

Cancer Help for Ethnic Communities (CHEC)

An evaluation of the service

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LIST OF ABBREVIATIONS

ASWCS	Avon Somerset and Wiltshire Cancer Services
BME	Black and Minority Ethnic
BMEG	Black and Minority Ethnic Groups
BOME	Black or Minority Ethnic
CHEC	Cancer Help for Ethnic Communities
LA	Local Authority
NICE	National Institute for Health and Clinical Excellence
NHS	National Health Service
PCT	Primary Care Trust
WHO	World Health Organisation

DEFINITIONS

Supportive Care is defined by the NCHSPCS (2002) as: helping the patient and their family to cope with cancer and treatment of it – from pre-diagnosis, through the process of diagnosis and treatment, to cure, continuing illness or death into bereavement. It helps the patient to maximise the benefits of treatment and to live as well as possible with the effects of the disease. It is given equal priority alongside diagnosis and treatment. Supportive care is therefore an umbrella term for all services, both generalist and specialist, that may be required to support people with cancer and their carers.

Palliative care is defined by WHO (2002) as: the active holistic care of patients with advanced, progressive illness. Management of pain and other symptoms and provision of psychological, social and spiritual support is paramount. The goal of palliative care is the achievement of the best quality of life for patients and their families. Many aspects of palliative care are also applicable earlier in the course of the illness in conjunction with other treatments.

Client is used throughout to refer to users of CHEC.

Practitioner is used throughout to refer to professional staff employed in the health, social or voluntary services.

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Executive Summary

CHEC is a local initiative seeking to address nationally recognised issues associated with improving the quality of cancer care and palliative care for people from BME backgrounds. CHEC has two aspects: holistic individual care for patients and their families and carers, and community development work to raise awareness of cancer. CHEC has operated within the Avon area since 2002.

This evaluation of CHEC focuses on its client support work. The study also explores how CHEC operates alongside mainstream services and works towards sustainable practice, and whether CHEC delivers a cost-effective service. The study consists of a review of the relevant literature and policy context, semi-structured interviews with 21 participants (6 service clients and 15 practitioners) and a cost-effectiveness analysis based upon service records.

Service users are uniformly enthusiastic and positive about CHEC's work. Particular strengths of CHEC's client support work are identified as: the provision of holistic and continuous care and support that spans boundaries; facilitation of patients and their families' use of other services, both health and social care; championing cultural competency and BMEG issues within mainstream palliative care services; and providing a route for mainstream services to link with different BME communities. One potential weakness is the seemingly ad hoc nature of referrals to CHEC, which indicates potential users who could benefit from the service might not be reaching it.

These aspects are supported by an analysis of CHEC service monitoring data and associated secondary sources. Economic analysis shows that: CHEC has become more cost-effective over time, using its budget to meet the needs of a rising number of service users; CHEC is approaching capacity in respect of its client support work; and there is scope for expansion of CHEC's community development work.

Some specific recommendations emerge from this research study. These include: CHEC should build a team structure rather than relying on a sole practitioner; there should be more publicity about CHEC to facilitate greater numbers of referrals; CHEC's location within the NHS is appropriate and helpful and should continue; monitoring service use by ethnicity should be encouraged to assist ongoing evaluation; and commissioners should continue to publicly recognise and appreciate both aspects (client support and community development) of CHEC's work.

CHEC is an innovative model for providing cancer care support of people from BME backgrounds. It provides or facilitates a comprehensive range of services for clients from BME backgrounds in the Bristol area. CHEC works from within the NHS to advance practice and reform palliative care services. CHEC appears to provide a highly valued and cost-effective service for its clients.

1.0

Introduction

Cancer Help for Ethnic Communities (CHEC) was established in 2002 with funding from the New Opportunities Fund *Living with Cancer* initiative and the five Avon Primary Care Trusts (PCTs). Initially called 'The Palliative Care Service for Culturally Appropriate Care', the service was renamed as CHEC in 2004 in order to give it a more simple and recognisable title. Since 2005 funding of CHEC has been picked up by three of the local PCTs (Bristol North, Bristol South & West, and South Gloucestershire).

A thorough evaluation of CHEC's client work is viewed as highly desirable given its innovative nature and time-limited funding. Commissioners, providers and users of services need to know whether CHEC provides value for money, how it dovetails with other services, and what constitute its distinctive aspects as a service model. To this end, it was agreed that researchers at the University of the West of England (UWE), Bristol would carry out an independent evaluation of CHEC. This was funded by the small grant scheme of the Faculty of Health and Social Care at UWE and CHEC. The evaluation was conducted during 2005.

Aims and Objectives of the Evaluation

The aim of the study is to evaluate the client support aspects of CHEC. The study's objectives are to:

1. Examine how CHEC promotes culture-sensitive cancer care issues for people from BMEGs living with cancer, their families and carers
2. Investigate the cost-effectiveness of CHEC
3. Examine the development prospects and sustainability of CHEC

2.0 Context

2.1 Introduction

This section summarises key literature and policy relating to cancer support and palliative care services for BMEGs. Recent evidence concerning BMEGs and cancer rates, BME experiences of health care, cancer care and palliative care services, mainstream policy responses, and the development of BME specialised cancer care services in England will be identified and examined. This section also provides an overview and profile of CHEC.

An electronic search was conducted for relevant empirical research, commentary, policy and service guidance using the British Nursing Index, CINAHL and the National Electronic Library for Health databases. Where Boolean search functions were available, a typical search string comprised 'black OR ethnic\$ OR culture\$' AND 'palliative care OR cancer care OR cancer services'. Literature published before 1994 was initially excluded. However, reference lists of retrieved articles were searched for further suitable literature which yielded relevant material as far back as 1980. In addition a hand-search was conducted of hard copies of certain specialist journals, such as the *International Journal of Palliative Nursing*, for the period 2000 to 2005. Key websites including: the Department of Health, the National Institute for Clinical Excellence, Cancer BACUP, the National Council for Hospice and Specialist Palliative Care Services, the Commission for Racial Equality, the National Statistics Office and Avon Public Health Network were also searched for relevant material.

CHEC project plans, annual reports, service user monitoring data and financial data were accessed to provide useful background information and to review the service context, its stated aims and objectives, annual performance, service use/uptake and financial performance.

2.2 Cancer Rates for Black and Minority Ethnic Groups

Ascertaining cancer rates for BMEGs is complicated by the consistent under-recording of ethnic status in official data sets. Although ethnicity is monitored through Cancer Registries, data are poorly recorded. For example, the South West Cancer Intelligence Service has estimated that fewer than 10% of reports to the Cancer Registry record ethnicity and, of these, most reports are of White ethnic background (Harling, personal correspondence, 2005).

Bearing in mind these limitations, some trends do emerge. Overall, there appears to be a lower incidence of most forms of cancer in the UK BME population compared to the UK White population (Deepak, 2004; Johnson, 2001). However, the general picture obscures differences with regard to specific populations and cancers. Reviews have found that, for example:

- the incidence of oral cancers is higher in African and South Asian people compared to White counterparts and may be linked to higher rates of tobacco use in these populations (ASH, 2004);
- childhood cancers have a higher incidence in certain BME communities (Deepak, 2004);
- liver and gall bladder cancer rates are higher amongst Bangladeshis (Johnson, 2004);

- cancers (especially of digestive organs) are the top cause of death among Chinese men and women (Johnson, 2001);
- cancer (especially of the prostate and breast) is the most common cause of death among Black Caribbeans (Johnson, 2001);
- mortality rates for cervical cancer appear to be higher in women of Caribbean and Irish origin than White British counterparts (Deepak, 2004).

According to Johnson (2001), evidence suggests that cancer rates for BME populations are converging with those of the majority White population. Cancer rates among BME populations are likely to rise with increased exposure to carcinogens and with the general trend towards an ageing population.

Studies of breast cancer illustrate the complexity of the epidemiology in this area. Watts et al's (2004) critical review of the research literature from 1996-2002 found that women from BMEGs have a lower incidence of breast cancer but poorer five year survival rates. Farooq and Coleman (2005) similarly found that South Asian women in the UK had the lowest rates of breast cancer, but, in contrast to overall BME rates, found higher than average breast cancer survival rates in each category of deprivation. They also found that five year breast cancer survival was 8-9% higher for affluent women in all BME groups. Different findings from studies may reflect a rapidly changing picture. For example, breast cancer incidence is rising among UK South Asian women at a faster rate than for other ethnic groups and is higher for this ethnic group than for their South Asian counterparts in the Indian subcontinent (Deepak, 2004; Johnson, 2001).

To conclude, BME patterns of cancer incidence, presentation and outcome are not uniform but heterogeneous, due to differing age profiles, residence, demographic and socio-economic variables both between and within specific BME groups.

2.3 Black and Minority Ethnic Experiences of Cancer Support and Palliative Care Services

Surveys of NHS patients conducted between 1998 and 2000 (Commission for Racial Equality, 2003) show that people from BMEGs are significantly more likely than average to report unfavourably on their experiences of health services, specifically with respect to:

- waiting times;
- understanding explanations;
- trust in health professionals;
- being treated with dignity and respect;
- help with pain relief.

A systematic review (Warwick Centre for Health Studies 2001) of access to health services for BMEGs living in London found that poorer experiences were attributed to:

- lower BME awareness of services;
- language and literacy difficulties;
- cultural differences (relating to religion, gender or work patterns);
- different needs of different populations;
- location of service delivery.

A number of reviewers (Ahmed, 2000; Johnson, 2001; Watts et al., 2004) suggest that mainstream research and policy responses tend to emphasise cultural deficits of BMEGs in

accounting for health service experiences. This emphasis underplays the significance of material disadvantage and overt, covert or institutional forms of discrimination within service provision.

Although a number of case studies have been published (Rees, 1986; Clarke et al., 1991; O'Neill, 1994), it was Hill and Penso's (1995) report that highlighted BME issues relating to palliative care and cancer support services. Hill and Penso (1995) found evidence of differences between White and BME populations in terms of quality, extent, experience and outcomes of care. Central issues concerned low referral rates, lack of knowledge and information about services, and ethnocentric assumptions of practitioners regarding BME care needs. Lack of accurate data on ethnicity, the demography of the BME population and the historical configuration of services compounded problems of service provision.

Subsequent studies provide further evidence to support the general argument that, compared to the majority White population, BMEGs experience poorer cancer care and support service provision. Specialist palliative care services, social care services and welfare benefits are all underutilised by people from BMEGs (Ahmed, 2000; Karim et al., 2000; Koffman et al., 2003; Johnson, 2001; Lees and Papadopoulos, 2000). BME informal carers report problems in accessing sources of support (Somerville, 2001). The reasons for these problems include: insensitive and inappropriate services, under-referral by GPs, communication difficulties, stereotyping and forms of discrimination (Johnson, 2001; Watts et al., 2004).

2.4 Development of Cancer Support Services for Black and Minority Ethnic Communities in England

Since the mid-1990s, measures to address inequalities in access by BMEGs to cancer care services include reforms of mainstream services and the development of specialised services for BME groups.

Mainstream Service Development

Hill and Penso (1995) recommend several measures for mainstream service providers to adopt in order to address inequalities in service provision for BMEGs:

- record ethnicity;
- develop an equal opportunities strategy;
- implement a staff code of conduct;
- provide appropriate staff training and recruitment measures;
- develop a communication plan;
- ensure culturally specific provision;
- provide support for carers and voluntary community health initiatives.

The Calman Hine Report (1995) proposes that services provide 'seamless' care from the patient's perspective, comprising:

- excellent information transfer that 'follows' the patient;
- effective communication between professionals;
- flexible responses by service providers to changes that may occur over time;
- a minimum number of professionals involved in a patient's care to ensure continuity and consistency with care needs.

These themes resonate with those of recent government reports (DH, 1995; DH, 2000). Three problem areas with regard to patient care have been identified (the Commission for Health Improvement and Audit Commission, 2001): poor recognition of the emotional needs of patients, poor co-ordination of services, and wastage of scarce resources. Existing palliative care provision is dominated by voluntary sector hospices which target the White middle class population. Hospices have proved less successful at meeting the needs of users with high levels of need, including people from BMEGs (NICE, 2004).

One response to these problems is the proposal that, to ensure services address the needs of local communities more effectively, frontline NHS staff should have greater control over, and responsibility for, services (DH, 2002a). A linked recommendation is that the co-ordination and configuration of cancer services be achieved through developing local cancer networks (DH, 2000).

The need to address inequalities in healthcare provision for BME communities with respect to cancer, cardiovascular disease, mental health and diabetes is stressed in a cross-cutting review into health inequalities (DH, 2002b). The NHS Cancer Plan emphasises the importance of refocusing services on the health needs of patients, including those from BME backgrounds, and proposes changes to the design and delivery of services to respond appropriately to the diverse health and social needs of individuals and communities (DH, 2000).

The National Institute for Health and Clinical Excellence (NICE) recommends that health services should be planned on the basis of need, "irrespective of ... age, gender or ethnicity" (NICE, 2004: 26). This implies that the specific and varied health and social care needs of people from BMEGs should be properly evaluated and addressed, and that services could be delivered in various ways to suit the needs of different communities. NICE (2004) also proposes that 'user involvement', facilitated by improved communication with BMEGs, should underpin the development and delivery of cancer support services.

Specialised Services for BME Communities

Despite the existence of national guidance and policy for developing cancer services to meet the needs of patients from BMEGs, mainstream NHS services have an uneven track record of effective action. Deepak (2004: 9) argues that the Department of Health and NHS Trusts "have been very slow to prioritise their responses to the needs of BME communities".

One response has been to develop specialised services that address the needs of ethnically and culturally diverse communities, and that then spearhead service development as examples of good practice. Since the early 1980s many local initiatives have been developed that have offered cancer care and support and palliative care for BME communities. Pioneering examples include: *Coping with Care* (Leicester), *Umeed Self-help Group* (Bradford), *Palliative Care Project* (Bradford) and *CYANA* (London) (Deepak, 2004). Such projects have provided baselines for good practice within the field of cancer support and been influential in terms of mainstream NHS service developments. Cancer support services for people from BME communities have increased rapidly since 2001, as a result of grant funding through the New Opportunities Fund, Health Action Zones, the Health Improvement Fund, Macmillan Cancer Relief, Marie Curie Cancer Care and local NHS bodies. Drawing upon CancerBACUP data, Deepak (2004) estimated that there were between fifty and sixty BME cancer support projects in England in 2003. These services performed a variety of related functions including:

- personal / psychological patient support;
- personal / psychological support for families and carers;
- spiritual support for patients, families and carers;

- social support for patients, families and carers (immigration, housing, benefits, etc.);
- patient, carer and family advocacy;
- user involvement;
- the facilitation of self help support groups;
- information and advice;
- drop-in services;
- translation services;
- co-ordination of volunteer social care services;
- BME community group outreach;
- complementary therapies;
- community health promotion events and campaigns;
- needs assessment;
- practitioner training and advice;
- cancer services strategic development and review.

Individual services vary considerably in terms of their aims, role definition of key workers, organisational location and funding scale. In 2001 CancerBACUP received a New Opportunities Fund grant to support this emerging field of provision through the development of a national network, which shares best practice, develops information resources, and co-ordinates work with external bodies. As a result of outreach and networking activities, in 2004 CancerBACUP published a review of key issues reported by services across the network (Deepak, 2004). Despite the diversity of initiatives, a number of common themes were identified that are also reflected across the associated research literature:

(i) Funding and Organisational Context

Most services are funded through time-limited and non-recurrent grants. This means that most initiatives lack long term security and are removed from mainstream service planning, monitoring and review. Deepak (2004) comments that such funding threatens the sustainability of services, and that sustainability is a precondition for the development of trusting relationships between services and users. Funding insecurity may lead to projects devoting resources towards seeking further income, to the detriment of service provision. The upside of grant funding is the ability to innovate, operate flexibly and work outside mainstream services.

(ii) Project Scale and Project Staffing Issues

Most projects operate from a small dedicated staffing base. Project stability is therefore highly sensitive to changes in the staffing composition. Roles often demand a broad knowledge and skill base, for instance spanning cancer care, social care, benefits advice, health promotion and community development. Staff need to understand both community needs and professional priorities (Randhawa et al., 2003). Combined with an understanding of BME community issues, staff appointments are sometimes problematic. Project roles are often innovative in nature but, as a consequence, are not always well understood by colleagues, service users and line managers. Managers may view the success of projects through numbers of users and fail to appreciate the importance of more intangible outputs such as networking. Ackroyd (2003), moreover, expresses concern regarding the emotional

demands of a role of this nature. Limited resources and small project scale also hamper the potential for highly important developmental work that seeks to build and improve relationships with BME communities.

(iii) Specialist Service Access for BME Service Users

Such services can be difficult to promote where there are competing priorities and interests within NHS and social care services, and poor awareness within mainstream services of the value of such initiatives. Service users often access specialist services through ad hoc routes and are not aware of the range of available resources and sources of support. Randhawa et al. (2003) found NHS professionals thought that, compared to White British patients, BME patients receive more thorough healthcare needs assessments. NHS professionals assumed that cultural and spiritual needs were more significant for people from BMEGs, and that this would enable them to access appropriate support. Paradoxically, they found that practitioners were unlikely to refer patients to specialist BME services.

(iv) Diversity and Commonality for BME Service Users

'Individualized multicultural care' (Diver et al., 2003a; 2003b) is a complex aim to put into practice. BME service users may have culture-specific care needs that should be addressed, yet they also have needs that are highly individual and needs that are more universal in character. Care that sets out to be culturally sensitive may fail to recognise personal biographies, micro-cultures and diversity within cultures. This highlights the complexity of cultural sensitivity at a vulnerable point in the lives of service users.

There has been much debate on the desirability of developing services to match specific BME communities. It is suggested that there are limitations in attempting to rely on matched BME staff recruitment. While service-BME matching has some recognised attractions, it is unlikely to address in itself all the issues (Diver et al., 2003). This reflects debates on the concept of cultural competency in health and social care (Papadopoulos et al., 1998). Nyatanga (2002) argues that the primary issue has been that of providing culturally competent care, defined as:

'... the ability to maximise sensitivity and minimise insensitivity in the service of culturally diverse communities. This requires knowledge, values and skills... The workers need not be, as is often assumed, highly knowledgeable about the cultures of the people they work with, but must approach culturally different people with openness and respect – a willingness to learn' (O'Hagan, 2001: 235).

Importantly, this should avoid stereotypical notions of cultural diversity.

(v) Needs Assessment, Performance Monitoring and Evaluation

Poor ethnic monitoring at local and national levels means that specialised services for BME communities struggle for to demonstrate their performance or effectiveness. Services that are able to undertake needs assessments, project evaluations and service capacity monitoring operate from a better recognised basis. BME specialised services encounter the same difficulties recording and accessing ethnic data as mainstream services. Nonetheless, funding bodies or sponsors usually require monitoring and evaluation data to enable them to make commissioning or future budgeting decisions and may therefore be reluctant to continue to support initiatives that appear to duplicate mainstream services or to bring no 'added value'. Without clear baseline data, it is difficult to measure service effectiveness or quality, and this is further compounded when small projects have meagre resources and therefore lack the capacity to evaluate their progress. It is, moreover, difficult to measure

'success' in terms of patient throughput or satisfaction when such projects commonly work with whole – sometimes extended – families and often with small, unrepresentative numbers of clients.

(vi) Service Catalysts and Service Champions

Despite the small scale and marginal position of some BME specialised services, there is some evidence that they can have an impact on mainstream provision and on outcomes for service users. Ackroyd's (2003) local study in Bradford illustrated how a single outreach link-worker could make a significant impact on the number of referrals to local palliative care services. Ackroyd recommended that link-workers constituted a good model for service development. Similarly, Jack et al's study (2001) highlighted how a single liaison worker was overwhelmingly well received by professionals across a range of services. The liaison worker heightened awareness among professionals of BME inequalities, provided rapid case support and was able to give assistance in complex care situations. Such services evidently play a significant mediation role in supporting mainstream service providers in their work with BME communities.

Such findings also reinforce the need for staff training that prepares health professionals with culturally specific knowledge combined sensitively with an individualized care philosophy (Diver et al., 2003b). In this regard, several commentators have discussed the notion of developing healthcare providers' 'cultural competencies' (see Purnell and Paulanka, 1998). Indeed, this has gained some currency within UK healthcare training and provision and has been perceived as an organising framework for the development of supportive and palliative care services. As Diver et al. (2003) have argued, cultural competence is particularly relevant for practitioners working in particularly stressful situations, such as with cancer patients and their families, where the patient may seek support through aspects of their cultural heritage (Diver et al., 2003). Developing or nurturing cultural competence among mainstream healthcare providers is arguably a useful means of complementing the already relatively good awareness healthcare provider's share of other specialist support services, including hospice chaplains, dieticians and others (Diver, 2003b).

(vii) Translation and Language Services

A number of reviews (Diver et al., 2003; Dunckley et al., 2003; Randhawa et al., 2003) have identified communication difficulties as a significant source of worry for health professionals. One problem concerns the use of poor quality printed information, such as patient leaflets. Another problem relates to inappropriate use of staff or relatives, professional or otherwise, as interpreters, especially where interpreters either do not understand the healthcare context/issues or the specific cultural or social issues concerning the patient (Randhawa et al., 2003; Diver et al., 2003b). In this regard, interpreting should constitute more than a translation role (Diver, 2003b).

Conclusion

To sum up, there are both strengths and drawbacks to the provision of specialised services for BME communities. The strengths include the ability to: provide continuous holistic and culturally competent care, crossing organisational and role boundaries; act as a champion and trailblazer for reformed mainstream services; and act as a mediator between different services, practitioners and users. Drawbacks include: marginalisation and removal from mainstream provision; lack of visibility due to gaps in ethnic monitoring and data; and lack of sustainability due to funding and staffing arrangements.

2.5 Cancer Help for Ethnic Communities (CHEC):

Overview of the Service

CHEC operates in the PCT areas of South Gloucestershire, Bristol North and Bristol South and West and is embedded in Avon Palliative Care Service. Bath and North East Somerset PCT and North Somerset PCT, which initially helped fund CHEC, have now dropped out of the funding arrangements due to the very small numbers of CHEC users' resident within their areas. CHEC remains a signposting service for North Somerset and North Gloucestershire PCTs.

CHEC currently operates from Avonmouth Medical Centre and employs one full time practitioner. At the time of the study, the CHEC practitioner was a White woman with a background in health promotion. CHEC comprises two related areas of work:

- BME cancer care and service development work
- BME patient, family and carer support work

The development work of CHEC involves advertising and promoting the service in a range of community forums, both in person (project worker) and via leaflets and posters. CHEC is involved in the BOME (Black or Minority Ethnic) Cancer Forum, which is in turn linked with the local Cancer Network (ASWCS – Avon Somerset and Wiltshire Cancer Services). The project worker also provides cancer awareness training for interpreters and cancer awareness sessions within the local community. Figure 1 summarises the organisational context of CHEC, illustrating how CHEC is linked to many different statutory and voluntary services and agencies.

CHEC's support role involves working with people from BMEGs with cancer and their families and carers, to develop a holistic care plan. Depending on individual circumstances, support may be sought from a variety of services including: advocacy, language support, practical help and information provision. Where appropriate, referrals are made to statutory and community agencies. The CHEC practitioner works with users one to one and in partnership with other service providers. Care is delivered across a range of healthcare settings, including hospices and inpatient hospital settings. Figure 2 illustrates the range of client support CHEC facilitates.

FIGURE 1 The organisational context of CHEC, illustrating its links with other statutory and voluntary services and agencies.

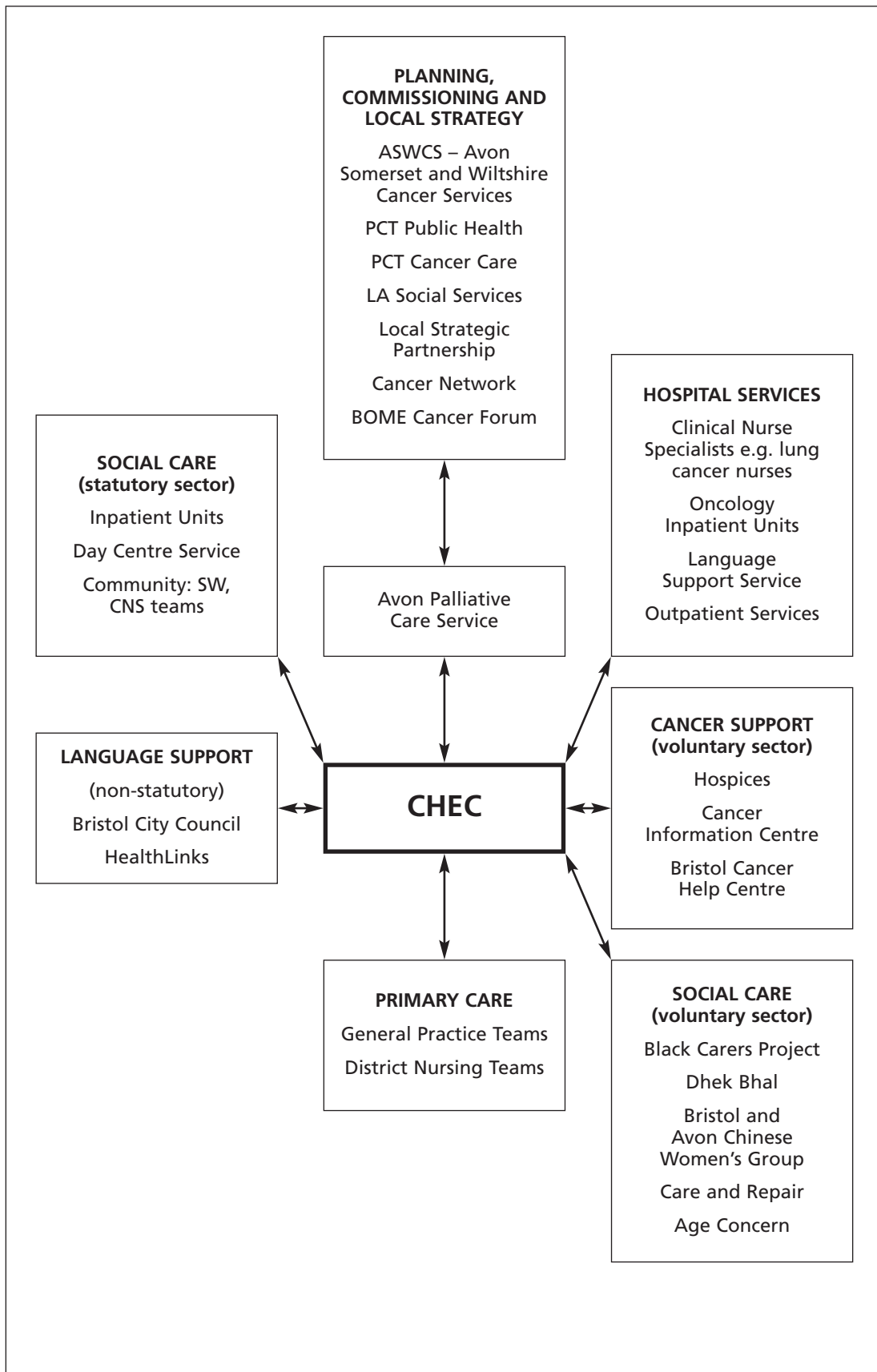
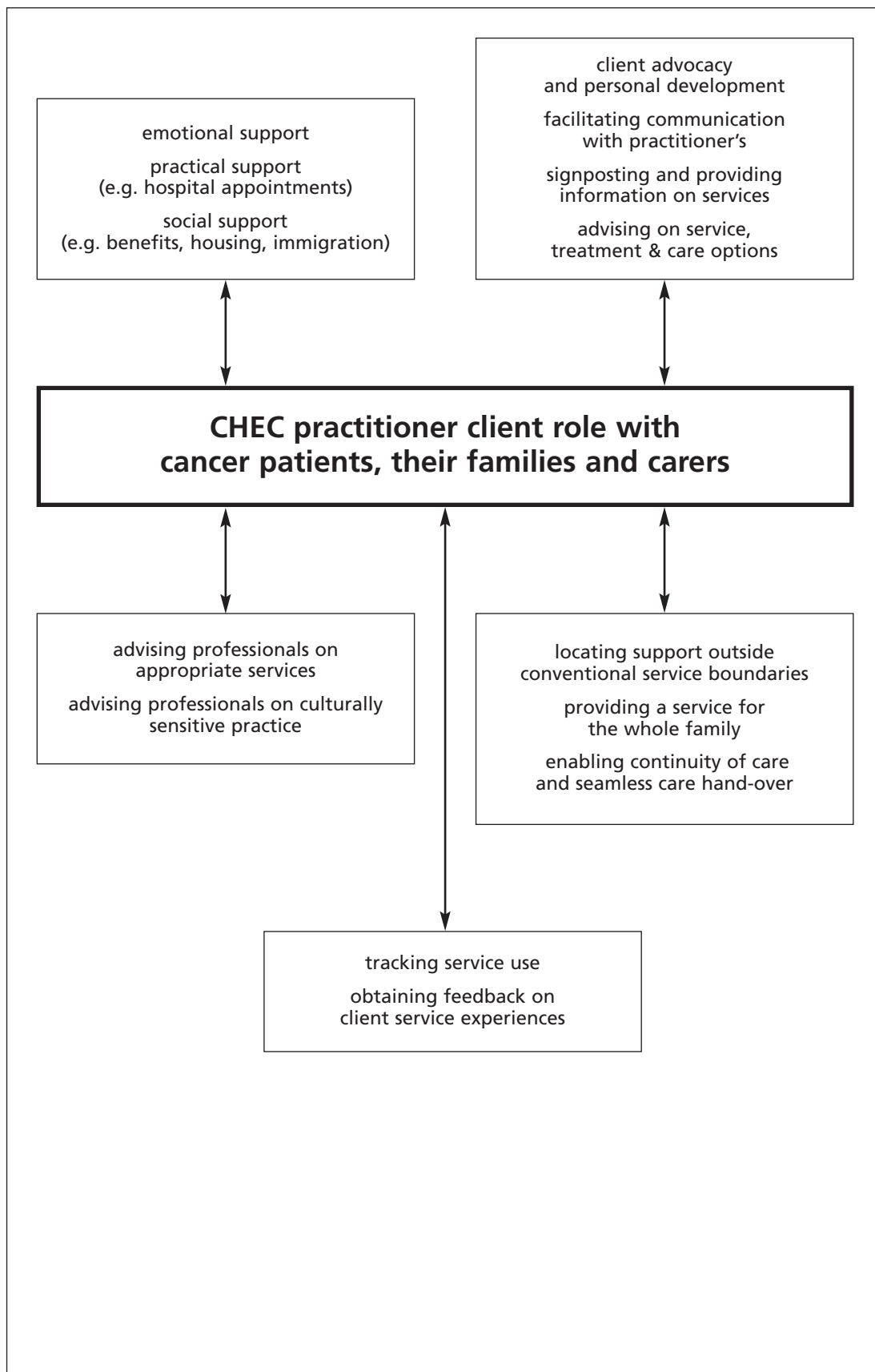


FIGURE 2. Range of client support facilitated by CHEC for people from BMEGs, their families and carers.



The work of officers with similar roles has been evaluated elsewhere. Jack et al. (2001) found that the aims of a liaison officer working within a BME community were firstly to raise the profile of palliative care within an Asian community and with other agencies, and, secondly, to maintain and improve the quality of care provided to patients and their carers from BME groups. This second aim was facilitated by improving communication and access to specialist palliative care services. This is one example of a combined development role, but, unlike CHEC, it targeted only one BME community. Jack et al. (2001) also found that the use of generic or specialist link workers varied between palliative care teams across UK cities.

Prior to the establishment of CHEC, the 2002 Report of the Avon Palliative Care Service for Home Support and Culturally Appropriate Care reported 131 new users, of whom 129 were identified as White British, and only two were from a Minority Ethnic background. The 2003 Report stated that forty-five of the 410 service users were from BME communities, that eleven families were helped directly and that a further seven families were helped indirectly via a third party. By 2004, there were 686 service users, of whom 100 were from BME communities (fifty-four from Asian and forty-six from African Caribbean communities). Thirty-eight families had been supported via CHEC. These figures demonstrate clear ongoing success in reaching out to BMEGs, and illustrate how a dedicated service can reach people who are usually viewed as 'hard to reach'. In one year, CHEC had managed to double the number of individual clients and families to whom it offered support and help. Unlike the Home Support Service, CHEC offers a service for clients with cancer whatever the stage of their illness. Some of the increase in numbers reached may therefore be attributable to some long-term clients and their families who were counted in both years' figures.

The following charts provide data from 2004 to 2006 on referrals by area, ethnicity, duration of case work and types of support offered.

FIGURE 3: Patient referrals by Area. April 2005-January 2006 (N=94)

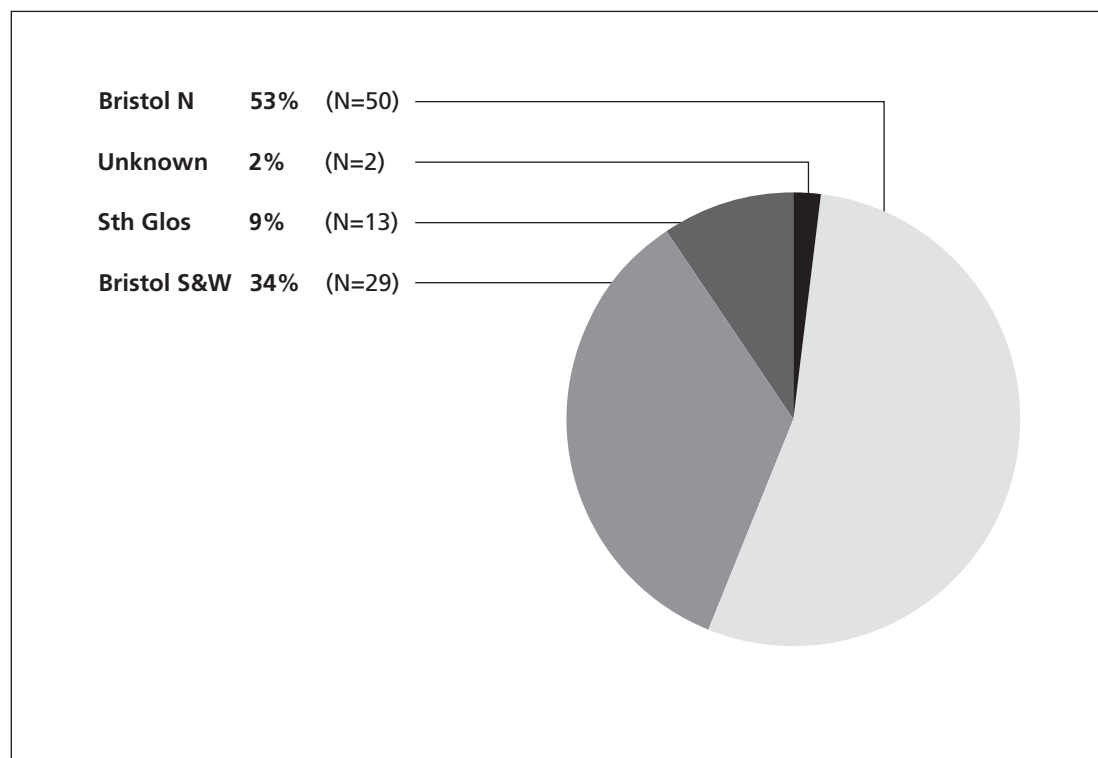


FIGURE 4: Patient referrals by Ethnicity. April 2005-January 2006 (N=94)

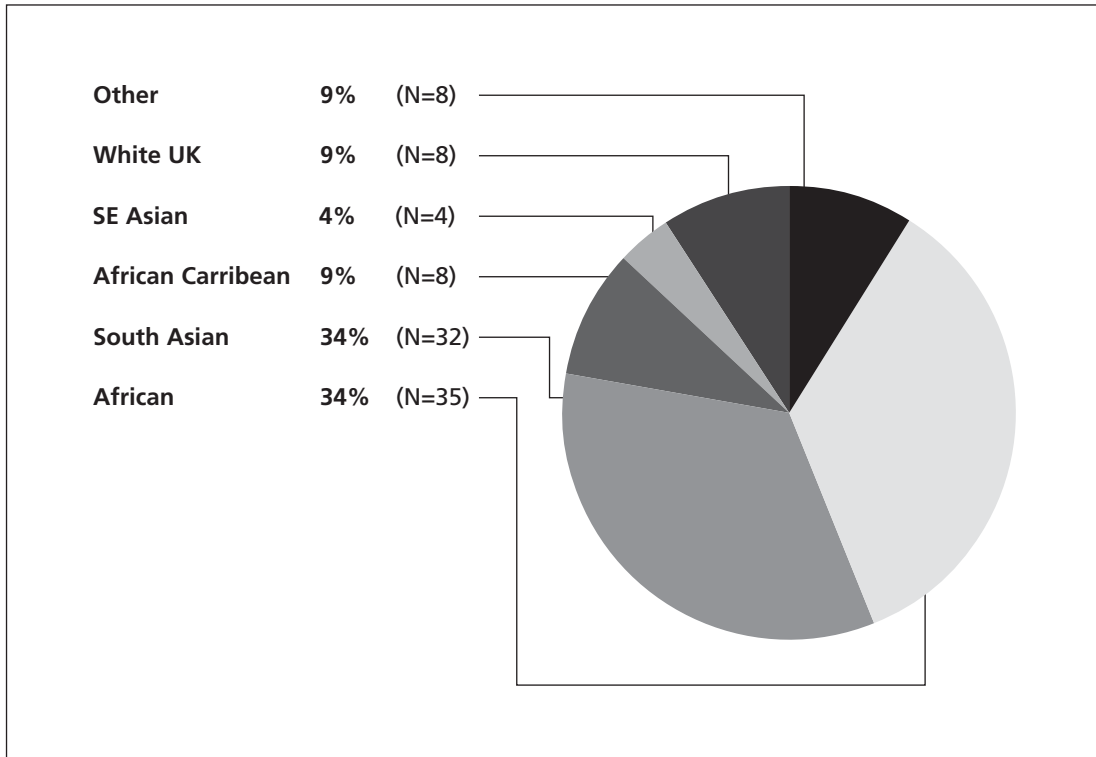


FIGURE 5: Duration of Case Work. April 2005-January 2006

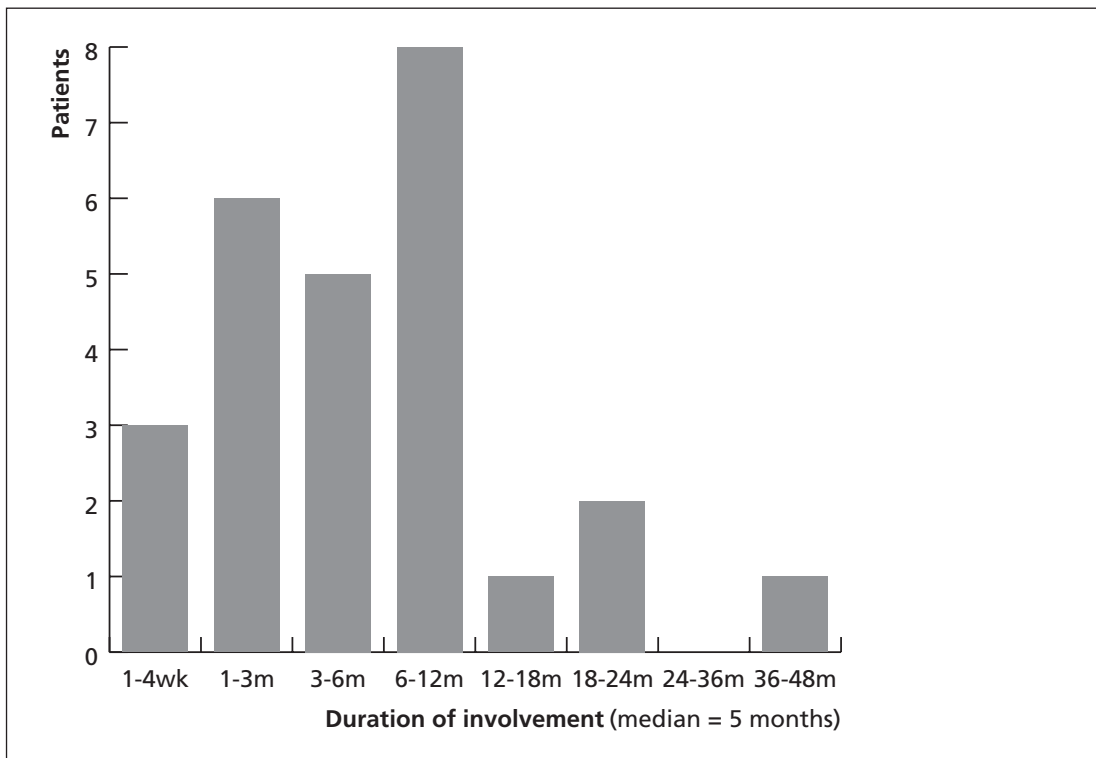
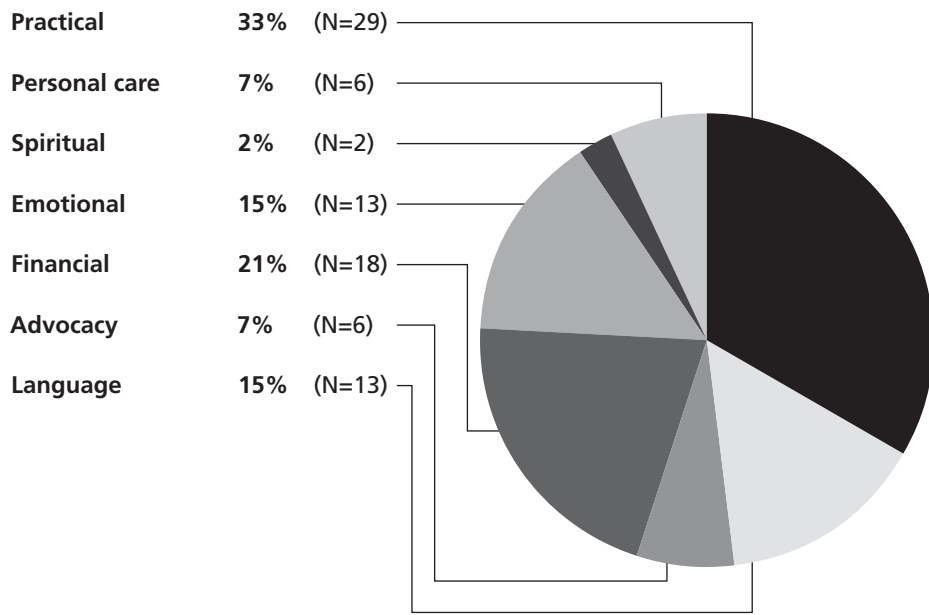
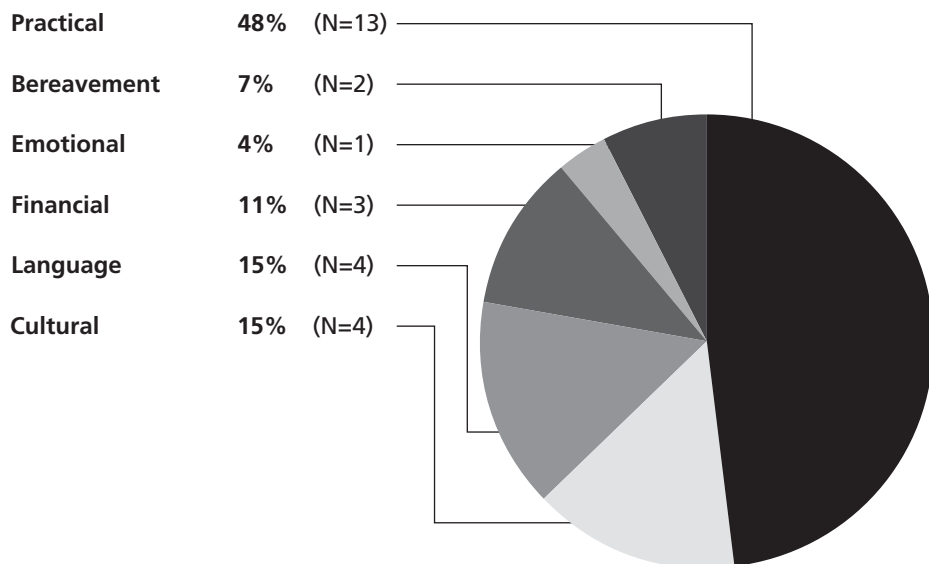


FIGURE 6: Patient & Carers requests 2004



Patient requests 2004 & ongoing. N=87



Carer requests 2004 & ongoing. N=27

3.0

The Evaluation Methodology

3.1 Introduction

A mixed methods approach was used to evaluate CHEC. Firstly, semi-structured interviews were conducted to explore participants' perspectives of the service; participants included service users (patients, relatives and carers) and service providers from across a range of statutory and non-statutory services. A semi-structured interview approach was felt to be appropriate because we were interested primarily in eliciting users and practitioners' knowledge, beliefs and perceptions of the service. Secondly, a cost-effectiveness analysis was undertaken to assess the economic value of the service. The cost-effectiveness study used financial and project data relating to costs and throughput over several years to ascertain trends.

3.2 Access to and Protection of Participants

Ethical approval was obtained from the Local Research Ethics Committee prior to commencing the research.

During the initial planning stages of the evaluation, the CHEC practitioner produced a list of potential participants. These included clients whom she felt it would be appropriate to approach and a range of health providers within statutory and voluntary agencies. The CHEC practitioner was careful to select clients who were not facing an immediate crisis and who had used a range of services accessed through CHEC. A 'snowballing' approach was then used to approach further potential participants (clients and professionals). Although the research team had access to translation and interpreting support, it turned out that all participants were able to communicate effectively in English.

Potential participants were then invited by letter to participate in the study. An information sheet (Appendix 1) was enclosed with the letter informing prospective participants that they were not obligated to take part in the study and that they could discuss the study with either the CHEC project worker or a member of the research team prior to making a decision whether or not to participate. The information sheet clearly stated that participants had the right to withdraw from the study at any time without repercussion. It also informed them of the approach to be used to conduct the interviews, that their informed consent would be required and that their anonymity and confidentiality would be guaranteed. Participants were then asked to use a tear-off slip and stamped addressed envelope to indicate their consent to participate in an interview at a location and time of their choosing. Non-respondents were followed up with a single telephone call.

In total, twenty one people were interviewed for the study. These comprised six clients and fifteen health or social care practitioners. The latter comprised NHS professionals (from health visiting teams, community/district nursing and radiography) and practitioners employed by agencies that included Care and Repair, St. Peter's Hospice, Black Carers, and Healthlinks. Five people declined to participate, of whom one was a client and four were practitioners. Written consent was obtained prior to commencing each interview. The interviewers endeavoured to be sensitive to the needs and feelings of patients and family members in attempting to minimise the potential for distress and informed them that they

could choose to withdraw from the study at any stage. Interviews were taped-recorded (with consent), transcribed and the original tapes were then destroyed in accordance with data protection and ethical procedure. Computer files containing the transcripts were stored within password protected computers and printed transcripts were stored within a locked filing cabinet. Transcripts (electronic and hard copy) were also anonymised using codes and by removing any identifying material from within the text. All data held by and known to the research team was treated in confidence.

3.3 Semi-Structured Interviews

The interviews lasted between twenty and forty-five minutes, depending on the length of time that was acceptable to the interviewee and, where possible, the extent to which the interviewers were able to reach 'saturation' in terms of exploring the questions within the interview schedule. They were conducted at a location chosen by the interviewee. Each interview took an informal, conversational style, based on open and closed questioning, to enable a certain degree of latitude, clarification and elaboration by interviewees and the opportunity to explore unpredicted issues (Fielding & Thomas, 2001; Berg, 1995; May, 1997). Two interview schedules were designed, one for the client group, another for practitioners. These broadly reflected the aims of the evaluation and key findings from the literature (Appendix 2).

In brief, the interviews with clients and their families/carers explored the following:

- their experiences of cancer support services;
- their awareness of cancer support services;
- their experiences of CHEC; and,
- their suggestions about how to improve services for people from the BME local communities.

Interviews with practitioners explored the following:

- their experiences of working with BME patients, carers and their families;
- their perceptions of the needs of BME patients;
- issues they perceived as relevant or important in terms of delivering services to BME service users;
- care needs they perceived to be problematic or difficult to meet;
- their perceptions of how CHEC was facilitating multicultural care; and,
- their recommendations for changing CHEC or its service context.

3.4 Analysis of Interview Data

The interviews were transcribed and subjected to content and thematic analysis. The latter comprised searching the interview data for emergent categories, themes and sub-themes, based on Alvesson and Sköldbberg's (2000: 22) three-stage process:

1. reading a transcript thoroughly, word by word and line by line;
2. interrogating the material for categories that were understandable and meaningful to the research subjects and then coding the material; and,
3. identifying key data categories and the material that fell within them.

Each transcript was independently analysed by two members of the research team to achieve consensus regarding emergent categories and themes and interpretation of the data (Silverman, 1993; Robson, 2002). The findings were then further validated with reference to published literature within the field, local sources and national policy.

3.5 Cost-Effectiveness Analysis

Cost-effectiveness analysis (CEA) is applied to evaluate service delivery with one activity-related outcome. In CEA the evaluator calculates total (and component) costs and measures activity for one relevant outcome. The outcome results need to be reviewed by decision-makers, the different outcomes weighed up (informally and subjectively), and compared with costs. CEA can be used to look at issues of changing quality of life that are so crucial to palliative care support services. CEA attempts to combine measures of activity, for example, the annual number of service users, into a single measure of effectiveness. It can be used to rank interventions, but is limited in that cost-effectiveness ratios are not directly comparable across treatment and service evaluation. Nevertheless, it is a systematic technique that allows decision-makers to see changes in incremental cost per service user over time.

CEA in this report focuses on service delivery through CHEC. Outcomes can be measured in terms of quality adjusted life years (QALYs), healthy year equivalents (HYEs) or disability adjusted life years (DALYs). However, the CEA in this report is restricted to activity measures around numbers of service users because that is the outcome data that is available. Ideally, and perhaps in the future, common currency estimates of outcome would be compiled by capturing service user self-report quality of life scores from an established measurement tool.

The activity outcomes in this report relate to numbers of White and BMEG service users with cancer and their carers accessing CHEC. The report focuses upon potential costs to the NHS although CHEC is likely to confer resource savings to society as a whole. Whilst it is important to acknowledge that these savings to other sectors will occur as a result of CHEC's activities, it is not possible to estimate them with any accuracy with current data. Also, as the debate about the value-added aspect of CHEC is likely to be conducted through the NHS, it makes sense to restrict the CEA to an NHS perspective in this report. Incremental cost-effectiveness ratios were calculated. A cost-effectiveness ratio for CHEC over time would compare cost (minus the saving in resources) with a unit of activity outcome i.e. numbers of service users.

Assumptions will have to be made with regard to some of the cost items and resource savings and this introduces a level of uncertainty into the analysis. These assumptions can be challenged and reinterpreted, but will form a useful debate as the cost-effectiveness of services dedicated to BMEG users is an under researched area.

4.0 Findings

4.1 Introduction

This section presents the findings from the semi-structured interviews and the cost-effectiveness analysis. Initially, the intention was to present the interview findings from service users and practitioners in separate sections. However, given that both groups raised similar issues with respect to the range of topics explored during the interviews, the findings are collated together and, where appropriate, specific attention is drawn to particular participants' responses. The section uses sub-headings that broadly reflect the data categories that arose from analysing the interview transcripts. These are as follows:

- working with culture-specific cancer issues;
- promoting referrals and uptake of services;
- comprehensive personal and social support;
- complex and additional-need case work;
- advocacy;
- resourcing partner agencies;
- service catalyst, champion and development role;
- development work through client work.

These sub-sections are then followed by discussion of the results from the cost-effectiveness analysis, where an overview is provided of the financial profile of CHEC. The section ends with discussion of the development prospects and sustainability of the service.

4.2 Working with Culture-Specific Cancer Issues

Six practitioners emphasise the role of CHEC in working with culture-specific cancer care issues. There is a need to respond appropriately to the stigma associated with cancer, and views around care and support. It is felt that there is a need for cultural sensitivity with regard to each BME community.

I think the word cancer within different cultural groups conjures up fear and a feeling they maybe – how do I put it - they have done something wrong. [P-07]

Culture-specific responses to cancer sometimes create a challenge for services:

Also some cultures, I'm thinking about our experiences here, where it was very difficult to control her pain and we wanted to increase her analgesia but actually in her culture you were supposed to suffer pain, which was very difficult for the nurses. We are used to the idea that people should have their pain symptoms controlled and actually in some cultures it is felt that you need to feel the experience of, perhaps, dying. [P-07]

We had to provide a taxi for someone but what we didn't realise was that if it was a female that needed the taxi then the person needed someone female to drive or accompany them. So it really made me stand back about offering things and ask whether I'm doing this right. [P-08]

You need understanding to do with things to do with their diet, their faith, and also the way the person dies – whether there are particular rituals. Then it can be much more stressful with a family where you may not have that background understanding. [P-06]

It's very much a taboo area [we've] had experiences of people being in complete denial and not talking about it within the African-Caribbean community. [We are often not informed initially] but you might find out later that they died of cancer. We are told for instance that they have 'problems with the water-works'. Very, very few people say 'I care for someone with cancer'. [P-02]

In the Asian community it is so hard for people who have cancer to speak about it - people will know they have that illness but you tend to only find out if they get better. [P-03]

4.3 Promoting Referrals and Uptake of Services

A central issue is perceived to be problems in awareness and uptake of services.

Difficulties sometimes arise from cultural interpretations of services:

Any patient admitted to a hospice will feel anxiety and you need to be able to communicate very clearly. We have some fundamental issues – for example in some languages the term 'hospice' doesn't translate very well – it simply means a hospital. More than 60% of our patients go home - hospices are not places where people necessarily come to die. [P-07]

It is felt that it takes a lot of time and groundwork to win people's trust:

[CHEC] role is really about support and information to ENABLE more access to specialist palliative care and cancer care needs for the community. [P-07]

I think it's about making sure that people are linked into services. [P-05]

The need to improve systems for referral is highlighted as a major issue. Referrals from GPs to community nurse teams and on to other services including CHEC are felt to be uneven across practices.

I'm aware of GPs who make less use of us than others. There is the importance of a good rapport with district nurses and hospitals. I'm sure there are people who missed but hopefully they are not a great number of people. [P-08]

The system has improved in some areas with direct referrals to District Nurse teams from the point of entry onto the Cancer Registry:

We can now get new cases from the register, make the first contact, explain what we've got to offer – give them our contact numbers – they might decline. I feel this is big step forward – it's a breakthrough. [P-06]

Building trust networks appears to improve referrals. This includes referrals on to BME care organisations:

Once we've made the link and done more networking and met staff at events we get referrals. It is so reliant on having had personal contact with someone who works for the project. I'm surprised how little use professionals seem to make of our printed and website information. Just to get people to think about carers is a challenge – if you think about someone holistically as a carer. [P-02]

We certainly get people who come to us and say "I wish I heard about you before – and why didn't the social worker tell us about you". [P-02]

Referral and uptake of BME patients to specialist palliative care services is perceived to be particularly problematic.

From a hospice point of view we are aware that we are providing a service mostly to the white middle class and are well aware that we may not look particularly attractive to those people, BME groups, because of our image – I know this is a very sweeping statement. [P-07]

I think with our hospice there is always a percentage of people out there that you will never see – it's a question of raising our profile to make sure that you seen by as wide a group of people as possible. [P-08]

I was quite concerned that the hospice didn't have any links with (pause) ... We have wanted to get ethnic groups in to discuss with them the sort of roles [we could have] in the community [but] it's been a very slow process. [P-08]

On the whole (our patients) are a similar sort of group. Sadly, there is an awful lot of people there that we would like to access – but we don't. ... Maybe they don't need us, but our philosophy is that we serve anyone with a life threatening disease. It's sad, at one point about two years ago we had quite a few but I'm sure that at the moment there is no one from (small voice) from a black and ethnic minority. [P-04]

There is a real lack of awareness about the role of hospices in the BME community. One service user was terrified of going to a hospice it just wasn't in their experience – so there's a huge thing about helping workers understand more about hospices. [P-02]

Some difficulties associated with referral to CHEC from these services are also reported:

I was concerned because the [community hospice] nurses suddenly stopped seeing me. At that time I hadn't got anybody. I was living all alone, had had two heart attacks – survived – and had cancer. [SU-05]

4.4 Comprehensive Personal and Social Support

Working within the constraints of confidentiality the CHEC practitioner often works with a whole family.

I will work with the whole family to see how they are doing. Even [for example] down to telling an eight year old that their parent is going to die, which was pretty tough... [P-01]

There was one case where someone felt that they were not being told about what was wrong with their parent – we worked with mum in order to get someone to talk to him – even when it came to saying “You can talk to him but I don't want to know what you are talking about”. She was in complete denial she said “I know what I've got and I don't want to talk about it”. [P-01]

In many cases the CHEC practitioner works with the patients from the point of diagnosis, through treatment, remission, palliative care and, with the family, on bereavement support.

Continuity of having me is important – when you are a cancer patient you can end up seeing so many people, can be far too much. That's what the specialist nurse's role is in a way as well – but they're medically focussed and they have lots of areas where they can't get involved. [P-01]

I have come to feel comfortable to talk to her – sometimes with your illness you don't want to talk to everybody. When I talk to [the CHEC worker] I feel that she understands me a lot. [SU-02]

This wide-ranging role is appreciated by service users and other practitioners:

I see her every month, sometimes twice. Even if she can't visit I can call her and ask for help. I can joke with her and talk to her like I can talk to my family. CHEC service has been a life saver for me. [SU-05]

We're often short staffed, so it's sometimes hard to take a broad view and take a look at what is going on for patients. Often we need someone who can go beyond the practical nursing role. [P-06]

The CHEC worker is able to put service users in touch with appropriate services and work more flexibly than some mainstream practitioners:

I was having a particular pain here [points to chest] and she gave me a nudge to go to the doctors. They were able to give me medication. I was going to delay it until I was at the consultants – but she explained that I needed to see a doctor for this sort of thing. [SU-05]

I have had the freedom to act as necessary. I can say there is a need and I'll find out how to support the person. I've got lots of flexibility with my diary to prioritise my work and I'm incredibly autonomous. [P-01]

This flexibility presents difficulties on occasions:

My main worry is that they want too much of me – a lot of people are just not ready to run by themselves. [P-01]

For some individuals they just like having a visitor – someone they know they can trust who is outside the family that they can be utterly honest with and not worry about what others might think – quite often its then about encouraging them to talk to the family. [P-01]

Sometimes I come across an issue and I wonder whether this is an issue I should be dealing and sometimes it's not. [P-01]

4.5 Complex and Additional-Need Case Work

While recognising that all cases are complex, interviewees identified the CHEC practitioner as someone who is particularly important in working with highly complex cases. For example, for one service user CHEC provides emotional support and continuity, help with benefit claim forms, arranging a visa for her husband's mother to visit and additional services as required, including home help and equipment for use in the home. For this service user, CHEC provides a lifeline and is unique in attending to all needs whatever and whoever was involved. For another service user, perhaps the key point was that CHEC supports and helps her and her daughter, as well as her mother who had cancer.

With all the help I'm getting now I can face life, I can say that now. [SU-04]

Provision of this service can be broken down into component parts, including: raising awareness of services, facilitating contact between users and services, linking services with BME communities, and acting as a central co-ordinator and facilitator.

Many of the issues encountered by families are multilayered and difficult to address using the standard package of services.

It is apparent since I've come to this agency that the needs for BME carers are high– you'll know that their needs are stronger for lots of areas anyway – but for advocacy they are hugely more than I thought that they ever were. [P-02]

We had one really complicated case [our practitioner] worked in terms of co-ordinating and checking who was going in around the care plan. We needed advice in the specialist field of palliative care, such as advice on organisations and grants. [The case] really needed shared knowledge. [P-02]

Recently I've been in touch with an Asian family who had a number of problems. The son had medical problems – I think a kidney problem where there were all sorts of issues in this family – cancer issues, financial, support for the children in school. So quite a number of things that needed support. [P-05]

In these and similar cases the CHEC practitioner works closely with the family.

I would say she [CHEC practitioner] was able to do more through having a greater understanding of important issues for the patients and the family and they felt that they could share those concerns more openly – there was quite a lot of input – her service complemented ours in that we could concentrate more on symptom control and the management of the nursing needs of this man. She was able to complement that through emotional support and practical things like looking for funding which, with the best will in the world, we wouldn't have had the resources to deal with. Much as we try to provide everything we can't always, sometimes you have to concentrate on the issues of that moment – which is often making sure the patient is out of pain and these sorts of needs have to be prioritised. So yeah what she was doing was equally important and it was great to have that expertise. [P-06]

This kind of work is felt to be highly rewarding for all practitioners:

I don't know how to explain it. It was invigorating and it was satisfying and it was just good to be able to help her. [The CHEC worker] was able to help with the social aspects, the aspects of what was going on at home she was like the go-between in a way, she kept us informed of the patient's position, of what was happening at home and the family dynamics, and as someone out there in the community. Although the community nurse had been involved, [the CHEC worker] was able to act as the liaison between us. [P-04]

This kind of work is perceived to be highly demanding emotionally and requires good managerial and colleague support:

The client work does get to you – there's definitely something called cumulative grief – you can find yourself having an almighty sob and snot fest which is because you're grieving for everyone that you've been working with for the past six cases. [P-01]

I don't have formal meetings – but do inform my line manager of where I'm at – in terms of high rates of cases where a person may die or domestic abuse. I also talk to people in the team and within confidentiality I talk to SW friends. [P-01]

4.6 Advocacy

Many interviewees feel that a central role of CHEC is advocacy. Advocacy includes practical or emotional support for people who lack confidence or are overwhelmed as well as helping people to access services that they are not aware of:

We've had patients who haven't wanted services, mostly because they haven't understood them, or were worried about having people in the house, so it's been about explaining the service to people – the role of joint visits has been important in this respect. [P-01]

Advocacy also means helping patients negotiate their way through a complex field of service provision:

I've heard everything through [the CHEC worker]. I've felt it's so difficult to understand all the systems, [the CHEC worker] has helped me – I don't know what I'd have done without her. [SU-02]

I've been meeting so many different people and [the CHEC worker] has been able to help me find a way through and knows about all the other things that are available. When you've got a bad illness you need those kind of people to help you out. [SU-02]

[The CHEC worker] was able to write a letter to the Home Office for me. She was able to express my conditions better than myself. [SU-06]

The CHEC role involves gaining access to services for patients and their families, through raising awareness of services and accompanying users on first contact. CHEC's work is possibly even more crucial for members of BME communities living in largely White areas, where community support is less apparent and/or accessible.

4.7 Resourcing Partner Agencies

The CHEC practitioner is perceived to act as an important resource for mainstream practitioners. Practitioners feel that they can access a specialist who has up to date knowledge of many sources of support:

(The CHEC practitioner is a) point of contact with ethnic minority groups. I was quite ignorant about some of the issues and I just wanted somebody who I could ask for advice to see whether I might upset someone and who could resource things like carers – in the right language. The patient in question was a lady who didn't speak any English and we needed support for both herself and her daughter. [The CHEC practitioner] was the best point of contact – much easier to just go to one person and ask for help. She was able to set up someone who could speak the language – [The CHEC practitioner] had an awareness of the range of sources for support. [P-08]

I see [CHEC] as supporting people from ethnic minority groups and to help us as a resource that we can link into and vice versa that they can draw upon us. Its been very important to know that [the CHEC worker] is a point of call and source of knowledge. [P-02]

I think [the CHEC worker]'s just very good at obtaining support. She can really help support around complex cases and she will go on to support the family after the patient has died. [P-05]

I can think of one family in particular where it's been about helping them be in touch with organisations to understand THEIR issues. It can help the services users and the organisations that are provided in the service in terms of what to provide. Which you know sometimes the organisation, sometimes the organisations don't understand the pressures on the family. [P-05]

[CHEC] is one source for us to check that we are getting it right. [P-07]

While translation services are central to the support of some BME families and patients, CHEC is able to provide a wider resource for mainstream services.

We've had problems finding enough translators to support us. Sometimes we have had to work through a teenage child which is very difficult when you are asking intimate questions. Then there might be some questions that come back to us that really are difficult for the child to hear. For example, if the child might hear first that their parent is dying. [P-12]

There are quite a lot of sources of support when there is a wider family to draw upon – so you can communicate through younger members. We had one Chinese patient who was discharged from hospital who was post surgery and that involved getting an interpreter from the BRI so that was tricky because it was a three way conversation – especially when talking over the phone. [P-06]

CHEC is not felt to duplicate other services

I don't think there is overlap, I would go in, assess the patient for physical needs and symptom management, equally another part of my role would be to support the daughter. [The CHEC worker] would be offering her practical help because she has those contacts that I don't have. He also listens to the patient allowing someone to say how they feel. [P-08]

Interviewees emphasise that the idea of 'service duplication' is too simplistic. The CHEC practitioner has the autonomy and flexibility to build close working relationships in cases of complex need. In such cases, mainstream practitioners are rarely in a position to provide holistic and dedicated family support. The CHEC practitioner works with service users throughout the cancer journey. Through client work the CHEC practitioner has a specific remit to transfer learning into service development. This specific remit develops learning with regard to the needs of BME communities.

4.8 Service Catalyst, Champion and Development Role

CHEC acts as a local champion for BME cancer care service issues. Prior to the creation of CHEC there was no champion in this field of service development. The CHEC practitioner has an awareness and appreciation of the community development aspect of CHEC's work.

In its relationship with other services CHEC acts as a 'linkpin', networking with other agencies and services (e.g. respite care, Care and Repair and mainstream hospital services) as required.

Practitioners' awareness of CHEC comes about primarily through informal professional/service networks. While CHEC appears to be widely publicised, practitioners make more use of the service following personal contacts with the CHEC practitioner. Personal outreach work into primary care, social care and community service settings plays a central role in developing the service. In a complex area of service provision this highlights the significance of networks of professional trust.

The development role for bridging links between service users, community groups and practitioners has worked to break down barriers. [P-06]

Through CHEC and the BME Forum I have been made aware that there are other BME support groups so it's been quite an education for me. [P-08]

4.9 Development Work through Client Work

Client work is perceived to have a close relationship to the development aspect of CHEC.

It's so important for the development worker to keep the case-load because it helps you keep in touch with the client issues. [P-01]

Being hands on and part of management is not an easy role but then if you lose touch with patients you lose touch with what it's all about and you don't manage to keep the momentum going. You just need to be in touch with what's going on. [P-04]

I know how much her work has been appreciated. There was a Chinese day, [the CHEC worker] doesn't just help on the day and do the talk but she works on all the preparation beforehand. For example, she is on the health subgroup of the Chinese women's group – she's been very hands on. [P-02]

The links with CHEC and BME Cancer Forum have been good for networking and sharing knowledge. [P-02]

However,

When you are working with health [professionals] a lot of people don't know what development work is. The nurses and medics tend only to understand client work. [P-01]

There are also issues associated with the reliance on one person to run the service:

My first question is how does [the CHEC worker] manage to do it all on her own? It feels like quite an enormous task really. [P-07]

4.10 Development Prospects and Sustainability of the Service

CHEC was set up to work across established organisational boundaries and professional roles. CHEC's location within the NHS was discussed with interviewees.. The CHEC practitioner feels strongly that the current location of CHEC within the NHS provides enormous benefits, namely guaranteed communication and 'clout' with other NHS practitioners, and also a supportive team and management structure. Practitioner interviewees consistently felt that mainstream services were striving to incorporate cultural sensitivity into their practices. However, the changing service needs of BMEGs means that dedicated provision is essential to maintain service momentum and commitment. Rather than enabling mainstream services to opt out of providing culturally sensitive palliative care services, the CHEC practitioner perceives CHEC as an effective catalyst and champion that is driving change across mainstream services. In this respect, CHEC's location within the NHS is important, especially in terms of rolling out the service to other areas within and beyond the NHS.

Interviewees are concerned about the sustainability and development of the service. In part this arises from past experience of the closure of effective but non-mainstream services.

While CHEC is currently securely located as part of Avon Palliative Care Service, given the national diversity of service models, interviewees were asked to consider a range of alternative locations both in the voluntary and statutory sector. Table 1 summarises the key issues raised in relation to the prospects and pitfalls associated with potential organisational locations. The current location of CHEC is recognised by some interviewees to present some difficulties. However, in the medium term there is a clear consensus that continuity will consolidate existing networks and sources of support.

TABLE 1: The organisational location of CHEC: a prospects and pitfalls analysis

Potential organisational location	Interviewee perspectives
Palliative Care Service (Home Support Service)	<p>Prospects:</p> <ul style="list-style-type: none"> • Current organisational location. • Established line management and team relationships. Multidisciplinary support. • ‘Service recognition value’ for partner agencies and practitioners. <p>Pitfalls:</p> <ul style="list-style-type: none"> • CHEC development role not central to a clinical, personal care focused agency. • CHEC’s work at any stage of illness in contrast to the end-of-life care offered by Home Support.
PCT Public Health & Community Development	<p>Prospects:</p> <ul style="list-style-type: none"> • Service development expertise. Strong LA and voluntary sector partnership functions. • Population and community focus. • Health promotion expertise. <p>Pitfalls:</p> <ul style="list-style-type: none"> • CHEC currently works across PCT service boundaries. • Public Health practitioners do not focus on personal care support.
Healthlinks	<p>Prospects:</p> <ul style="list-style-type: none"> • Established BME health care liaison service. • Good links with BME-led organisations and communities. • Advocacy expertise. <p>Pitfalls:</p> <ul style="list-style-type: none"> • Generic health support rather than cancer care specialised service. • Operates within different service boundaries to CHEC.
UBHT Cancer Information Centre	<p>Prospects:</p> <ul style="list-style-type: none"> • Information, communication expertise with diverse groups of cancer service users. <p>Pitfalls:</p> <ul style="list-style-type: none"> • Information service rather than a personal care service or community development service.
Cancer Black Care (voluntary sector organisation currently operating Manchester and Birmingham)	<p>Prospects:</p> <ul style="list-style-type: none"> • Similar service aims, values and practitioner role to CHEC service. <p>Pitfalls:</p> <ul style="list-style-type: none"> • Currently not in operation in Bristol area. Specialises in African Caribbean cancer support.
Voluntary sector BME Social Care Agencies (Black Carers, Dhek Bahl, Chinese Women’s Association)	<p>Prospects:</p> <ul style="list-style-type: none"> • Strong BME carer expertise often for chronic illness, cancer care and terminal care. • Combined development and client functions. • Advocacy expertise. • Good BME-led organisation and community links. <p>Pitfalls:</p> <ul style="list-style-type: none"> • Ethnic group specific services. • Generic care rather than cancer care specific services. • Operate within different service boundaries to CHEC.
Incorporation into mainstream health care provision: specialised palliative care services, community/primary care services	<p>Prospects:</p> <ul style="list-style-type: none"> • Good practice becomes incorporated throughout mainstream cancer care and palliative care services. • Personal cancer care expertise. <p>Pitfalls:</p> <ul style="list-style-type: none"> • Loss of service champion, focused expertise, development function.

Interviewees identified a number of future priorities for the development of the service:

- Develop a strategic plan for the service in conjunction with service heads and partner agencies.
- Explore the potential for support workers to take on some of the client work. Main CHEC practitioner would then be more selective in client work and focus on the development aspect of the service.
- Explore the potential and service capacity implications for volunteer workers in, for example, befriending and peer education work.
- Undertake focused work with specialised palliative care service, notably in-patient and out-patient hospice services.
- Examine how CHEC can support the development of BME specialised services for other conditions, notably CHD and diabetes.
- Pursue community specific outreach work, for example, with Somali communities.

Three practitioner interviewees are aware that they have made less use of the service than they would have hoped. One barrier is the pressurised nature of their own work – this has prevented them from having the time to develop more streamlined and effective links with CHEC. Some practitioners feel that they are not clear on the full remit of CHEC. Most practitioners are comfortable with this ‘need-to-know’ arrangement. While combined client-development roles appear to be more familiar to practitioners in the social care/voluntary sector, this is less well understood in the health sector:

We as a project haven't made the most of it. [P-02]

4.11 Project Financial Profile and Economic Assessment

Costs

Table 2 summarises the costs recorded by the Bristol Public Health Directorate (Raffle., 2006 Personal Communication).

TABLE 2: Annual breakdown of costs

Years:	Jun 01-May 02	Jun 02-May 03	Jun 03-May 04	Jun 04-May 05
Salary	0	18,315	21,051	23,630
NICs Pension	0	2,981	3,426	3,846
Training for volunteers	0	0	0	0
Recruitment costs	2,854	0	0	0
Telephone, post, room hire, insurance fees, repairs, maintenance	0	2,742	2,453	4,427
Information & publicity	0	736	765	140
Consultancy fees, advice	0	950	1,219	320
Travel and subsistence for staff and volunteers	0	354	475	446
Interpreting and linkworkers	0	3,213	1,533	2,994
Agency work	0	0	0	0
Total cost	£2,854	£29,291	£30,922	£35,803

TABLE 3: Cost-effectiveness analysis of CHEC service

Years:	Yea 02/03*	Year 03/04	Year 04/05
Cost of service £	29,291	30,922	35,803
Number of clients	42	76	112
Number of service users	227	248	**254
Cost per client £	697	407	320
Cost per service user £	129	125	141

*The CHEC worker was appointed June 2002, but the first six months was used to set up the service. Client work was therefore undertaken during six months of 2002/03 only.

**An additional 337 people were reached through events and outreach work but are not included in this table.

Note: A client is a patient with cancer. Service users include relatives and carers supported by the service, as well as cancer patients.

Table 3 indicates that over time CHEC has become more established, has grown in terms of number of service users (clients and carers) and has broadened its reach in terms of contact with BMEGs as a proportion of total service users. The average cost per client has fallen from £697 in May 2002 to £320 in May 2005.

5.0

Discussion

5.1 Limitations of the Study

Before exploring the findings in the context of wider evidence it is important to recognise a number of limitations to the study, of which the following are worth highlighting:

1. Given the diversity of BME cancer support service configurations in the UK, the findings of this case study of one service may not be applicable to other local contexts.
2. CHEC consists of both development and client support work. This evaluation focuses on the client element and does not seek to provide a full account of all aspects of the service.
3. The evaluation has a service focus and does not reflect the full extent of BME cancer support work in the study area. Important work is being conducted by other agencies and forums.
4. A small number of clients participated in the interview element of the study. Client interviews were limited by ethics of appropriate access and the constraints of research funding. Nevertheless the key themes that emerged from interviewees in this group are corroborated in the practitioner interviews and the analysis of the service data.
5. An assessment of service outcomes forms only one aspects of the study. Given the complexity of CHEC, the study seeks to illuminate its practices and put the work of CHEC in context.

5.2 CHEC in National Context

Recent years have seen a considerable growth in services providing specialised cancer care support for BME communities in the UK (Deepak, 2004). These services do not conform to a single model: they offer diverse services and work within different local organisational contexts. Palliative care has been identified as a field that is slow to respond to ethnic diversity. CHEC aims to supplement, enhance and help reform mainstream palliative care services. Characteristics that distinguish CHEC include the comprehensive and flexible nature of the care provided, the breadth of the CHEC practitioner role, the work across different BME communities, and the location of the service within the NHS.

Drawing upon the findings of the study, the next part of the discussion therefore focuses on three specific aspects that characterise CHEC:

1. Wrap-around client support work
2. A cancer support service for all BME groups
3. A specialised service located in the NHS

The first two are concerned with the practitioner role, the third concentrates on the configuration and location of the service.

5.3 Holistic Client Support Work

One of the key characteristics of CHEC is its provision of holistic individual client care. Holistic care meets the cultural, language, practical, emotional and spiritual needs of clients with cancer and their families. This involves undertaking a needs assessment, identifying what other agencies and services are required, and mediating between clients and services. Mediation includes signposting to other services, liaison and networking with other services, acting as a lynchpin or source of continuity when complex care packages are put together, and being the client's advocate in communications with a range of health, social and welfare agencies. One of the distinctive features of the CHEC practitioner is that she spans boundaries and is willing to engage with whatever services and agencies are deemed necessary, including statutory and voluntary health and social services, benefits agencies and immigration authorities. The role of the boundary spanner – to broker links between the home organisation and external world and act as an innovator (Goldring 1990) – bears many similarities to the linkworker role identified by Ackroyd (2003) and Jack et al., (2001).

This holistic approach means that CHEC is clearly focused on client quality of life. The emphasis is on maximising the benefits of treatment and to live as well as possible with the effects of the disease. In future an assessment of quality of life might be a central outcome measure for CHEC. Quality of life data from service users would allow a cost-utility analysis to be undertaken and this would produce incremental ratios that would be comparable across many different treatments and services in the NHS.

A second distinctive feature is the comprehensive overview and continuity achieved by the single practitioner employed by CHEC. Although this also has potential disbenefits, one of the benefits is that the project worker achieves a truly holistic picture of clients' circumstances and needs. The CHEC practitioner is able to use this knowledge to link up with the most appropriate services and to monitor usage and outcomes, thus enabling constant fine-tuning to effect the most appropriate care package for each individual client and their family.

Learning that arises from this client work directly informs the development component of CHEC. The complexity and distinctive character of each new case means that the CHEC practitioner routinely makes new contacts with diverse organisations. Issues emerging from case work also inform priorities for service development in the local context. Moreover the CHEC practitioner can use her routine contacts with client focused practitioners from other agencies to promote organisational change. The combined role of client and development work is also recognised as having similar strengths in other studies (Ackroyd, 2003; Jack et al., 2001).

5.4 A Cancer Support Service for All BME Groups

National evidence indicates that most specialised cancer care services work with a specific ethnic community. CHEC is unusual in its remit to provide cancer support for service users from all BME backgrounds. This service model carries some risks. BME communities with diverse needs may be inappropriately grouped together. In so doing, service users may receive a form of generic multicultural support that fails to recognise micro-cultures and individual circumstances. BME-wide services may also struggle to respond to the specific issues raised by ethnic community organisations – and fail to engage mainstream services in more than a blanket commitment to cultural sensitivity (Diver et al., 2003a; 2003b; Nyatanga, 2002).

The evaluation found no evidence that the BME-wide remit of CHEC had adverse outcomes for specific BME communities or for service delivery. Indeed the study identified a number of positive aspects of the model:

- As a BME-wide service, CHEC can work to focus resources on minority groups that currently lack support networks and organisations.
- Working across BME communities, the CHEC practitioner can transfer elements of good practice arising in different contexts.
- CHEC can offer individualised care while drawing effectively upon more specialist support services e.g. language support services.
- For service users, the CHEC practitioner has a bridging and signposting role with ethnic community-specific organisations.
- As a BME-wide service, CHEC maintains an emphasis on health inequalities and issues of cultural diversity in the field of cancer care support. This is consistent with national guidance that supports the need for coherence in mainstream services and advises against service fragmentation.
- With rising numbers of service users from diverse backgrounds, the model appears to offer an increasingly cost-effective approach to specialist service provision.

While the case for ethnic community matching of services and practitioners may be stronger for other local health and welfare services, the BME-wide remit of CHEC appears to offer a pragmatic and clearly accepted model for cancer care support in the project area.

5.5 A Specialised Service Located in the NHS

Nationally, BME cancer care support services are located in a variety of organisational settings within both statutory and voluntary sectors (Deepak, 2004). CHEC's location as part of the Avon Palliative Care Service is within an NHS organisational setting. Interviewees clearly feel that the current organisational setting offers a number of advantages. The importance of making 'change from within' is recognised by many people in the study. Some of the key benefits identified are the following:

- Nationally, there are concerns that projects in this field lack the infrastructure to become sustainable over time. Yet it is also recognised that reforms should be seen as a long term process. The location of CHEC provides the basis for sustainable practice. It offers formal and informal sources of staff support, a robust management structure and a well defined organisational home. The recent decision by local PCTs to fund the project, following the end of Lottery funding, illustrates the commitment of both CHEC and NHS commissioning bodies to maintain the current service delivery configuration.
- Location within the NHS helps CHEC's aims to be embedded within national health priorities in relation to health inequalities, cancer care support and palliative care, social diversity and patient and carer service involvement.
- Poor ethnic monitoring at the point of cancer registration is an ongoing problem for CHEC. Currently, CHEC is unable to pro-actively contact potential service recipients. Moreover, in the absence of reliable figures, it is difficult to arrive at a formal assessment of potential service demand. Referral trends indicate latent demand. Given that these are nationally recognised areas for development CHEC is well placed to advocate within the NHS for improvements to ethnic monitoring and patient contact.
- Location within the NHS also means that CHEC can advocate for improvements to referral processes. Developing public and practitioner awareness of the service involves sustained processes of formal and informal awareness raising. The CHEC practitioner's role and position lends itself to natural lines of communication with mainstream health and social care practitioners and with service users.

6.0

Conclusions and Recommendations

6.1 Conclusions

This study examines how CHEC promotes culture-sensitive cancer care issues for people from BME backgrounds living with cancer, their families and carers. The study also examines how CHEC operates alongside mainstream services and works towards sustainable practice, and whether CHEC delivers a cost-effective service.

In recent years there has been an increased focus on promoting culture-sensitive cancer care support and palliative care. Currently in the UK there exist a diverse range of local service approaches and initiatives. In this context, CHEC is an innovative service model for the cancer care support of people from BME backgrounds. It provides or facilitates a comprehensive range of services for clients from across all BME backgrounds in the Bristol area. CHEC works from within the NHS to advance practice and reform services in a complex area of provision.

The following are the key conclusions arising from the evaluation of CHEC:

- All interviewees with a knowledge of the individual client work of the CHEC practitioner unanimously felt that the work had been of considerable benefit to clients, their carers and families. Benefits include the provision of holistic and continuous care by a single CHEC practitioner who is able to span boundaries. Service users consistently identified that CHEC had been instrumental in opening doors to all kinds of services and had facilitated practical help and emotional support for patients and their families.
- A valuable aspect of the work is the ability of the CHEC practitioner to devote a large amount of dedicated time to individual clients. This allows a real sense of their needs and desires to emerge, including emotional needs that are often not readily expressed or identified. It is only in this protected one to one relationship that the full expression of needs can occur.
- The CHEC post combines the roles of individual client work and development work with local agencies and community groups. The two roles are largely complementary:
- Clients are informed of sources of support by a specialist who has an excellent knowledge of a complex field of provision.
- Service and community development issues are informed through detailed and up to date knowledge of service user circumstances.
- If CHEC continues to expand, the combined role is potentially beyond the scope of a single practitioner. The current reliance on one individual is a source of vulnerability for the service.
- Interviewees perceived that BME service users' uptake of mainstream hospice services is less than would be anticipated. CHEC has facilitated greater BME group use of hospices. On the basis of this work CHEC is in a good position to facilitate further development work in this area.
- Interviewees perceived that CHEC offered a route into various BME communities, thereby opening the door for greater cancer awareness and promotion of cancer screening services amongst different BME communities.

- CHEC has been able to support community development aspects of the role but this is very slow work and needs an assurance that it will be prioritised and resourced if it is to continue to expand.
- Public and professional awareness of CHEC is variable and this is reflected in the ad hoc nature of referrals. Nevertheless there are clear indications that awareness of CHEC has increased considerably over the last two years.
- Over time, CHEC has become more cost-effective, spreading its costs further and further across a rising number of service users. The analysis suggests that the service is approaching capacity although there is further scope for expansion in provision to meet community needs.

6.2 Recommendations

The evaluation of CHEC leads to a number of recommendations regarding the future sustainability and effectiveness of the service. These are given below, in sections according to whom the recommendations are directed.

Recommendations for CHEC:

- CHEC should be regularly reviewed in order to assess its outcomes, effectiveness and cost-effectiveness. The annual reports should continue, with a more thorough evaluation in two to five years time.
- CHEC should expand into a team rather than remaining reliant on one person. This would enable capacity to extend and the development of both aspects of the service, client support and community development work. One possibility is for CHEC to expand to include support workers who undertake the more 'routine' personal client support roles. Alternatively, or in addition, CHEC could expand to include community development workers who undertake the community liaison and development roles. The CHEC practitioner would need to retain a broad overview and probably undertake the more complex client support work and facilitate the boundary spanning aspects of CHEC.
- CHEC should remain organisationally embedded within the Avon Palliative Care Service. This location's benefits, in terms of providing support and resources, facilitating usage of CHEC and driving through reforms of mainstream services, are a real strength of CHEC.
- There should be more targeted and systematic publicity and sign posting of CHEC. This should enable referrals to be more aligned to needs. CHEC should tap into NHS marketing and media resources to publicise itself within the local area, concentrating particularly on GPs, nurses, and lay communities.
- CHEC should monitor its 'reach' into different BMEGs with regard to both its client support and community development work.

Recommendations for commissioning authorities:

- There should be better ethnic monitoring and data regarding the use of both mainstream and specialised services.
- Public health specialists should monitor cancer rates by ethnic status, either locally or modelling on the basis of national statistics and local demographic data.

- Managers of services need to recognise and appreciate the value of boundary spanning, networking and community development work, and include these aspects in service monitoring and evaluation data.
- Commissioning authorities should recognise that CHEC does not duplicate other services, is cost-effective, and should be sustained with mainstream funding.
- Commissioning authorities should recognise the value of both aspects of CHEC's work, and meet staff development needs to support both aspects.

Recommendations nationally:

- The CHEC model should be recognised nationally as one model of service provision that is appropriate, effective and cost-effective.
- Hospice and palliative care provision nationwide are relatively underused by BMEGs, and this deserves further investigation and attention.

7.0

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Appendix 1

Study information letter

Transcript of the study information letter, version 3 – 8/07/05

An evaluation of Cancer Help for Ethnic Communities (CHEC) – a Palliative Care Service, Bristol

Principal Investigator: Jennie Naidoo, Principal Lecturer, University of the West of England, Bristol.

Research Team: Mat Jones, Nick de Viggiani, Jane Powell, University of the West of England, Bristol.

We would like to explain the research we are doing and then ask if you would like to take part in it. Before you decide it is important for you to understand why this research is being done and what it will involve. Please take time to read the following information carefully and discuss it with others if you wish. You do not need to take part, if you do not wish to do so and you may withdraw at any stage.

Please ask us if there is anything that is not clear or you would like more information. Take time to decide whether or not you wish to take part. Thank you for reading this information sheet.

Reasons for doing this study.

The CHEC is a new service which started in the Bristol area in 2002. The service is funded until 2005 with New Opportunities Funding. The service aims to provide cancer support for members of Black and minority ethnic groups (BMEGs) and their families and carers who might otherwise miss out on these services. Research has shown that members of BMEGs often have above average health needs, yet are less likely to receive health services. Research is needed to find out what CHEC brings to users, and whether it is a good use of resources. This information is needed to decide how to develop the service using NHS funding after July 2005.

We want to find out what you think about CHEC. We would like to interview you to give you the chance to tell us your views. We will be asking you how you have found using this service, how easy or difficult it has been to use, how (if at all) it has helped you, and how it might be made better. If you agree, we would like to make a tape recording of the interview so that we do not miss any of your views. If you would prefer the interview to be in a language other than English, we will provide an interpreter. We think the interview will take around half an hour. We will interview you in your own home or workplace, or if you prefer, at another place you suggest. You do not have to answer all the questions and can stop the interview at any time. We hope you will take part and tell us what you think of this service.

The purpose of this study.

The purpose of the study is to evaluate CHEC and to find out how users of the service benefit. We also want to find out the views of other key people including carers, health care workers, and community members. This evaluation will help CHEC to develop services and support.

Why have I been chosen?

You have been chosen for this research because you are a user or have contact with CHEC.

Who is organising this study?

The study is being organised by Jennie Naidoo, Principal Lecturer and a research team from the Public Health and Primary Care Development Research Centre, University of the West of England, Bristol. Research team members are: Jennie Naidoo, Mat Jones, Nick de Viggiani and Jane Powell.

What will happen to me if I take part ?

If you agree to take part in this study, a member of the research team would like ask about your views of CHEC. You will be asked to take part in an interview that will last for around half an hour. If you would like to be interviewed in a language other than English we will provide an interpreter.

Are there any disadvantages or benefits in taking part in this study ?

The results from this study will be used in a report that will make recommendations about the future of CHEC.

Confidentiality – who will know I am taking part in the study ?

All the information you give to us about yourself will be completely CONFIDENTIAL – no one else will be told what you have said. No names will be used in the report or records of interviews. Information from the interviews will be kept securely and destroyed when the research is complete. If we wish to use quotes that might identify you, you will be asked for your permission and you can say no.

Contact for further information.

If you take part in this research, you will help the study to be accurate and complete. If you have any further questions, or need any information or advice during the study, please contact either:

Jennie Naidoo 0117 32 88837

Mat Jones 0117 32 88769

THANK YOU FOR YOUR HELP

Appendix 2

Practitioner Interview Schedule

CHEC STUDY INTERVIEW SCHEDULE: PRACTITIONERS

How would you describe your role?

What do you perceive to be the aims of CHEC?

In your experience how would you describe BME groups' experiences of cancer support services?

How does CHEC work together with/alongside your service?

How do referrals work? (If appropriate)

How effectively do you feel the work of CHEC fits together with that of other services?

In what ways does the service you provide complement/support that provided by the CHEC project?

To what extent does your practice/service benefit from the work of CHEC?

In your experience how have your clients/patients benefited from CHEC?

Can you recall/describe any instances of working with patients from BME backgrounds prior to the arrival of the CHEC project?

Are there any problematic aspects to working with CHEC?

Do you perceive any differences for cancer patients and their families who received CHEC services compared to those who don't?

Do you think that CHEC could be provided as part of a mainstream service instead of as an additional service?

What observations do you have about the current and future organisational home for CHEC?

How well do you feel CHEC has understood and responded to the particular circumstances of patients and families?

How if at all do you think could the service(s) be improved?

How if all do you think that the service could be developed?

Is there anything else you would like to say about the service?

