse who conducted the checks self-reported growing in competency in BME issues as the programme was delivered.

4.2 Health and Well-Being Checks Booklet

It was agreed in training that it may not be possible to complete the whole booklet with a participant, particularly if they are unused to being questioned or have particular issues in one or two areas. Project workers were encouraged to start filling in the booklet in the sections that most apply or the participant is most interested in.

The training staff received in being focused, managing time and meeting resistance produced remarkable results in completing the booklet. Almost all completed every section and included SMART goals.

There were surprising results in the sections about life-style choices, particularly alcohol and gambling, which the Project Workers had predicted would be rejected outright. Many carers were prepared to discuss these issues and look for solutions.

Many participants were interested in becoming 'better carers' once they understood caring was considered a skill, which could be improved. Requests for further training in aspects such as first aid, moving and handling, understanding dementia were recorded. There was also interest in computing skills (particularly e-mail and skype to reduce isolation and share decision-making with family overseas). Referrals were also made to the handyman service, and for aids such as rails, as well as to English classes.

Carers across the area joined Devon Carers Link, particularly in North Devon and Exeter where the Hikmat connection to the agency is stronger.

The concept of planning, rather than just surviving from day to day, was accepted with relief, and it is hoped that more work will be done on this in the future, with the help of Devon Carers Link.

3.2 Raw Data Forms

Almost all the participants reported finding the amount of paperwork arduous. This is to be expected, as most do not read and write in English. However, the potential this problem had to undermine the project was overcome by encouraging the project workers to do as much as possible with the participant in advance. The St John's Ambulance Nurse was also very helpful with paperwork, which was acknowledged by participants.

Some of the forms were seen as replicatory, particularly around the evaluation.

The role of the Administrator was paramount in ensuring all paperwork was completed on time and forwarded to the correct agency.

Additional paperwork was created by Hikmat to ensure efficient clinics, with accurate timing and breaks for the nurse.

3.3 Evaluation

The Sahara Project Team agreed with Plymouth University that an evaluation would be useful locally, and agreed to participate in an additional piece of work, supporting carers to contribute to Focus Groups or complete questionnaires.

Explanatory notes for the evaluation were précised and translated.

Four Focus Groups were convened, and approximately one third of participants completed questionnaires. Although the full evaluation report is not currently available, it is interesting to note that the Interim Report (2010) showed almost a third of BME respondents spending more than 51 hours a week in caring tasks.

Unfortunately, the General Health Questionnaire was not available in all four languages.

Informal feedback from participants in the focus groups to Sahara staff afterwards indicated that those who had attended focus groups where support was offered by familiar Sahara staff were more comfortable with the process than those who had attended when no such support was available.

4 *Health and Well-Being Checks*

4.1 Vascular Checks

The vascular checks were successful in all but one case, where a husband accompanying his wife withdrew her from the check part way through.

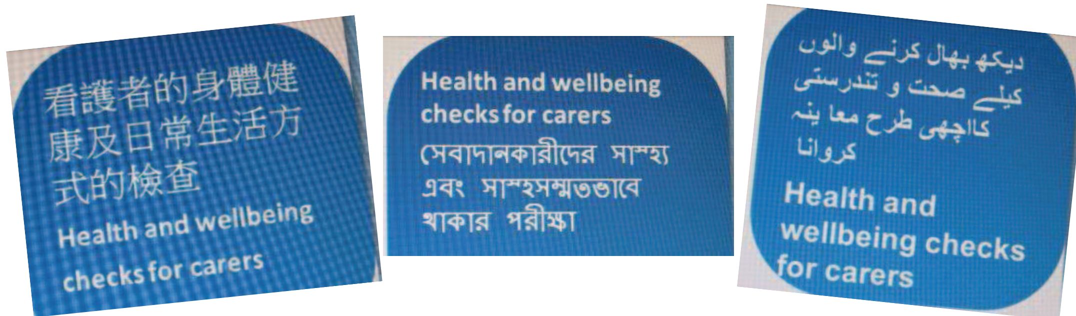
Many reported that they never attend their GP for their own health needs, only for those of the cared for person, and they were gratified that someone was interested in their health.

The Chinese community sent a collective ‘thank you’ to Hikmat, because ‘caring’ is a cultural priority for them, and is usually expected without acknowledgement.

Most people said they preferred to be ‘asked’ to attend a check, and were unlikely to ask for it themselves because of embarrassment

3 *Documentation*

3.1 The Health and Well-Being Check Booklet



It was agreed that the booklet would be translated into four languages: Bengali, Urdu, Arabic and Mandarin. What was not realised from the start was the Urdu and Arabic are much easier to translate than Mandarin and Bengali. This was reflected in the differential cost of preparing the booklet, as converting it into a Word document was rejected outright to provide equal treatment of all groups. Generic translating tools did not contain the specialist vocabulary we were working with and it became necessary to use the services of specialist translators.

Although more expensive, this proved to be a pivotal decision as on-going personal interaction with the booklet was one of the most successful parts of the project. Participants reported that they felt respected because of the effort that had been made and therefore engaged in a more committed way. The drop-out rate throughout the project has been low, and the feeling of having control over the event, because documentation was in their language, may have been significant.

The cost of reproducing 75 plus booklets had been under-calculated, and further funding was agreed to cover this.

The section on check-ups and screening was useful in encouraging those who were not registered with a dentist to ask for help with this. Optician appointments too were made with the support of project workers. However, screening (e.g. cervical, breast) was consistently rejected as too invasive.

Clinically taken weight and girth measurements influenced some to take up a weekly exercise or walking activity, particularly those whose referrals resulted in a diagnosis of diabetes. And there was feedback from a few that the positive impact was being felt immediately!

and/or benefits. It is generally believed among immigrant communities that receiving state help reduces the right to stay here and/or claim benefits. The project discovered, as an unintentional outcome, that people are not signing up to GPs, despite having indefinite leave to remain, or British citizenship, because of this reason.

One of the biggest barriers to engagement in some South Asian communities has been convincing the men of a) the value of the project, and b) that the clinical tests will not compromise the modesty of any women who undertake it. It was discovered that additional preparatory work was necessary with individual families, explaining the process and benefits firstly to the men, and then to the women who were to be the participants. This issue was brought back to the commissioners and an extra hour was allocated to the preparatory time where required. Additional interpreting time was also required, which pushed up the Translating/Interpreting costs by nearly £900.

It was discovered that a complex matrix of influences impacts many female carers from BME communities. They include isolation, resistance to talking about problems because of shame and guilt, frustration, pre-existing family conflict, religion and a lack of ability to articulate the complexity of problems more generally. A bonus outcome for the project has been how the focus groups which were conducted by the University of Plymouth as part of the local evaluation have produced a new level of confidence and ability to be self-expressed among the participants, who were able to witness other people struggling to explain their issues first hand. The peer support, inherent empathy and expanded vocabulary were all valued by participants. Feelings of resentment and anger, tiredness, depression, pain and sleeplessness were discovered to be common and no longer something to be hidden.

Some participants spoke a language that was not covered by the team. This meant that the checks and preparatory work were conducted by both parties in a second (or third) language (usually English, but sometimes a composite of more than one language).

In line with Hikmat's in-house capacity building training, follow-up telephone calls were made to participants, between their preparatory session and the Health and Well-Being Check, to ensure the level of commitment was maintained and participants attended their appointments.

Many participants reported how the Health and Well-Being Check process had made them feel important, and they liked the unaccustomed attention and recognition it brought.

1.3 Retaining Project Workers

All project workers recruited at the start of the project have been retained throughout.

Although project workers have been encouraged to find solutions to problems by themselves where possible, they work secure in the knowledge that supervisory support is available through either a quick phone-call with the Co-ordinator, or where care planning or conflict situations are the concern, a more structured formal supervision. This has helped staff have confidence in their ability and feel their contribution is valued, and has helped the project retain its full team.

Facilitated team meetings have also fostered an atmosphere of shared effort, and provide a background against which staff members can request and expect help from each other.

2 *Participants*

2.1 Identifying Participants

Hikmat Centre staff had already identified some carers as potential participants for the project. However, a major concern was that almost none of the service users known to staff thought of themselves as 'carers', having little or no understanding of the concept. A common attitude in all the target communities is that caring is a duty and just part of the normal responsibilities of family members, usually but not always women. To expect extra support, or to be paid for this role, is to bring shame on the family. This was expected to be the biggest obstacle to success.

For this reason, three awareness sessions were built into the project costings. One of these was undertaken at the Hikmat Centre in Exeter, one at Exeter Mosque, and one in North Devon. All were well attended, and generated lively discussion. Not only was the issue of "What is a carer?" addressed, but also what aspects would be covered in the Health and Well-Being Check Booklet.

At later awareness sessions, earlier participants shared their positive experience of the process, which helped enormously.

Other potential participants were identified by partner agencies, for example Rejuve-Nation and the BME Mental Health Community Development Workers.

2.2 Engaging with Participants

The two biggest fears amongst participants (at all stages of the project, not just at the beginning) were whether participation would impact negatively on immigration status

Practical considerations were also discussed at this meeting, such as who would do the clinical sessions, and how would we translate documents in the pdf format, which was difficult to change. Participants were able to hear first hand exactly why it was necessary to have a specialist BME contract for the initiative, and to get an idea of what problems were likely to be faced in the future.

It was predicted by Hikmat management that a considerable amount of training would be required in order to overcome a range potential barriers to success. This would need to include:

Listening skills
Acknowledging, reflecting and summarising
Body language and eye contact
Boundaries (saying No and meaning it) and confidentiality
Self disclosure, being non-judgemental
Overcoming resistance
Encouraging personal responsibility
Establishing agreements and SMART goals
Time management

Sessions in healthy eating and lifestyle choices were also included in the training programme for the Project Workers.

Training sessions to ensure competency in completing paperwork were also delivered. Documentation was scanned and reproduced on power-point for project workers to copy (parts of the Booklet, for example, and sample forms filled in for An-Other), and were completed and checked by facilitators during the training.

Easy Read step-by-step instructions for the Health and Well-Being Check process were distributed to all staff at significant points during the induction period.

All project workers conducted a practice interview with a friend or colleague.

All those involved in delivering training to the programme acknowledged the enormous contribution the sessions brought to developing their *own* practice, by highlighting cultural aspects of the project, as well as by demonstrating the particular requirements of BME learning processes.

It was agreed that the clinical and vascular training would be attended by the project managers and administrators only.

1 *Staffing*

1.1 Recruiting Project Workers

As effective communication was such a pivotal factor to the success of the project, speaking at least one language other than English was included as an essential requirement for the role of BME Project Worker. In this way, the seven project workers who were recruited to the team spoke at least nine ethnically distinct languages between them (Mandarin, Cantonese and Haka for the Chinese community, for example).

Languages spoken by the team were Urdu, Hindi, Punjabi, Bengali, Farsi, Arabic, Cantonese, Mandarin and Haka.

Those supporting Carers to receive a health and wellbeing check were expected to prepare by studying the Health and Well-Being Check Booklet and identifying areas where culture is likely to impact on the process. It was anticipated that some of the questions around lifestyle choices (particularly alcohol and gambling) would be problematic, as moral and religious imperatives could prevent honest discussion. It was also expected that action planning around education and leisure activities would be difficult, as these would be new concepts to many of the women whose lives had previously been restricted to activity within the home.

As well as project workers, volunteers from the target communities were encouraged to come forward to help explain the project and build confidence amongst potential participants.

1.2 Training Project Workers

By the third quarter of 2009, sufficient project workers had been recruited and staff training began. Firstly, an awareness session was held, bringing together project workers, Hikmat managers and statutory sector staff who would be contributing to or monitoring aspects of the project. This proved to be an invaluable meeting, where issues and potential problems were identified and acknowledged. For example, staff from mainstream services who attended acknowledged that they gained understanding of ethnically distinct interpretations of the role of 'carer', when previously they may have assumed that differences in approach would be mainly between the BME and the mainstream communities. The mainstream professionals present were quick to grasp the significance of the enormous range of attitudes articulated by the project workers during the session. The discussion provided the means to address any scepticism they encountered about the need for the special arrangements for BME carers represented by the Sahara contract.

Introduction – purpose of this report

This report is intended to complement the Final Programme Report and Research Evaluations of the HC31 Devon Carers' Health and Wellbeing Checks Programme 2009-11 by providing an account of process and the learning from the point of view of Sahara as a delivery partner in the Programme.

Demographic Background

Although 'guestimates' have been attempted for the number of people from black and minority ethnic (BME) backgrounds who are resident in Devon, by extrapolating from school attendance for example, accurate figures must wait for publication of the *Census*. Trends would indicate a growth rate over the past ten years at least double that of the country as a whole, with the influx spreading far more evenly over the county than in previous decades.

There are various reasons for this; public sector workers following jobs (in hospitals, schools and care homes), increasing demand for multi-cultural choice locally in restaurants and take-aways, people looking to retire in pleasant surroundings, and other family members joining a core group already here. In addition, the Islamic Studies Unit at Exeter University continues to attract both teaching staff and students.

Because of the traditionally low demographic densities, there has been little development of statutory services for BME residents, and service provision has been predominantly provided by the community sector, in particular the Hikmat BME Centre, who were contracted to carry out the Carers Health and Well-Being Checks for the project. It is acknowledged that the success of the Carers initiative was very much predicated on previous penetration into these communities by Hikmat Project Workers. The main targets groups for the project were all South Asian communities (Bangladeshi, Pakistani and Indian), Middle Eastern and North African communities, and Far Eastern communities (China, Thailand, Philippines, Korea, etc).

Some of the hardest to reach groups were those who had been resident the longest. Bangladeshi families, in particular, required a great deal of preparatory work to overcome issues of trust and family honour. Refugees and asylum seekers were also hard to identify, as fear and ignorance about immigration status and entitlement result in many remaining hidden and isolated.

Intended Outcomes

The primary target for the project was completion of 75 Health and Well-Being Checks, to include completed booklets and action plans. Sixty-five checks were completed in their entirety. Approximately ten were only partially completed or rejected totally at the last moment, the main reason being given was that carers did not have a GP and were afraid of jeopardising their immigration or benefits status.

Additional desired outcomes included: improvements in partnership working across all sectors; increased membership of Carers Link within all the communities; increased take-up of primary and secondary health treatments and social care support.

Peripheral objectives were increasing engagement with educational, training and sport opportunities and enrolment in English (ESOL) courses.

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Hikmat BME Centre

Carers' Health and Well-being Checks Project

Final Report

April 2011