

S · C · E · E · S

Securing Care for Ethnic Elders in Scotland

Report on

- **Prevention: Active Ageing, Physical and Mental Health**
- **End of Life Issues: Palliative Care**
- **Long Term Conditions**

Funded by the Scottish Government

PRIAE

Policy Research Institute
ON AGEING & ETHNICITY

PRIAE 10 years:
Passion, Pride & Progress in
ageing, ethnicity and migration



SCEES

Securing Care for Ethnic Elders in Scotland

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About PRIAE

PRIAE (pronounced 'preeya') is a not-for-profit, independent international charitable Institute, established in 1998. As the only international organisation specialising in ageing and ethnicity/migration, PRIAE occupies a unique position and plays an essential role in policy, research, information and practice on:

- Employment, enterprise and income;
- Health, social care and housing;
- Citizenship and quality of life.

PRIAE's vision is to develop the area of ageing and ethnicity/migration with leading developments that help benefit minority ethnic older people. PRIAE works with minority ethnic elders and age organisations, policy makers, research bodies, healthcare providers and the voluntary sector to produce ground-breaking research and development work influencing and informing policy. PRIAE has since its founding in 1998 pioneered considerable progress in diversity and equality in employment, pensions, health, social care, housing, enterprise, organisational development and leadership.

PRIAE was founded in 1998 by Professor Naina Patel OBE who recognised the need for a dedicated organisation that focused and concentrated on the various issues faced by black and minority ethnic elders and their organisations amid increasing population change and slow policy and practice developments. Naina built PRIAE up with zero finance and with support from a distinguished Management Board, chaired by Lord Herman Ouseley, Vice Chair Lord Navnit Dholakia, Liam Hughes Treasurer, Professor Sashidharan (Co-Chair of SCEES) and Jeffrey Greenwood and, later, staff when longer term funds were secured in year 2001, to the international organisation it is today. PRIAE has its first patron, Dr Chai Patel, CBE, FRCP. Please visit us at www.priae.org

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Foreword



Delivering high quality health care is a challenge as well as an opportunity. A challenge since this requires that not only are health care targets met, albeit in a financially tight context, but that patient care that we provide

bears the hallmark of all that we value in 'quality'. It is an opportunity because we know that there are gaps in our services that we need to address. One such group that is consistently showing us gaps in services and that they can be inadvertently overlooked, concern the health of ageing of minority ethnic groups. How do we best address gaps in knowledge, information, access barriers and known unmet needs that minority ethnic elders face is of paramount concern to those of us engaged with the NHS, social care and housing organisations.

One national initiative that I have had the pleasure of being a part of is the Securing Care for Ethnic Elders in Scotland (SCEES) developed by PRIAE. This flagship initiative focussed on active ageing, palliative care and long term conditions working across Glasgow, Lothian, Forth Valley, Ayrshire and Arran. In my role as a PRIAE trustee, I have consistently observed that minority ethnic elders are keen to gain knowledge of health conditions and want to do better in accessing services and require support. They do not see



The NHS Scotland *Better Health: Better Care Action Plan*, published in December 2007, describes a 'mutual' NHS where patients and staff value each others' experiences, knowledge and skills.

A truly mutual NHS is one where patients have more control over their own health and where decisions about how the NHS is run are shared by all – patients, staff and

'ethnicity' as a blockage, rather that everyone has 'culture'; and that knowledge about minority ethnic elders can enhance care and services instead of being seen as a burden. So working effectively with community organisations can be an opportunity for the NHS and social care organisations in Scotland while we seek to strengthen our professional development and practice in the area. By doing so, we can accelerate progress to benefit *all* elders' health. Here this SCEES publication offers much insight into active ageing, palliative care and long term conditions. The message in the publication is clear: we are not starting from a zero base in any of these three areas. Resources and developments exist – and some that have developed during the course of this project by PRIAE, if adopted, can pioneer change. I commend this publication as an important resource to all those in leadership and to their colleagues so that our NHS and social care in Scotland is at the leading edge of innovations in active ageing, palliative care and long term conditions. That would make a big difference to Scotland's minority ethnic elders as part of *all* elders that we work with and provide quality patient care where needed.

Professor S.P Sashidharan
Co-Chair of SCEES Steering Group
PRIAE Trustee based in Scotland

planners. It is a relationship where patients and the public are affirmed as partners rather than recipients of care. They are not just consumers - with only rights - but as owners - with both rights and responsibilities

The Scottish Government has established a Mutuality, Equality & Human Rights Board in 2008 to oversee the development of more 'person centred' services. Amongst their actions, the following are particularly important in relation to our ethnic elders

- Building capacity and capability of staff and patients – in attitudes, skills and leadership to equip them to participate in a mutual NHS
- Change on the ground to ensure accessibility and appropriateness of services, making sure people can access the services they need, when they need them
- Understanding and learning from patient experience – good and bad
- Developing clear measures on participation and self care and improving on current approaches to community engagement and community development in shaping our services

To be truly patient centred, we need to understand and respond to the needs of the

diversity of the population. We, therefore, need to recognise the impact of disadvantage and discrimination on the lives of our ethnic elders, and the barriers they face in accessing health care. This understanding enables policy-makers and health care providers to find ways to improve access, service uptake and service user experience.

Working in partnership with our ethnic elders, we can achieve the aspiration and positive change of a ‘mutual’ NHS where they can take greater control over their health and well-being.

Dr Wai-yin Hatton
Co-Chair SCEES Steering Group
Chief Executive
NHS Ayrshire and Arran



I welcome this document and its emphasis on active ageing, proving good palliative care and helping people with long-term conditions.

The Care Commission register and monitors care in Scotland. From the very young to the very old, these services care for some of the most vulnerable in our society – and it’s up to us to make sure these services deliver care consistently and to a high standard.

We use Scotland’s National Care Standards to monitor care. They are clear and explicit on the quality of care people should and can expect. They ensure the outcomes are right for each individual and are absolutely central to the relationship between the care providers and the people using care. The care standards are based on the principles of dignity, privacy, choice, safety, realising potential and equality and diversity. This means that older people using residential care services have the right to live an independent life, rich in purpose, meaning and personal fulfilment. To do this older people need better information, more involvement in their service and care tailored specifically for each individual. It is an older person’s right to expect high standards

and receive good care and we want their expectations to rise. We want them and their families to demand improvements – older people are entitled to a service personal to their own unique needs especially when they are nearing the end of their life.

In April 2008, we introduced our grading system so that care services in Scotland continue to improve. To achieve better grades, care providers must show that they have involved people who use their service and their carers or family members in assessing the quality of care. Clear grades will help people make more informed choices about the care services they want to use. We are already seeing evidence of good practice in older people’s care homes.

In one service, residents say they feel valued by being involved in the recruitment process for new staff and also assessing staff in their training. This has achieved a better balance of power with staff taking advice and guidance from residents.

Another care home has transferred responsibility for the in house newspaper from management to staff. This has given residents a greater sense of purpose, interest and achievement. The manager has also seen change in the residents who are visibly proud of their achievements, happier, more involved and enjoying life more.

The aim of such initiatives must be to make life more fulfilling and create a sense of empowerment in older people. People using care services know better than anyone what is right for them. They want to be asked what they think and whether anything should

change. So, good quality care comes when the people who receive it are better involved.

Jacquie Roberts
Chief Executive
Care Commission

Acknowledgements

Many individuals and organisations helped to implement the SCEES pilot development. Our warm and special thanks to everyone involved to the elders, to the community organisations' staff, and lead staff and professionals working in the SCEES areas particularly the four health boards who all contributed much to the implementation of SCEES – active ageing, palliative care and long term conditions.

The Steering Group members with their heavy work schedules gave generously of their time particularly when the project began and to the Co-Chairs Dr Wai-yin Hatton and Professor Sashidharan whose engagement has been continuous and encouraging.

Our sincere thanks to staff in the Scottish Government's social inclusion unit's multiple and complex needs initiative who responded positively with all our enquiries and were keen to learn as well as exchange relevant information with us on the subject.

SCEES development was designed and conceived by PRIAE's director. NRCEMH's then director Dr Rafik Gardee worked with PRIAE to ensure that contribution on minority ethnic elders' health was made and funded. Upon his retirement Eileen McKnight continued and supported the SCEES base at NRCEMH. We are most appreciative of their support.

Finally our thanks to PRIAE's staff: then SCEES project manager Carrie Ho who enthusiastically implemented the major part of SCEES development with care and creativity until December 2007. She generated much interest and support to the SCEES work across the four development sites selected in the SCEES development. Maariyah Chaudhry joined as PRIAE consultant and completed some of the work until end July 2008, to Dr Yasmin Gunaratnam who contributed to the analysis of active ageing element of SCEES and to Ahsan Malik for project managing the administration aspects of SCEES. Sunjeeda Hanif for making arrangements for the SCEES launch with her determination to make this event special which will take place on 23rd March at Assembly Rooms in Edinburgh and to Hazel Waters for her critical read of this publication.

Our appreciation to everyone involved in the SCEES development. Thank YOU and we hope that you will find this work as an important contribution in advancing active ageing, palliative care and long term conditions for all elders in Scotland.

Professor Naina Patel OBE
Executive Director and Founder

Dr Kathryn Watson
PRIAE consultant

Executive Summary

SCEES Securing Care for Ethnic Elders in Scotland is a development project that used community engagement, research, information and promotion methods to inform multiple and complex needs agenda. It was developed by engaging with black and minority ethnic (BME) elders and organisations and professionals specialising in specific areas of SCEES. The project worked with health boards, social care and community organisations, and elders in four health board areas: - Lothian, Forth Valley, Greater Glasgow & Clyde and Ayrshire & Arran

There were three key elements to the SCEES project:

- Prevention: promotion of active ageing through physical and mental activities
- End of life issues: palliative care
- Patient-centred hospital care

Active ageing

Chinese and South Asian service providers in Glasgow and Edinburgh provided a wide range of services and activities for BME elders with a strong emphasis on promoting healthy lifestyles, fitness and exercise; social and cultural involvement; facilitating access to mainstream services and overcoming barriers and isolation.

The majority were well established and had been set up to meet a recognised need within their community. Services were culturally sensitive and often targeted at one particular group.

Funding of the Black and minority ethnic (BME) organisations was a key issue and lack of ongoing funding threatened continuation of services and hindered expansion.

BME elders were proactively engaged with voluntary organisations, taking part in active ageing activities organised by them. For

some though, barriers including needing a companion/assistant, language, travel and distance. Despite a high incidence of health problems, elders were keen to participate. In addition, many were interested in volunteering and subsequently did so.

The Champions' Training Programme was well received by members of the BME community and was successful in greatly increasing their knowledge and awareness of a number of health and lifestyle related issues.

Many critical issues were identified in the sessions and subsequent evaluation. These included: lack of interpreters; lack of awareness of services for older people; interest in skills training; desire for education and broadening of knowledge; importance of culturally sensitive services.

Palliative care

Six Palliative Care Listening Events were held for the Chinese and South Asian community to raise awareness and understanding of palliative care services and allow professionals to ask questions of community members about issues that were of concern to them.

The events were very well received and served to highlight many of factors that influence the take-up of palliative care. These included, for example, prayer opportunities and facilities; provision of familiar food; family and friends' visiting rights; gender issues; interpretation services; and the role of family and friends in caring for their loved one.

Long term conditions health notebook

A small pilot project, involving elders with long term conditions keeping a patient

notebook to help them manage and monitor their condition, as well as facilitating communication with health care professionals and so improve access to services was well received by the South Asian participants. They had few problems with it, finding it beneficial. But it was rather less well received

by the Chinese participants. The main problem appeared to be that many of the elders were not literate in their own language or in English, and therefore had problems understanding the purpose of the notebook, so were less inclined to continue with it.

1 Introduction

PRIAE has worked in Scotland since its inception in 1998 as a result of the commissioned report from the Royal Commission on Long Term Care for the Elderly. This was the first UK policy event that engaged BME elders to formulate policy proposals on funding, active ageing and care. Scotland's BME elders engaged fully and the work was delivered with VOCAL/MECOPP and the CRE Scotland (see www.priae.org for the full report). Findings and recommendations from this policy engagement work have set the scene for SCEES, together with PRIAE's work during its Minority Elderly Care (MEC) Research which is the largest research in the area in the UK and across Europe. In 2005 PRIAE held a Conference on Report on Delivering Quality Minority Ethnic Elders' Health and Social Care in Europe, which has further underpinned SCEES development in Scotland.

Securing Care for Ethnic Elders in Scotland (SCEES) is a PRIAE conception and the first dedicated project for Minority ethnic elders funded by the Scottish Government Multiple and Complex Needs Initiative. The project was designed by PRIAE to improve and manage dignified and active ageing

life for Scotland's black and minority ethnic (BME) elders where the presence of multiple identities gives rise to multiple and complex needs and to support service innovations and identify and promote good practice development.

Working with local and national BME support groups, the health board and local authorities, the project explored service responses under three themes: Prevention (active ageing), palliative care and patient centred hospital care. Black and ethnic minority older people currently access services less and experience poorer service outcomes. The project aimed to improve understanding of how these barriers can be overcome and address a range of health related issues in relation to the growing BME elder population particularly in Edinburgh and Glasgow. By addressing such issues, the objective of the project was to share best practice between health organisations and service providers in order to improve access, service uptake and service user experiences. Thus the aims and objectives of the project reflect the Scottish Government's over-arching agenda to promote equality and social inclusion.

2 Project Design and Research Methodology

There were three key elements to the SCEES project at PRIAE:

- Prevention: active ageing, physical and mental activities
- End of life issues: palliative care
- Patient-centred hospital care

All three elements were undertaken between 2006 and 2008. The project was managed by PRIAE initially working with NRCEMH and advised by a Steering Group comprised of health and social care professionals and minority ethnic community representatives and was co-chaired by Dr Wai-yin Hatton, Chief Executive NHS Ayrshire and Arran and Professor S P Sashidharan, a PRIAE Trustee.

Four health board sites were selected to implement the project. They were: Lothian, Forth Valley, Greater Glasgow & Clyde and Ayrshire & Arran

The three elements of the project consisted of a number of fact-finding and development activities involving ethnic minority elders.

The first element: referred to as **Active Ageing Programme** involved the following questionnaire surveys:

- A questionnaire administered to 14 service professionals working in BME voluntary organisations in Edinburgh and Glasgow
- A survey of 108 minority ethnic elders in Edinburgh and Glasgow contacted through BME voluntary organisations
- A number of “Champions” were recruited, also through BME voluntary organisations, and trained to promote active ageing and act as mentors and role models for their communities. After completion of the Champions’ Training Programme they were asked to complete a questionnaire to learn about their views about the programme

The questionnaires for the Service Providers and Champions were administered by face-to-face interview and all involved a large qualitative aspect. Thus the style of questioning was more conversational although quantitative responses were elicited where appropriate. The questionnaires for the elders were administered by the respective organisations of which they are members. The samples are not considered representative of the populations of BME elders or professionals in the wider community.

Following the survey phase, information and activity events were organised to establish the range of community resources that already exist within as well as supplanting with specific information and promotion on exercise and nutrition.

Reviewing the results from the questionnaires and the information meetings, a Champions’ Training programme was developed and implemented.

Palliative Care

Six listening events were organised involving South Asian and Chinese elders. They were held in Edinburgh, Glasgow and Forth Valley. Translation and interpreting facilities were organised and available

Long Term Health Conditions

A notebook was developed with professional interests to establish how elders across South Asian and Chinese background engage with a tool designed to increase self awareness of health, conditions and its consequent response. The notebook was translated into Urdu, Punjabi, Chinese, Bengali and Hindi.

3 Background and Context

3.1 Population Facts

Scotland's Population 2007: The Registrar General's Annual Review of Demographic Trends, 153rd Edition (National Statistics, 2008):

- The total population in Scotland as at 30 June 2007 was 5,144 million – the highest since 1983. In the year to 30 June 2007 gains from migration (from other parts of the UK and elsewhere) were higher than in any year since records started in 1951
- Between 2006 and 2031, Scotland's population is projected to age markedly. The number of children aged under 16 is projected to decrease by 7 per cent, from 0.92 million to 0.86 million. The number of people aged 60 and over is projected to rise by 54 per cent from 1.12 million to 1.72 million

All Our Futures: Planning for a Scotland with an Ageing Population:

- By 2031 the number of people in Scotland

aged 50+ is projected to rise by 28% and the number aged 75+ is projected to increase by 75%.

Analysis of Ethnicity in the 2001 Census:

- The size of the minority ethnic population was just over 100,000 in 2001 or 2% of the total population of Scotland
- Pakistanis were the largest ethnic minority group followed by Chinese, Indians and those of mixed ethnic backgrounds
- The size of the minority ethnic population has increased since the 1991 Census. Whilst the total population increase between 1991 and 2001 was 1.3%, the minority ethnic population increased by 62.3%
- In general, minority ethnic groups in Scotland are younger than the general population.
- Minority ethnic groups are concentrated in urban areas; for example, 80% of Pakistanis but only 39% of white Scottish groups live in large urban areas

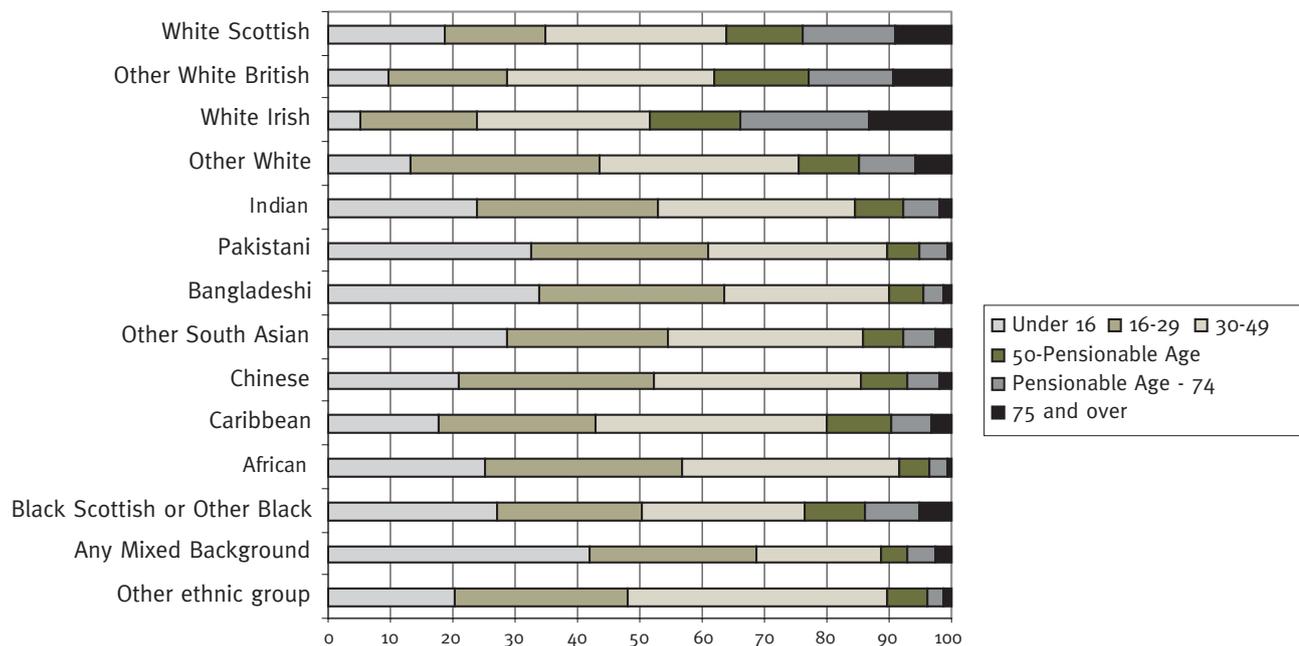
Table 1. Scottish Population by Ethnic Group

	% of total population	% of minority ethnic population	Base
White Scottish	88.09	n/a	4,459,071
Other white British	7.38	n/a	373,685
White Irish	0.98	n/a	49,428
Any other white background	1.54	n/a	78,150
Indian	0.30	15	15,037
Pakistani	0.63	31	31,793
Bangladeshi	0.04	2	1,981
Chinese	0.32	16	16,320
Other South Asian	0.12	6	6,196
Caribbean	0.04	2	1,778
African	0.10	5	5,118
Black Scottish or any other black background	0.02	1	1,129
Any mixed background	0.25	13	12,764
Any other background	0.19	9	9,571
All minority ethnic populations	2.01	100	
All population	100.00	n/a	5,062,011

Source: Analysis of Ethnicity in the 2001 Census, Scottish Executive, February 2004

Chart 1 shows the age profile of the population of Scotland by ethnic group. For both males and females (separate charts not shown), the ethnic minority groups have a younger age distribution than the White groups.

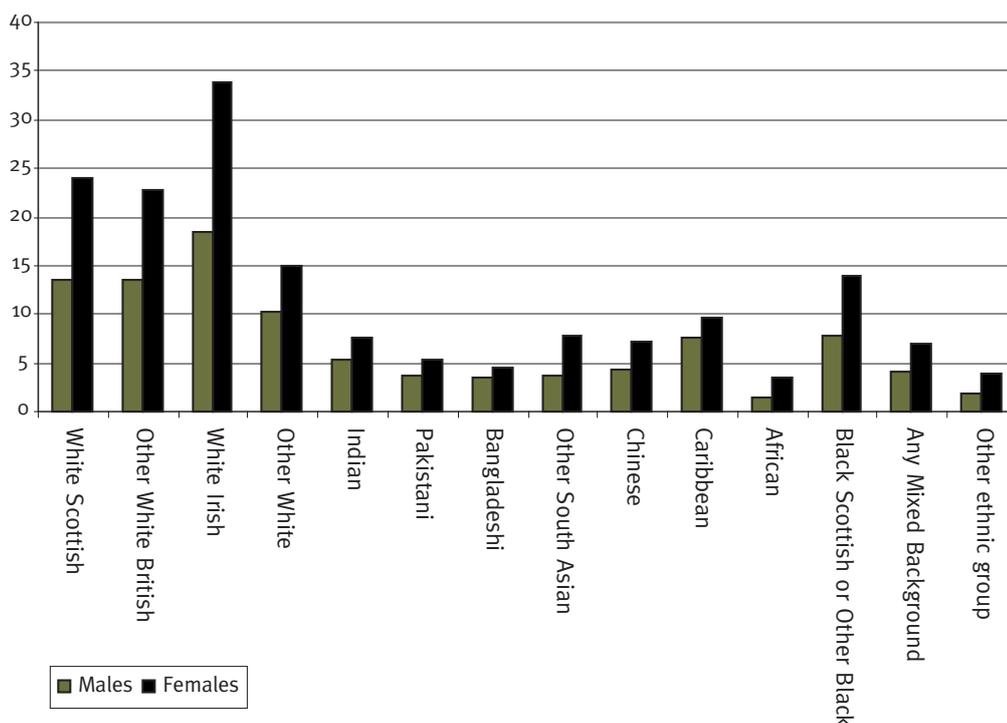
Chart 1. Age Profile by Ethnic Group – All People Scotland



Source: Analysis of Ethnicity in the 2001 Census, Scottish Executive, February 2004

Chart 2 shows that the ethnic minority groups with the highest proportions of persons of pensionable age are the Chinese and Black Scottish groups.

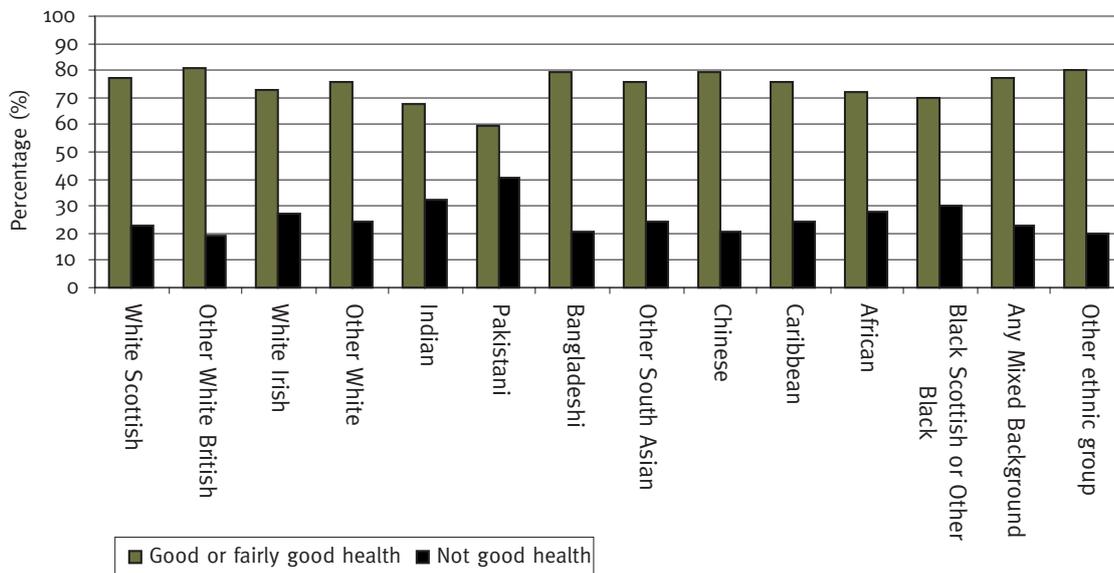
Chart 2. Persons of Pensionable Age and Over by Ethnic Group
Proportion of Total Population



Source: Analysis of Ethnicity in the 2001 Census, Scottish Executive, February 2004

Chart 3 shows self-reported general health for the Scottish population aged 60 years and over. The Pakistani group reported the poorest health, with only 59% of people aged 60 years and over reporting good or fairly good health.

Chart 3. General Health by Ethnic Group – All People Aged 60 Years and Over



Source: Analysis of Ethnicity in the 2001 Census, Scottish Executive, February 2004

Table 2 shows that the Pakistani and Indian ethnic groups have the highest proportion of the population 60 years or over with a long term limiting illness or disability at 66% and 56% respectively. These groups are followed by the White Irish and Black Scottish/Other Black groups both at 55%.

Table 2. Long Term Limiting Illness and Disability by Ethnic Group – Population 60 Years and Over

	Base Number	Per Cent of People 60 Years and Over with LTLI/Disability
All people	1,066,633	51%
White Scottish	956,069	51%
White British	78,410	47%
White Irish	14,656	55%
Other White	11,010	51%
Indian	1,244	56%
Pakistani	1,974	66%
Bangladeshi	103	45%
Other South Asian	400	53%
Chinese	1,174	49%
Caribbean	178	48%
African	162	45%
Black Scottish/Other Black	132	55%
Mixed	786	54%
Other	335	44%

Source: Analysis of Ethnicity in the 2001 Census, Scottish Executive, February 2004 (Extracted from table with all ages)

3.2 Policy Context

All Our Futures: Planning for a Scotland with an Ageing Population (2007) is the Scottish Government's latest strategy focused on enhancing the quality of life and access to opportunities for assisting older people to age actively in all spheres of life. Some of the specific points the strategy addresses are that:

- People enjoy more years of healthy life, and are enabled to manage long term health conditions
- People are enabled to continue to work for as long as they want or need to, in the way that suits them best, supported by flexible approaches to employment and retirement
- Older people have ready access to information technology and the internet
- Older people are able to participate in learning activities, both vocational and for personal development
- Older people are enabled to volunteer for as long as they want, in the way that suits them best, and that their contribution is fully recognized
- Vulnerable older people are protected, safe, and able to live free from fear
- Older people have access to public services which are people-centred, accessible and 'joined up'; and can access quality services appropriate to their needs, when and where they are required
- Authoritative, up-to-date sources of advice and information are accessible to older people, when and where they are required and in a format that is accessible and user-friendly.

The National Forum On Ageing Implementation Group and the Older People's Consultative Forum are the two structures to implement the national strategy.

The Lifelong Learning Strategy for Scotland exists to widen opportunities for "personal

fulfilment and enterprise, employability and adaptability, active citizenship and social inclusion" (Life Through Learning; Learning Through Life Summary document: 3, 2006). Whilst the strategy does not exclusively relate to older people and learning, it is inclusive of that group and the work around this strategy reflects that.

The Enterprising Third Sector Action Plan, 2008-2011 was launched in 2008, to enable the right conditions to be created in which the Third Sector, including social enterprises, can excel. The main premise is to create opportunities for all people to contribute toward Scotland's economic growth.

According to Scottish Government findings, 30% of people aged 50-59, 26% of those aged 60-74 and 15% of those over 75 are involved in some kind of voluntary work. The Scottish Government undertook a review of its policies relating to volunteering which informed a five year strategy for volunteering in 2004. This has led to several initiatives:

- The Healthy Living Campaign: This comprises a telephone help-line which can be called for information and advice; an interactive website which has sections on 'Eat Well, Stay Active' and 'Getting Fitter Needn't be a Marathon', both tailored for older people
- Health in Later Life: NHS Health Scotland have developed this tailor-made programme for older people which focuses on meeting health education needs
- Mental Health and Well-being in Later Life: Older people are one of the six priority for the National Programme for Improving Mental Health and Well-being
- Physical Activity Strategy: Launched in 2003, 'Let's Make Scotland More Active' is aimed at increasing physical activity levels across the country. Specific recommendations are highlighted for older people, i.e. for people in residential homes; for people who are frail, etc.

4 SCEES Active Ageing Programme

4.1 Introduction

The World Health Organisation (2002) defines active ageing as, “the process of optimising opportunities for health, participation and security in order to enhance quality of life as people age”.

The Active Ageing Programme in SCEES project comprised three components:

- A survey of service providers
- A survey of ethnic minority older people
- A Champions’ Training Programme and related survey

In this section we report the findings of the surveys conducted on each element and provide an overview of the events which were held during the Champions’ Training Programme.

4.2 Survey of Service Providers

Fifteen voluntary community organisations working with South Asian and Chinese older people in Glasgow and Edinburgh were contacted and sent a questionnaire which was designed to inform what kinds of services are provided; kinds of activities that are mostly frequently used; gaps in service provision and funding issues. There was an extremely good return rate of 93% i.e. fourteen out of fifteen questionnaires.

The organisations chosen to participate are a convenience sample and were contacted because they were known to be working pro-

actively with ethnic minority elders. The focus was on Edinburgh and Glasgow because, as the population statistics in Section 3 show, the majority of individuals from ethnic minority groups live in urban areas (80% of Pakistanis live in urban areas). In addition, because of the higher population numbers, the urban centres are where voluntary service provider groups have been established. Researchers previously working for PRIAE in Scotland (PRIAE 2005) found very few ethnic minority voluntary organisations based outside the major urban areas. Given the distances involved in travelling, it was considered more efficient to focus attention on the main population centres of Glasgow and Edinburgh.

Table 3 shows the role of the 14 respondents together with the names of their organisations and their organisation’s aims. All the organisations which took part in the survey were non-statutory.

The organisational aims are interesting and reflect a common theme of activities within the following areas:

- Improving health and quality of life
- Providing specific services in the areas of health and social care
- Providing information/advice, promoting awareness and also providing education in specific areas
- Organising social events and activities
- Relieving the effects of poverty and reducing isolation
- Promoting equal opportunities and overcoming barriers to accessing services

Table 3. Respondents' Roles, Their Organisation, and Their Organisation's Aims

Job Title	Organisation Name	Aims of Organisation
Pharmacist	Pakistan Society	To improve the health of the ethnic minority population
Project Manager	Dixon Community Ethnic Minority Centre	To provide a range of caring, supportive, culturally sensitive services to minority ethnic elders living in Govanhill and surrounding areas of Glasgow. It also provides advice and information to assist them to remain living within our community
Chairman	Pakistan Society Advice and Information Services	Provide health and social services for BME; improve and manage dignified and active ageing for Edinburgh BME elderly; create awareness among the elders; organise social events and holiday trips; improve the quality of life for elders
Chairperson	Lai Kok Women's Group	The objects of Lai Kok Women's Group shall be to promote the benefit and culture of, further the health of, and advance the education of Chinese women within the wider community in the central region
Project Worker	Central Scotland Chinese Association	To advance the education and promote culture of the Chinese community in the Forth Valley area in Scotland. We advocate on their behalf to promote equality of opportunity in the wider society
Chairman	Anonymous	To promote the health education and cultural awareness of elder Chinese people in the Forth Valley area. To provide social activities to overcome isolation
Service Manager	Polish and Ukrainian Support Service	Advice, information and support to older Polish and Ukrainian people. Day opportunities for Polish, Ukrainian and Italian older people
Coordinator	Edinburgh Chinese Elderly Support Association	The objects of ECESA are to relieve poverty, further the health, and advance the education of persons within the Chinese community in the area of benefit and to promote racial harmony within the wider community in Lothian
Access Initiative Development Officer	MECOPP	By working in partnership with carers, the voluntary and statutory sectors, MECOPP will actively seek to challenge and dismantle barriers that deny BME carers access to health, social work and other social care services in Edinburgh and the Lothians
Development Worker	Sikh Sanjog	To provide a range of quality opportunities for Sikh women and their families in response to educational, recreational, cultural and social needs, recognizing the potential for life-long learning, social and economic inclusion. We also promote links between the Sikh and the indigenous communities encouraging access to mainstream resources and services
Project Manager	Wing Hong Chinese Elderly Centre	To promote equal opportunity for the Chinese elderly in access to various social, health, welfare and housing services
Befriending Co-ordinator	Saheliya	To maintain and support the positive mental health and well being of black and minority ethnic women in Edinburgh
Manager	Milan (Senior Welfare Organisation)	To develop provisions for older people from Indian, Pakistani, Bangladeshi and Mauritian communities in Edinburgh and the Lothians which meets their social, cultural, recreational, language and care needs
Chairperson	Edinburgh Chinese Women Association	To promote unity among the Chinese women of Edinburgh and nearby areas and enhance mutual help and concern through educational, cultural and recreational activities, as well as advancing their welfare. To relieve distress caused by illness, isolation and domestic problems and provide appropriate support if possible

The target user groups for the organisations were 6 organisations working with Chinese elders, 4 with South Asian elders, 1 with Polish/Ukrainian elders and 3 with BME generally. 5 of the organisations worked with women elders only and the remaining 9 worked with both men and women elders.

5 of the organisations worked with all age groups including young people and elders. A further 2 organisations indicated that the age group varies depending on the service. Of the remaining organisations, 5 worked with those aged 50 and over and 2 with elders over 65.

4.2.1 Services

Table 4 shows the services provided by the organisations. This table was compiled from qualitative data so it is possible that the organisations have additional services which were not mentioned by the interviewees. Nevertheless, the data provide a good overview of the types of services provided and it is clear to see that there is a strong emphasis on physical activities and exercise, health awareness, checks, advice and information, and also on social and cultural activities, including in particular trips out.

Table 4. Services Provided by the Organisations

	Day care service	Lunch club	Home and hospital visiting service	Health talks	Other talks	Health clinics / checks	Language classes	Other classes	Keep fit / dance classes / swimming	Advice / advocacy	Befriender service	Chiropody service	Housing surgery/ advice	Massage sessions	Carers' support	Cultural events / celebrations	Holiday trips	Day trips	Walking trips	TOTAL
Pakistan Society						•														1
Dixon Community Ethnic Minority Centre		•					•	•				•	•							5
Pakistan Society Advice and Information Services				•		•								•		•	•			5
Lai Kok Women's Group		•							•							•		•		4
Central Scotland Chinese Association				•	•		•									•				4
Anonymous		•		•	•				•							•		•	•	7
Polish and Ukrainian Support Service				•					•							•				3

	Day care service	Lunch club	Home and hospital Visiting service	Health talks	Other talks	Health clinics / checks	Language classes	Other classes	Keep fit / dance classes / swimming	Advice / advocacy	Befriender service	Chiropody service	Housing surgery/ advice	Massage sessions	Carers' support	Cultural events / celebrations	Holiday trips	Day trips	Walking trips	TOTAL
Edinburgh Chinese Elderly Support Association	•	•	•							•						•		•		6
MECOPP				•	•				•						•			•		5
Sikh Sanjog					•				•	•								•	•	5
Wing Hong Chinese Elderly Centre	•	•		•		•	•		•									•		7
Saheliya			•						•		•							•		4
Milan (Senior Welfare Organisation)		•	•							•	•									4
Edinburgh Chinese Women Association				•	•				•							•				4
	2	6	3	7	5	3	3	1	8	3	2	1	1	1	1	7	1	7	2	64

Table 5 below shows when services were commenced and what the motives were for setting them up. Four of the organisations started their services in the 1980s; five in the 1990s and two in the 2000s (one did not answer these questions). The unanimous reason for setting up services was an identified need within the community among the particular group of people that each serves. One organisation indicated that the need was identified by research and two organisations indicated that they had consulted with the community.

Table 5. Date and Motivations for Starting the Services

Organisation name	When the services started	How did the service/activity come into being
Pakistan Society	2004	Due to research project and patient request needs
Dixon Community Ethnic Minority Centre	March 1993	Stirling University did research on ethnic minority communities in the Govanhill area. It was found during their research that there were no facilities available for BME older people
Lai Kok Women's Group	Dance Class - September 2006 Lunch Group - 15 years ago	Members' ideas to increase participating and involvement of the group. To learn about their own culture
Central Scotland Chinese Association	1989	The group began their activities as a group of Chinese volunteers during the 1980s. They felt that there was a need to organise a community group to promote the Chinese culture within the Forth Valley area. The group then moved on to expand their range of activities to include the elderly project, women's project, advocacy project and the Chinese school as time went on
Anonymous	from June 1995	The Central Scotland Chinese Association identified the special needs of the Chinese older people who are living in the Central region back in the 1990s. They then applied for funding from the social work services. A lunch club was then started
Polish and Ukrainian Support Service	May 2000 - Outreach service, May 2004 - Day opportunities.	No services were available for Polish community who were the largest and oldest community in the Lothians. Application made to ethnic minority grant scheme was successful initially for 2 years and then for a third year
Edinburgh Chinese Elderly Support Association	May 1988	After consultation with service users and needs assessment, partnership working with social work department and other statutory/voluntary agencies to start the service
MECOPP	Since the organisation started 1996	Normally the activity began as a result of an identified need which was found amongst a group of carers
Sikh Sanjog	1989	Established in 1989 to combat the isolation experienced by Sikh women due to cultural restrictions placed on them by their families. They were restricted on what they could access i.e. leisure activities, youth groups, mother and toddler groups
Wing Hong Chinese Elderly Centre	Since Wing Hong was established in 1989	Response to unmet needs
Saheliya	The service began in 1995	Consultation of the communities
Milan (Senior Welfare Org.)	October 1991	The elderly from the four communities wanted a place where they could get together, relax, reminisce and chat and share educational and recreational activities
Edinburgh Chinese Women Association	November 1999	As a voluntary organisation (self-supported group) established within the community

With regard to the people who took the lead in developing the services/activities, it is apparent that they were split 50/50 between those started by professionals such as an outreach worker or development worker and those started by volunteers getting together. Some caution is required in interpretation of the comments as no doubt in many situations it would be a case of people from different backgrounds working together. The volunteer workers had appropriate language skills and knowledge of the culture and the community they were aiming to serve.

Table 6 shows that most of the organisations target their services at specific BME groups being community based, although four of the organisations aim more generally at all BME groups. Nearly all respondents were in agreement that the cultural aspects of service attracted more users and specific mention was made of food, prayer, language and festivals. One of the organisations indicated that “yes”, culturally sensitive aspects did help but that adequate funding, staff and facilities would mean they could do more and one respondent indicated “yes” but said that lifelong learning was equally important to their service users.

Table 6. Who the Services Are Aimed At, Importance of Culture and Why Particular Service Was Decided Upon

Organisation name	Whether service/ activity aimed at a specific group	Whether cultural aspects of the service attract more people	Why did they decide on this particular service
Pakistan Society	No, open to everybody	Yes, on ladies only	People need culturally sensitive exercise
Dixon Community Ethnic Minority Centre	Yes, language classes, exercise class, sewing class, Ethnically sensitive food.	Yes, BME older people feel more comfortable in their own environment where they can eat their culturally sensitive food, have facilities for prayer and speak in their own language	Our older people were socially isolated, culturally and because of lack of English. Women were particularly suffering from depression
Pakistan Society Advice and Information Services	Black and Minority Ethnic, 50+, disabled, language difficulties	Yes, but can do more with adequate funding and staff and facilities	Demand by the 50+ people who were isolated and finding it difficult to carry on with normal life
Lai Kok Women’s Group	For our members - mainly Chinese (we also welcome others)	Maybe, but most our member will be taking part	Our members’ interests and hobbies
Central Scotland Chinese Association	Chinese	Cultural area is very important, however lifelong learning/adult education are equally important to the local users	They can make direct impact on Chinese peoples’ lives. They are also very relevant to their culture and education needs
Anonymous	older Chinese people	Special cultural activities, e.g. Chinese New Year celebrations are very popular and attract more than 100 people	Consultation with members to assess their needs in order to develop appropriate activities/ services

Organisation name	Whether service/activity aimed at a specific group	Whether cultural aspects of the service attract more people	Why did they decide on this particular service
Polish and Ukrainian Support Service	Polish, Ukrainian, Italian and their Scottish spouses	Yes	No previous service for these people, gap discovered and funding sought
Edinburgh Chinese Elderly Support Association	Yes, older Chinese community in Edinburgh and the Lothians	Yes, definitely.	Consultation with stakeholders (service users, funders and professional workers)
MECOPP	Yes, Chinese and Asian Carers	Yes	Activities are user-led. Lack of similar cultural appropriate activities within the local area
Sikh Sanjog	Sikh community	Yes	Activities reflect the context in which elders come from (Bhatra community whose origins in India were rural) and respond to a range of issues women face and opportunities to participate
Wing Hong Chinese Elderly Centre	Chinese elderly	Yes	To meet the needs of the elderly
Saheliya	For all ethnic minority women	Yes	Because of lack of cultural and mental health specific needs in Edinburgh
Milan (Senior Welfare Org.)	Four communities i.e. Indian, Pakistani, Bangladeshi and Mauritian	Yes	This is the only service for Asian elderly in South East of Scotland
Edinburgh Chinese Women Association	Yes, Chinese	Yes	As a self-support group

4.2.2 Funding

Twelve of the organisations responded to the questions regarding funding. Two of them indicated that they were completely self-funding, relying on fees, voluntary contributions or other means but not grants from any particular source. The remainder had multiple sources of funding. Six had money from a funding body such as the Social Inclusion Partnership and Award for All; seven had local authority grants and one had a grant from the Scottish Executive. Three had money from the Big Lottery Fund, one from the NHS and one from Age Concern.

Seven of the 14 organisations said they did have some charges or membership fees but for some of them these were rare or nominal.

All except one of the respondent organisations have paid staff and one of these have volunteer workers supervised by a paid employee. Three of the organisations also used external specialists.

The organisations were asked about the advantages and disadvantages of the way their services were currently managed. Four indicated that funding, especially the uncertainty of long term funding was an issue; two mentioned that reliance on voluntary workers could be problematic, one said that occasionally small group politics was an issue and one that finding appropriate space for their activities was a problem. The advantages were that they

could provide appropriate services (mentioned by five), with two in particular indicating that they could provide services with appropriate languages that were culturally sensitive. One organisation said an advantage was that the staff could control the organising of activities because the workers know service users and their needs best.

With regard to problems experienced at the start, eight of the organisations indicated that funding was an issue, four said finding the right venue (or having to make do with what they could get), two indicated staff, two more said resources and three mentioned managerial issues such as planning or finding a co-ordinator. Four indicated issues to do with recognition – either getting people on board to get services going or getting the service users to understand the need for what the organisations were doing. One organisation indicated that there was opposition from men in the community when women are the focus of its work.

Problems for the future centred very much on funding, which was mentioned by nine respondents. One indicated that if they did not secure funding they would have to close down the organisation and plan an exit strategy. One organisation indicated finding new members, another finding a better venue, another two organisations mentioned staffing or recruitment of volunteers, one indicated transport (for users) and another, dealing with regulations.

4.2.3 Benefits of the Service

Table 7 shows the specific conditions which the organisations seek to address and what they perceive as the main benefits of their services/activities. Seven of the organisations mentioned diabetes; six, coronary heart disease; eight, mental health including depression and stress; three, skeletal/physical problems; two, cancer, and two, healthy living generally. As well as specific health benefits, the attraction of the services is improved quality of life for users, social cohesion, and social and cultural benefits.

Table 7. Target Health Conditions and Main Benefits of the Project

Organisation name	Health conditions prevalent in the community that services/activities are aimed at	What are the main benefits of the project
Pakistan Society	South Asians are 4-6 times more likely to get type 2 diabetes and 2-3 times more likely to get CHD	Quality of life, health benefits, social benefits
Dixon Community Ethnic Minority Centre	Mental depression, Arthritis, Diabetes.	The project provides a range of caring, supportive services, advice and information, housing surgeries, chiropody, exercise classes, sewing class. The project also recognises and respects the rights of service users to maintain their independence. The project also works with Southside carers.
Pakistan Society Advice and Information Services	Diabetes, High blood pressure, Asthma, Heart problems, Depression.	
Organisation name	Health conditions prevalent in the community that services/activities are aimed at	What are the main benefits of the project
Lai Kok Women's Group	Mental Health, Diabetes, Healthy Living.	Improvements to all of them.

Organisation name	Health conditions prevalent in the community that services/activities are aimed at	What are the main benefits of the project
Central Scotland Chinese Association	Mental health, acute diseases like heart disease, diabetes, cancer etc.	Community cohesion, Chinese language education, social benefits to improve quality of life and cultural reliance and support etc.
Anonymous	High blood pressure, diabetes, cancer, mental health etc.	Health benefit, social benefit, improve quality of life, reduce of isolation etc.
Polish and Ukrainian Support Service	High blood pressure, heart disease.	Health benefits, improve quality of life, maximize benefits – DWP; relieve isolation, culturally appropriate activities.
Edinburgh Chinese Elderly Support Association	Poor physical health and mental health. Poor access to health and social care services (language problems), lack of understanding of statutory provision.	Improve quality of life, improve health and social benefits.
MECOPP	None	Improve quality of life - holistic approach.
Sikh Sanjog	Diabetes, Arthritis, Stress	All of these apply to service users. Sikh Sanjog (Sanjog means 'linking' in Punjabi) is the only organisation that is specifically designed to support Sikh women and their families integrate and link into mainstream activities.
Wing Hong Chinese Elderly Centre	Diabetes	Health benefits, social benefits, improve quality of life, respite for carers etc.
Saheliya	Depression, anxiety which causes insomnia, muscular pain, heart disease etc.	Mental health benefit, social benefits and improve quality of life.
Milan (Senior Welfare Org.)	All of them.	
Edinburgh Chinese Women Association	All of the above	

Nine of the organisations said they were considering expanding their services/activities at the current time. The expansions under consideration were:

- Massage therapy
- Photography class, art class
- More classes, opera singing, talks
- Language classes, physical activities
- Tai chi and other classes, trips
- Day care

Funding was the main issue which might prevent expansion and this was mentioned by all nine organisations, one also said finding the manpower, two said premises/venue and one said gender politics.

4.3 Survey of Minority Ethnic Elders

A survey questionnaire was sent to 145 minority ethnic elders through a wide variety of groups and organisations in Arran & Ayrshire, Glasgow, Edinburgh and Forth Valley. 108 questionnaires were sent back giving a 70% return rate.

The questionnaire covered the following topics:

- What organisation respondents belong to and whether they take part in activities
- What stops them taking part in activities
- Do they exercise on their own and/or with family/friends
- What motivates them
- When did they come to the UK and are there activities they did before that they miss
- Are there cultural activities in their area
- Do they eat fruit and vegetables and what kind of cooking oil do they use
- What is the state of their health and what illnesses do they have
- What type of housing do they have and do they live alone or with others
- Are they a volunteer or interested in volunteering

The questionnaire was in English but fieldworkers had appropriate language skills.

The list of organisations which the respondents were members of is shown in Table 8.

Table 8. Respondents and Voluntary Organisation

Voluntary Organisation	Number	Percent
Dixon Community	16	14.8
Central Scotland Chinese Association, Stirling	12	11.1
Indian Community, Forth Valley	7	6.5
Chinese Healthy Living Centre	6	5.6
Alzheimer Scotland	5	4.6
Asian Elderly Group, Edinburgh	5	4.6
Edinburgh Chinese Elderly Support Association	5	4.6
Milan Senior Welfare Organisation	5	4.6
Pakistani Community, Forth Valley	5	4.6
Saheliya	5	4.6
South Asian Ladies Exercise Class, Edinburgh	5	4.6
Wing Hong	5	4.6
Chinese Cancer Support Group	4	3.7
Chinese Church Edinburgh	4	3.7
Male Asian Group	4	3.7
Pakistan Society Advice & Information Service Ltd, Edinburgh	4	3.7
Sikh Sanjog	4	3.7
MECOPP	3	2.8
Chinese Community Development Program	2	1.9
Older Men's Health & Well-being project	2	1.9
Total	108	100

4.3.1 Activities

Of the 108 respondents, 88 (81.5%) said they did take part in arranged activities. These may have been arranged by the organisation through which they were contacted for this research or through another voluntary group or organisation. Table 9 shows the activities and the number of respondents who were involved in each activity.

Table 9. Participation in Group Activities

	Number of respondents taking part
Lunch Club	35
Sport/exercise group	34
Religious group (church or mosque)	36
Social/welfare group	13
Cultural activities (i.e. arts, music)	6
Ladies' group	10
Educational classes or group	11
Support or carers' group	13

Note multiple responses permitted (Base = 85)

The reasons given for not taking part in activities are set out in Table 10. The most frequently cited reasons were “need someone to take me” and “language barriers”. It is clear from the responses that transport and distance are also issues for some respondents.

Table 10. Reason for Not Taking Part in Activities

	Number of respondents taking part
Need someone to take me	12
Language barrier	12
Travel problems	8
Too far away/distance	8
Lack of knowledge	7
Don't have time	7
Not at a convenient time	7
Not for my culture	5
Lack of energy	2
Cost	2
Don't like to go out	2
Health condition	1

Note multiple responses permitted (Base = 32)

When asked what kinds of activities participants would like to see organised in the local areas, there was a rich and diverse response:

- Music
- Religious activities
- Educational classes
- Social events
- Exercise classes
- Day trips
- Films, TV, entertainment
- Games & hobbies
- Public gardens

Respondents were asked how often they attend the group activities referred to above. Where respondents took part in multiple activities, obviously this meant they gave more than one response but, taking the overall picture of how frequently they went to group activities, we found that:

	Respondents
■ Several times a week attendance	27
■ Weekly attendance	35
■ Fortnightly attendance	1
■ Monthly attendance	3

The remainder of the sample did not answer the question.

82 respondents (76%) indicated that they

exercised on their own. The types of exercises they did were as follows:

	Respondents
■ Walking	58
■ Swimming	15
■ Simple exercises	10
■ Yoga/palates	10
■ Jogging	8
■ Tai Chi	7
■ Dancing	1
■ Gym	1
■ Cycling	1
■ Badminton	1
■ Qi Quong	1
■ Gardening	1
■ Shopping	1

Forty four respondents (40.7%) said they exercise with family and friends.

Eighty one respondents (75%) said that there were cultural activities in the area where they live at present.

Many reasons were put forward to explain what motivated the individuals to take part in organised activities and exercise. The most cited reason was to 'keep fit and healthy'. This indicates that there is an awareness of the importance of maintaining a healthy lifestyle. The respondents also indicated that they liked to take part in group activities

where they could enjoy the social aspects of the activity. The other reason motivational reasons cited were:

- It's a hobby
- Fun
- Sense of belonging
- Lose weight
- Relaxation
- To cope with getting old
- Learn new skills
- To motivate others
- Passes the time
- Religious beliefs

4.3.2 Health

The majority of respondents described their state of health as satisfactory. 14 (13%) indicated that they were generally fit and healthy; 57 (52.8%) said their health was satisfactory; 28 (25.9%) that it was not good and 5 (4.6%) that it was poor.

The elders were asked what particular health problems they suffered from. Multiple responses were permitted and 79 respondents provided information in relation to this as follows:

	Respondents
■ High blood pressure	41
■ Arthritis	37
■ Diabetes	32
■ Heart disease	18
■ Asthma	8
■ Kidney problems/gout	5
■ High cholesterol	4
■ Cancer	2
■ Mental health problems	2
■ Stroke	1
■ Loss of hearing	1
■ Psoriasis	1

One hundred and one respondents (93.5%) said that they eat fruit daily. Not surprisingly this ranges from once or twice a day up to five a six times per day. 78 (72.2%) indicated that they eat vegetables for lunch and 90 (83.3%) that they eat vegetables for dinner. The vast majority (over 90%) indicated that they use either olive oil or vegetable oil for cooking – only one person mentioned 'ghee' (purified butter).

Twenty three respondents (21.3%) indicated that they were volunteering at the present time with local community organisations. The organisations they worked for were:

- Sikh Sanjog
- Chinese elderly support
- CSCA
- Polish Combatants Association
- Alzheimer Scotland
- Polish and Ukrainian support services
- Arthritic care
- ECESA
- Chinese Cancer Support
- MECCOP
- Ageing Well 50+
- Mosque
- Fair For All
- Age Concern
- Pakistan Advice Society
- Public Partnership Forum
- Chief Constable Advisory Group
- CHP Stirling
- CSRECL
- Church

4.4 Champions' Training Programme

SCEES worked in partnership with different community, charity, and mainstream services providers to deliver the Champions' Training Programme to people from the 50+ Chinese and South Asian (namely Pakistani, Indian and Bangladeshi groups) communities.

The training sessions were designed for Chinese and South Asian older people who were already leading an active lifestyle. The primary aim was capacity building and empowerment of the individuals and the group. The training was intended to help the champions appraise individual capacity, goals and social environment for the purpose of leading a life aimed at active healthy ageing.

The training programme included six training sessions and worked in partnership with the following organisations on the different themes:

- Engaging Community: Community Health Exchange
- Food and Nutrition: Community Dietician
- Physical Activity for Older People: Edinburgh Leisure Centre and Glasgow Sports Centre
- Mental Well-Being: Mental Health and Well-Being independent consultant & Glasgow Association for Mental Health
- Being Mature: Health Promotion Team Older People NHS Lothian & West of Scotland Seniors Forum
- Volunteering: CVS-RSVP

Language support was provided in all training sessions. Presentations and written information were translated into Chinese, Punjabi and Urdu. On-site interpreters were provided at each session. Four months after the events took place, an impact assessment questionnaire was undertaken with all of the participants to gauge how far the training has been effective in enabling them to lead more active lifestyles. The results from this questionnaire have incorporated into this section.

Regarding engagement to activities prior to the training sessions, participants mainly from the Chinese community were better engaged in a diverse range of activities. These included:

- Volunteers in Chinese lunch club
- Walking club
- Leading an elderly class
- Home visits team in the church
- Volunteer visitor to frail elderly
- Playing badminton regularly
- Going to the Buddhist Association
- Attending classes – physical exercise plus others
- Going to the parks and taking walks
- Attending Day Centres
- Going for day trips
- Helping people by taking them to doctors' and hospital appointments
- Socializing

The South Asian participants were more limited in the kinds of activities that they were involved in.

4.4.1 Engaging community

This session focused on what affects health in individuals and effects on the community at large. The groups discussed this concept and came up with some central themes they believed were important in this respect:

- Environment
- Pollution
- Growing old
- Language barrier
- Accessing information
- Relationships
- Finance
- Resources
- Mental well-being

Some interesting scenarios came to light when the groups were asked to act out situations where they felt they were being excluded from accessing services or in a wider social context.

- Scenario 1: Client being ignored by the GP as he focuses on the computer during a consultation
- Scenario 2: Excluded in a social gathering because the person is unable to communicate in English with other people

Participants highlighted some important issues they felt that they experienced/faced. Firstly, it was realised that there is a lack of interpreters (specifically Cantonese) in the community and that this has an impact on experiences in accessing/using services. Secondly, that there is not enough awareness of services and help available for older people, whilst there is considerable awareness of services available for children and young people.

The participants highlighted how the training sessions helped them to become inspired to get involved in community activities. In addition, the importance of increasing levels of mental preparation, in order to support community work, was recognised and conveyed well. There was also emphasis placed on upgrading/updating skills and knowledge from appropriate sources, i.e. training. In fact, many participants indicated

that increased training sessions would be welcome. It was felt that education was a crucial part of building self-confidence.

4.4.2 Food and Nutrition

This session was aimed at delivering information on what is meant by healthy foods, and to highlight the unhealthy aspects of traditional cultural cookery. The sessions also addressed how to maintain a healthy diet without losing traditional cooking methods. Participants from each group (Chinese and South Asian) were asked to allocate foods into different categories (fat, fruits, fibre etc) and worked out 'a breakfast, a lunch and a dinner for a person'.

Presentations on the five food groups of food and the importance of having a balanced diet were delivered. An interactive approach was used to help the Chinese group and the South Asian group to look into their diets and work incorporating the five groups of food in their breakfast, lunch and dinner. Cultural diversity does not necessarily mean lack of balanced diet but everyone agreed that it is important to have a balanced diet and the differences in the choice of food. There were lots of discussions on how to choose and include the five groups of food in their diets.

This session was welcomed by participants as being particularly useful for gaining knowledge about a balanced diet; improving their diets; raising awareness of the link between food and illnesses such as diabetes, heart disease etc; talking about the issues to others in their community; and how to adjust traditional cooking where required to make it more healthy.

4.4.3 Physical Activity for Older People

These sessions were held at sports facilities in both cities. The sessions introduced practical ways of exercising as well as group discussions.

The practical exercises introduced to the group were welcomed as a very positive aspect of the day. As well as allowing the

older people to see how they can use the facilities in their city, it also showed how they could easily exercise at home and in their own time.

Emerging from the discussion were some key barriers that the groups identified in accessing local services:

- Health problems that hinder them from doing exercise
- Lack of motivation
- Lack of companionship
- Lack of time
- Transport in getting to the leisure centres
- Financial implications: not able to afford fees

The participants in all the groups were keen to use exercise activities in their communities that were accessible and culturally sensitive. For example, many South Asian women want services that are women only. Many participants expressed an intention to go back to their community centres and see if exercise classes could be arranged. In order to break down some of the barriers that the groups identified, Edinburgh Leisure and SCEES worked together to set up an exercise group for the Chinese community. The Chinese exercise group chose a day and a set fee of £1 to use the gyms, with an instructor, and the swimming pool on a weekly basis. The first Chinese exercise group took place on the 5th November 2007 at the Royal Commonwealth Pool.

4.4.4 Mental Well-Being

The session held with the Chinese community in Edinburgh focused in Mental Health and Well-Being in Later Life based on the 'Promoting mental health and well-being in later life' report produced by Age Concern and the Mental Health Foundation. This session highlighted some of the specific issues raised by the Chinese community:

- Chinese people tend to be more reserved and laid back, therefore it would require a lot of encouragement to embrace an active lifestyle
- Chinese culture entails a close relationship

within the family; this is very important. However, the extended family make-up has eroded and the younger generation are more influenced by western culture. Therefore, there are differences in expectations between the older and younger generations

- The availability of transport, even getting to a bus stop because of mobility issues, could be a barrier hindering older people from engaging in the community
- Financial implications could be a constraint as well, as not everybody is able to pay the fees for activities
- In order to encourage people to attend events and activities, language support is essential for people who do not understand English

The participants highlighted some key issues that they felt were important in relation to mental well-being and health:

- Support from family/friends
- Access to information
- Individual responsibility in seeking out information
- Interrelated issues of living a positive and happy life
- Need to participate in more activities
- Regular physical activity

PRIAE's work on dementia (Care Needs of Older People with Alzheimer's CNEOPSA) and its European film show that some of the above issues are not restricted to one specific community: in the film for example, Asian carers speak about the importance of family support and the pressures faced in managing specific health condition. Equally on the importance of activity in old age, the cross section of elders from South Asian, African and Chinese backgrounds in PRIAE's BAFTA launched film, *Playing our part after 50* shows the necessity for language support to manage access and the importance of physical activity for both women and men:

'If you want to be happy in retirement, keep yourself active and busy, create work for yourself. If I have no work to do my brain becomes inactive and I can't let

that happen just because of my age'

Mr. SS Kohli MBE

Mel Milaap, Glasgow

4.4.5 Being Mature

This session focused on what is meant by 'being mature' and 'active ageing'. In particular the NHS policy and guidelines on Active Ageing were utilised. A presentation was also given by the West of Scotland Senior Forum to encourage Chinese and South Asian communities to engage in the forum. In general, there was a negative perception of growing old. Some of the issues raised in relation to becoming old were,

- Physical deterioration (symptoms of illness, chronic illness)
- Discrimination
- Unemployment leading to loneliness and poverty
- Having to use a walking stick
- Change of status: from professional to homemaker, from parents to grandparents
- Feeling worthless
- Getting state benefits: retirement pension, pension credit, bus pass etc
- Going into a nursing home

These negative feeling were counteracted by introducing the concept of being 'champions' which produced some interesting responses from the participants. It was recognised that as elders, with age, they are full of experience and thus able to act as 'teachers' on many things. This does not mean that increasing 'age' in itself produced 'full experience'. But many elders had diverse range of experiences and reflected on their meaning. In addition, they now have the time they did not have before to volunteer and give something to the community and to young people.

4.4.6 Volunteering

The volunteering sessions were lead by RSVP CVS and were productive. The sessions allowed the participants to hear about opportunities available to them, as

well as air their thoughts on active ageing. The participants were asked to share their experiences in active ageing and how they are going to make use of the information from the training to further develop an active ageing life in the community as ‘champions’.

Some useful developments emerged as a result of the session. Several participants felt they could form a Chinese knitting group in supporting the RSVP. The RSVP was left to liaise with the individuals to pursue the matter further. The participant came a few months later to another training session and shared her positive experience of joining a knitting group with others. The reassurance that it is possible to overcome the language barrier and commit as a volunteer in the wider Scottish society was warmly received and inspired the others in the group.

The participants were asked to formulate ideas about what they felt they had gained to help develop themselves into becoming ‘active champions’:

- Increased self confidence and self esteem
- health information
- Learnt how to get access to different resources
- Learnt to recognize myself
- Will invite others to participant in the forthcoming events and activities
- Good to have cultural exchange with the trainers
- Have learnt a lot on information and benefits for older people
- Have widened my horizons on the benefits of an active lifestyle
- Helped me to think of and prepare myself in the future
- Have raised awareness on volunteering and would like to find out more on the work with children in school
- In order to have good mental and physical health, it is beneficial to have a companion and something to ‘keep me going’

4.5 Evaluation – Impact Assessment

Six months after the Champions’ Training Programme, a second questionnaire was

drawn up, designed to explore the impact of the events on the attendees. The main purpose of questionnaire was as follows.

- To find out the extent to which the training sessions had enabled participants to become more ‘active’
- To explore what types of training could help in the future
- To explore potential gaps between current services and elders’ expectations

The questionnaires, combined with individual in-depth interviews as method, invited all the Champions back. Every interview was based on the same questionnaire and was recorded anonymously to make sure respondents could talk openly.

All the champions were contacted by phone in advance of meeting researchers. From Chinese respondents out of 20 champions, 18 responded, whilst none of the South Asian champions committed to interviews. Therefore, the assessment is only reflective of the Chinese community. The interviews lasted, on average, 1 to 1.5 hrs. The meeting places chosen were a café or community centre for the convenience of attendees, also to ensure they felt comfortable talking. Two participants were at the time employed by voluntary organisations and seven of them were doing regular volunteer work. All were from Edinburgh area. The 9 participants from Glasgow did not belong to an organisation but seven were doing some voluntary work occasionally.

Generally, all attendees felt they had benefited from the events, and believed they had made certain changes as a result. For the six workshops, participants expressed their likes and dislikes individually; in relation to the same workshop, participants from Edinburgh and Glasgow sometimes reacted very differently.

4.5.1 Engaging Community

Most people felt they got useful information from the session, including on community services and events. However, the take-up of the events and services was rather low

afterwards, mainly because of language barriers and time suitability. The language barrier was mentioned by all the participants. Current interpreting services are only free for mainstream services, and voluntary organisations rarely provide these services. Participants felt they could cope with simple activities, like physical exercises, or hiking but for events involving a lot of talking, few felt capable. Most people showed a preference for attending Chinese community events for that reason. None objected to socializing with other ethnic groups as long as interpreting services were available when complicated language was used. A minority of the participants who had experience of attending activities organized by mainstream groups said they had not experienced language constraints. On the contrary, their language skills had been improved. And mainstream, majority population groups they felt usually have better financial resources. Most such activities are free and the whole process was very enjoyable for them.

Few people felt their networks had been broadened since being involved in the events. Nearly all the participants felt it was difficult to encourage others to participate in community events. This is mainly because most of their family or friends work in the catering industry, which does not allow for much free activity time. One participant suggested that more minority ethnic men need to be encouraged to get involved in community activities. The lack of a male presence in community events discourages other men from minority ethnic backgrounds from participating. The participants who were employed by voluntary organisations emphasized that the essential elements for delivering successful services to minority ethnic elders are language support, easily accessible venues and transport.

Most of the participants were aware of and/or participated in community forums; such forums are known by most of them. However, most did not feel that forums are effective tools for bringing about change. It was believed that the forums are excellent for collating various opinions from the community, but are not able to influence

real change at the grassroots level. Only two people felt it was necessary for community forums to exist so that their voices could be heard.

4.5.2 Food and Nutrition

This session was felt to be very beneficial by most of the participants. The practical demonstration of food groups and their effects on health was felt to be a positive element which raised awareness. Some of the participants indicated that they have attended similar events before, specifically in Glasgow through groups such as the Chinese Healthy Living Centre, Meridian and the Chinese Women's groups.

In terms of the food introduced, most felt that whilst western-style food was good, it was not comparable to or suitable for Chinese people to adopt. This is one reason why few have changed their eating habits since the training session. Some felt they had already been eating healthily prior to the session. Nearly all the participants claimed themselves that they were eating regularly.

4.5.3 Physical Activities for Older People

Nearly all participants expressed their interest in repeating similar activities even although two of the participants had severe health issues and have to avoid strenuous exercise. Since the training session, an exercise group has been initiated in Edinburgh which is attended by around 10 people. The session is available at a £1 entry fee and is welcomed as a good resource. But participants from Glasgow did not manage to follow up with an activity, even though they were offered a free session card by the gym.

None of the participants have joined/ or are members of a gym due to the high membership fees. Rather, most of the participants use services provided by the CHLC as these were more affordable, although even discounted charges were felt difficult to manage.

Participants from Edinburgh expressed the

view that they do not have much choice over local facilities compared to participants from Glasgow. It was felt that the only facilities available were focused on older people and were often not inclusive of very 'active' activities and were less frequent.

All the participants expressed a positive outlook about exercising. Most prefer to attend activities within the Chinese community. However, given language support, it was felt that there would be no reason not to attend activities available in the mainstream. Activities in the gym and with directions from professionals were most welcomed.

The social aspect was very important for most participants. They stated that they felt more active when with friends, would usually keep exercising regularly and longer when surrounded by like-minded people. When faced with the prospect of exercising alone, most felt that they became lazy and would exercise less. In particular, many felt that they would not use mainstream activities unless they had support from their peers.

4.5.4 Mental Well-Being

Most felt they gained useful information from the session, though at the same it was felt that this was the least helpful session since this is an issue not many faced in their lives. None of the participants have ever used any statutory facilities before or after the training session. The main reason cited was the language barrier, together with low awareness of local services, as well as cultural differences. Participants mentioned cultural differences only in responding to this session. They generally felt it difficult to express their feelings to someone from a completely different cultural background. It was felt that this is not something that interpreters could help with, as it related to understanding cultural values and norms. Those participants who had better language skills expressed similar opinions. Only two participants said they would prefer to use statutory facilities provided by western people out of concern for a potential breach of confidentiality, due to the perception that

the Chinese community is small and so 'the word' would spread.

Participants generally held a positive attitude to mental health problems. They either thought they could deal with most problems by themselves or said they would go to talk with friends. Although friends might not be able to help, they would still feel much easier to have a person to talk with.

Most thought the available services for the Chinese community in the mental health field are very limited, and that the very limited resources are often provided by non-professionals. Some participants suggested that a one-off session on the topic of mental health would not bring about any changes.

4.5.5 Being Mature

Since the training session, most participants felt that their view on being mature was a lot more positive. Some admitted they found it hard at first, but adjusted themselves quickly. Most felt happiest when fully occupied by community activities.

Seven of the participants from Edinburgh are currently doing volunteer work for the Elderly Support Association from 1 to 3 days a week. Most of them have been volunteers for 1 to 4 years. One has worked for nearly 10 years. They all very committed to volunteer work, considering it as a real job and feeling satisfied by offering help to others.

In Glasgow, none of the participants engaged in regular voluntary work as did the participants in Edinburgh. However, they showed a strong desire to commit themselves to this, but mostly lacked the confidence to go forward and volunteer.

4.5.6 Volunteering and Action Plan

Most of the participants said they have a clearer knowledge of voluntary work and wider opportunities since the training session. A few mentioned that they felt disappointed at a lack of follow-up from organisations with whom they had put their names down for volunteering.

Participants generally felt they lacked confidence doing voluntary work in the community. This was because of poor language skills. However, they all expressed a desire to do community work wherever they could.

A knitting group was suggested in the Edinburgh session. Only one interviewee registered and started working. She has since finished two sweaters, and received a thank-you card shortly after the sweaters sent out. The organisation arranges regular meetings between volunteers and the people needing help. She felt very much rewarded. Those who did not take part in the knitting group said that they lacked time; some mentioned they needed to be taught to knit, whereas the organisation only provides materials.

4.5.7 Further Training

All the participants indicated their intention to seek out further training. Among all the topics, 'interpersonal skills training: communication' and 'using the internet' were the most popular. Many participants already possessed basic IT skills before, but feel that this is not enough and that they lack practice. The participants preferred more systematic, step by step training. In terms of communication skills, most participants considered it necessary for either work or their own daily life.

'Advocacy/link person training' was the most disputed topic. Those objecting claimed that the existing services within the community have been enough, the system is too complicated for them to understand, and this training requires English as a tool. But those in favour believed that through this training they could understand more about their local community. In doing so, they could help others as well as themselves to be more independent.

'Effective listening skills training' was widely accepted as an important skill as many act as 'counsellors' to their friends. They believed they could use this as a tool to help themselves as well as family and friends.

However, 'leadership training' and 'public speaking skills' were felt to be useful but not practical in their day-to-day lives, and therefore not as important.

Many of the participants had already had 'first aid training' but suggested that a refresher course would be useful. 'Anti-crime, abuse and violence' was a topic that many felt it was important to receive training and develop awareness on as they believed that racial discrimination is still a feature in today's society.

All participants highlighted their interest in knowing more about/getting involved in 'community events and activities' as well as 'organizing events, keep-fit events, and walking/exercising clubs'. The majority of participants were not interested in 'accessing funding' as they felt that it was something organisations should deal with.

Less than half of the participants already involved with voluntary organisations felt that the training benefited their organisation. Most participants felt that, because they were involved with basic tasks such as cleaning and helping people in care, very little of the training provided can be practically applied in their roles.

4.5.8 Summary

- There is a lack of easily accessible, culturally specific training for minority ethnic older learners. Minority ethnic elders want to learn and access services, but feel that their needs are not catered for.
- Mainstream service provision of tailored support and services to meet their needs is non-available
- There are language barriers in accessing information, guidance and training
- There is a lack of gender-sensitive provision; minority ethnic older men and women often would like separate learning opportunities and have a desire to explore avenues through which they can learn new skills

Minority ethnic elders:

- Want to have access to more information about services
- Seek training that is culturally and linguistically sensitive
- Seek to get involved in local organisations as volunteers and advocates as well as in a paid capacity
- Seek to find ways in which they can use skills they already possess
- Want to engage their local community and inspire others to do the same

The findings of the Impact Assessment were from Chinese respondents only and therefore cannot be regarded as fully representative of the views of all participants in the Programme. They do however give sufficient information for those responsible for planning active ageing programmes in local authorities and the NHS as well as sport related bodies to make necessary changes that could help Chinese elders in this case, and other BME communities as a result of widening access and opportunities.

5 Palliative Care

5.1 Introduction

The World Health Organisation (WHO) defined palliative care in 2002 as: ‘an approach that improves the quality of life of patients and their families facing the problems associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual.’

Palliative care is core to the delivery of care delivered by health and social care professionals to those suffering from long term incurable disease. Palliative care goes beyond providing support to patients in the last moments of their lives to enabling patients to maintain and improve their quality of life and to cope with the emotional aspect of their situation.

The Scottish Government has recognised in several policy statements the need to make appropriate palliative care available to those with long term progressive conditions:

- The Future Care of Older People in Scotland (2006) emphasizes the need for improved access to palliative care for all
- Delivering for Health (October 2005) and the associated Kerr Report (Building a Health Service Fit for the Future) set out a vision for a model of care under which people with long term conditions are cared for in the community where possible, without hospitalization, and with a shift from reactive episodic care to continuous support
- The National Framework for Service Change Action Team report – Care in Local Settings (May 2005) – recommended that Cancer Networks should collaborate with Community Health Partnerships (CHPs) to develop protocols for the delivery of palliative care in community settings
- The Coronary Heart Disease and Stroke Strategy for Scotland (2002) stated that palliative care should be available to everyone with end-stage heart failure.
- Cancer in Scotland: Action for change (2001) acknowledged the wider application of palliative care beyond cancer
- Our National Health, a Plan for Action, a Plan for Change (2000) recognised that palliative care should be available to all on the basis of need, not diagnosis.

5.2 Palliative Care Listening Events

There has been a low uptake of Palliative Care from the Black and Minority Ethnic Communities in Scotland. SCEES worked with the Palliative Managed Clinical Networks from Edinburgh, Glasgow and Forth Valley in delivering six Palliative Listening Events to the Chinese and South Asian Communities. These events were intended to raise the awareness and understanding of palliative care in those communities. Additionally, opportunities were created for the palliative care team to get to know the communities and work with them to better understand their specific needs. The Listening Events were a milestone development in palliative care for Black and Minority Ethnic Communities. A better and more appropriate palliative care service is therefore envisaged for Black and Minority Ethnic Communities in Scotland.

Registration forms for the Listening Events were sent out to the communities with the opportunity to indicate any needs for transport and language support. In all the events, language support was provided both through translated written information and the assistance of on-site interpreters. Lunch was provided according to cultural needs and where possible authentic ethnic meals were catered.

5.3 Questionnaire

A questionnaire on 'What do you think Palliative Care is?' was given to the group prior to the presentation to find out the understanding of palliative care from the community. The vast majority of attendees were not from a professional background (61). Most participants said they had already heard about palliative care mainly from health care professionals, family/friends and community organisations. But when prompted to describe what palliative care was, the vast majority said they 'have no idea'. However, many also said they understood palliative care to be 'care for the dying', 'care for cancer patients', 'Helping

patients and families cope with emotional upset and practical problems of the situation' amongst other related descriptions. After the session, an evaluation was carried out to learn about what the attendees understood palliative care to be. All responded by highlighting one or more of the following:

- Care for the dying
- Care for cancer patients
- Care for patients that are terminally ill
- Controlling pain and other distressing symptoms
- Improve the quality of life of patients and their families
- Supporting families and friends in their bereavement
- Care for patients that are suffering from an illness that cure is not possible
- There is a team of professionals to address the needs of patients and their families
- Helping patients and families cope with emotional upset and practical problems of the situation
- Helping people to deal with spiritual questions which may arise from their illness

These responses clearly indicate that the sessions were useful and insightful and that the participants left with a good grasp of what palliative care entailed.

5.4 Summary of Events

5.4.1 Edinburgh St Columba Hospice South Asian Event

The South Asian Palliative Listening Event took place at St Columba's Hospice on the 12th September 2007. Flyers and registration forms were sent to various South Asian community organisations: Minority Ethnic Health Inclusion Project, Minority Ethnic Carers of Older People Project, MILAN Senior Welfare Organisation, Sikh Sanjog, Khush Dil Project, Pakistan Society Advice & Information Service Ltd, Saheliya and other individual contacts. There were seventeen attendees; RDU translated written information and interpreters were provided at the event and received good feedback in the evaluation.

Some of the questions put by the participants to the presenters included:

- Is palliative care mainly for people with terminal illness?
- How willing are GPs to refer patients to the hospice?
- Patients that are not keen to go into a hospice - would they have the same quality of care at home?
- The reason that patients do not go to a hospice could be due to a concern about their cultural needs. Dying is a special moment to be near to God.

5.4.2 Edinburgh Marie Curie Hospice Chinese Listening Event

The Chinese Palliative Listening Event took place at Marie Curie Hospice on the 19th September 2007. Flyers and registration forms were sent to various Chinese community organisations: Minority Ethnic Health Inclusion Project, Minority Ethnic Carers of Older People Project, Edinburgh Chinese Elderly Support Association, South East Scotland Chinese Cancer Support Group, Saheliya and other individual contacts.

There were twenty-four attendees and Chinese translated written information and interpreters were provided at the event.

A Chinese Marie Curie volunteer was invited to give a brief account of her experience in the hospice. She shared her scary and frightened perception of the hospice before volunteering at Marie Curie and how she found it was very different from her preconception.

5.4.3 Forth Valley Strathcarron Hospice Chinese Listening Event

The Chinese Palliative Listening Event took place at Strathcarron Hospice on the 9th October 2007. A short presentation had been given in September 2007 at the Central Scotland Chinese Association; this is an organisation that runs a lunch club for the Chinese elderly in Forth Valley every Tuesday and was therefore able to invite the local Chinese community to attend the

listening event. A coach was organised to pick up the group at the Chinese Association at Bannockburn and take the group to Strathcarron Hospice at Denny. A PowerPoint presentation was translated into traditional Chinese and an on-site interpreter was provided at the event.

The discussions included views on dying from the group. There were different opinions from the group which included:

- It would be important to have family members around at the time of the death
- It would be important not to suffer
- All the needs from the patients should be addressed before or at the time of death
- For older generation, they might wish to die at home. However, it can be very difficult for the family to provide care for the patient in the end stage of life. Professional support and care would be more appropriate

The group also felt that it was very important to have home-made food for the patients because it could bring comfort to patients while staying in the hospice. Not being able to communicate with the health care professionals in the hospice was also a major concern for the group. The group was reassured that the hospice has facilities for families and friends to stay overnight. However, the group felt that it would be a good idea to have bilingual staff in the hospice because friends and families might not be available readily.

5.4.4 Glasgow Prince and Princess of Wales Hospice South Asian Listening Event

The South Asian Palliative Listening Event took place at Prince and Princess of Wales Hospice on the 15th November 2007. Invitations were sent to various South Asian community organisations, which included ASRA Day Centre, Minority Ethnic Group Dixon Community Centre, Mel Milaap, Shanti Bhavan, and Muslim Day Care Centre.

There were twenty attendees; an on-site Urdu/Punjabi interpreter provided language

support throughout the event and written material had been translated into Urdu and Punjabi as well.

The group found the presentation very informative and raised the following questions:

- Who to contact in accessing the hospice?
- Do I need a membership for accessing the service?
- Would male and female patients be placed in mixed unit?
- Have you got a praying room or a single room?
- Would you provide Halal food and would you allow family to bring in home cooking?
- Can you be flexible in the visiting hours?

5.4.5 Glasgow Marie Curie Chinese Listening Events

The Chinese Palliative Listening Event took place at Marie Curie Hospice on the 5th December 2007. Clients from Chinese Healthy Living Centre were invited to attend the event. There were eighteen attendees. Chinese translated written information and interpreters were provided at the event, which received good feedback from the participants.

A power point presentation on ‘What is Palliative Care?’ was delivered and the group was keen to find out if there were any bilingual staff in the hospice that could speak to the patients and the families directly.

5.5 Evaluation

The main aims of the evaluative forum discussions were as follows:

- For the hospice multi-disciplinary team to learn about the needs of the South Asian and Chinese communities and in particular the provision of a culturally sensitive services
- What are best methods of communication for the palliative team to improve the service provided to the South Asian and Chinese communities? Through information leaflets, information events, face to face

communication, a language helpline etc?

- To understand how the participants feel about palliative care

An open forum discussion took place at each event with a multi-disciplinary team on the panel. The participants engaged very well and enthusiastically with all the teams and both panel members and participants raised some key issues.

5.5.1 Culturally Sensitive Services

Provision of Food

“Families of South Asian patients usually bring in food from home. Is that due to concerns over the quality of the food already provided, how the food was cooked or is it a traditional practice?” (Panel Member)

Participants highlighted some key reasons for the preference for home-cooked food. It was felt that hospice food was not spicy enough and not in tune with South Asian tastes. This would lead to concern on the part of the family that their family member was not eating enough food, due to its blandness.

The Chinese participants emphasised that it is very important to provide authentic Chinese meals. One of the participants volunteered to demonstrate to the catering staff how to prepare and cook a Chinese meal with language support to communicate with the catering staff.

Death and Dying

“When a patient is dying, is there a cultural norm on who to come to visit the patients. Would there be any expectation from the patient?” (Panel Member)

The South Asian participants explained that the norm is for people from the whole community to visit and pay their respects. It is seen to be disrespectful not to visit someone when they are dying. In addition, at the time of death, a family member or a religious person would be preferred to be at the patient’s side. Normally the patient would make his/her wishes known prior to the time of death.

On the other hand, the Chinese participants felt that Chinese older people do not in general have any special requirements in relation to family and friends at the time of death, although it was noted that the older generation may have specific requirements such as wanting to face China or Hong Kong near the time of death. It was mentioned that rituals differ depending on families, but that in Scotland they are rarely practised.

“Is it part of the Chinese culture for lots and lots of people to come to visit the patient when it is close to the time of death?” (Panel Member)

The Chinese participants responded by saying that the number of visitors depends on whether the individuals have a large extended family and friends. If the patient is religious, then the congregation from the Chinese Church may want to visit. But some individuals may not want anyone to visit, so it is important not to make assumptions.

“In western society most support comes from family/friends, hospice and other organisations, what happens in the Chinese community?” (Panel Member)

The Chinese participants said that in the first month of the patient’s death, family will not go out to visit people and nobody will come to visit them as, culturally, it is seen as bad luck.

“How should we approach questions on delicate issues such as death and dying, do not resuscitate. Should it be discussed with patient only, family only or patient and family together?” (Panel Member)

The view expressed by the South Asian participants was that perhaps it would be appropriate to make use of community/voluntary organisations such as the Minority Ethnic Health Inclusion Project or Minority Ethnic Carers of Older People Project in tackling this question. The bilingual link workers would be well placed in relation to the families and the patients. In addition, a lot depends on whether the patient requires language support and whether the family

is happy to use an interpreter. Most family members (especially the younger members) understand English, therefore they can help with communication.

“Are there any rituals that the Chinese people would like to perform at the time of death or immediately after” (Panel)

The participants said that there were rituals in the past which were practised which have since declined. The question brought a discussion about having cats around patients at the time of death since at one of hospices, cats were often on the premises. There is an old myth in Chinese culture that cats should not be around at the time of death. It was believed that if a cat jumped over the body, the body would jump up and become a ‘zombie’.

“Back in our country in the villages in the past, we stayed with the body for several hours so that we can chase the cats away. But we have faith in the system in the hospice that the body will not be left out in the open space for hours; it will be taken to the morgue very quickly.” (Chinese Participant)

Chinese participants were asked whether it was taboo to talk about cancer and death. Some felt strongly that they were not able to talk about this as they found it frightening. It can also be disrespectful to talk about death. At the same time, it was said that talking about death was not taboo and that many people choose their coffins and plan their own funerals.

“In the community who cares and supports the patient and family when someone is dying? Would you seek help from outside the community, such as the hospice?” (Panel Member)

It was felt that family and friends are most likely to provide emotional support and that generally the concept of seeking help outside the community is still taboo. Statements such as, “why would you go for help when the family is here? Do you not consider us the family?” are commonly made in this situation,

“In the western society, it is completely acceptable for people to say my father needs counselling, but this is completely different in South Asian communities. People prefer to keep things within the family rather than discussing it with other people.” (South Asian Participant)

“Have people in the community ever had the need to use the support of a bereavement counsellor?” (Panel Member)

The participants felt very strongly that counsellors are very unlikely to be used as it is seen to be the family’s role to offer support – to the extent that if a family member sought out professional counselling, the family would feel as though they had ‘failed’.

An important consideration that may need to be made is in relation to offering family members’ choice and capacity to ask for support if required. While the motivation and cultural norms are to self manage, this does not mean that always, families can be self reliant and not require a range of support. Information and choice are the guiding principles.

5.5.2 Improving Care and Communication

Interpreters

South Asian participants believed that involving family members as interpreters would have a negative impact on the whole process. It is likely to be very hard for family members to hear bad news and communicate it fully to their loved one. In addition, they may not want to worry them, therefore not revealing the full truth. It was agreed that language support is vital but that it cannot be solely dependent on family members. An independent and confidential interpreter should be present, particularly for female patients, as this may be their only opportunity to make informed choices for themselves. The Chinese participants indicated that they felt there were no ‘gender issues’ as such to note.

It was also believed that it is good practice for health care professionals to bring in independent interpreters to provide language support rather than using family members in order to make sure patients understand the care provided and are able to make choices accordingly. However, if the patient insists on using family to provide language support, it would be up to the professionals to decide whether to enlist the help of an interpreter. In addition, both family and patient should be included in all discussions; however, patient’s confidentiality has to be observed. If the patient does not want the family to be included in all discussions, this should be respected.

The Chinese participants also felt that an impartial and qualified interpreter was the best option as family members may ‘filter’ information in order to ‘protect’ their loved one. It was also noted that when the interpreter needs to leave, the family and patient may be left with health care professionals without any support.

“I asked my son to help out in language support; he might not be able to say the medical terms in Cantonese, however, he is not in a rush and can stay with me throughout the consultation.” (Chinese participant)

Information Dissemination

South Asian participants suggested various ways that would be effective in disseminating information about palliative care to the community:

- Preferably to have someone to come to speak to the community and put on a presentation or bilingual events such as this one
- Approach various community organisations to work in partnership, for example, Minority Ethnic Health Inclusion Project, Minority Ethnic Carers of Older People Project, Pakistan Society Advice & Information Services Ltd
- Information leaflets could be sent to community organisations so that leaflets can be distributed along with the newsletter

- DVDs would be good, they are cheap to produce and can be in different languages. They can be shown to larger groups with little difficulty and the information is readily available. Messages can be brought to wider audiences including the older generations who are perhaps illiterate
- Useful to recognise gender differences. For example to have consultations with female members of the community to ensure that their viewpoint on palliative care/ death and dying are heard. Some female members may be quiet or passive within the community. It is especially important for their opinions to be heard and respected during the final stages of life, it is their right and dignity
- GPs can help actively in promoting palliative care as opposed to waiting for the patient to ask for a referral, as some people do not know of the existence of such care

The Chinese participants similarly contributed their views on what would be appropriate and acceptable methods to employ in spreading information on palliative care and hospices in the Chinese community. They felt that it would be better to use the term palliative care exclusively, not 'hospice' because the word hospice has a strong association with death and dying. There were different and sometimes conflicting views on how to raise awareness of palliative care in the Chinese community:

- Display Chinese information leaflets in Chinese community organisations or have information stalls at the Chinese supermarkets where most Chinese people will go
- Work in partnership with Chinese community organisations to run information events
- 'Death and Dying' is not openly discussed in the Chinese community and people would perceive it as bad luck to talk about this. So it might be better not to have information available at Chinese supermarkets

5.5.3 Palliative Care and Minority ethnic elders

The participants in the sessions asked important questions that highlighted some of the concerns that they had about palliative care.

Volunteering

"There are many professionals within the hospice to help to provide support. Are there any South Asian Volunteers to provide some emotional support?" (South Asian Participant)

It was found that the hospices do not have any South Asian volunteers, primarily due to a very low number of South Asian patients. The majority of volunteers have existing links with patients.

Non-Traditional Medicine

"How does the community feel about using Traditional Chinese Medicine alongside Western Medicine?" (Panel Member)

The participants felt that it was more important to understand the view of professionals working in the field. The main cause of concern for professionals is lack of knowledge of the effects of traditional Chinese medicine on western medicine.

One of the participants posed a hypothetical situation in which a Chinese patient was in the terminal stage of his illness and requested the use of Chinese medicine. The panel members responded by saying that procuring and administering Chinese medicine would be the major drawback in such a situation. However, if the individual provided the medicine they would respect the individual's choice as part of the person-centred approach to delivering palliative care.

Spirituality

Participants suggest that the hospice facilities for prayer, i.e. the chapel, can be inclusive of all faith groups by displaying a symbol representing all faiths as well as providing a large enough space to accommodate different needs.

The Chinese participants indicated that families and friends would be happy to attend a non-religious memorial service after the death of a loved one. However, it would be necessary to have any written material available in Chinese.

5.6 Summary

- There is a general lack of awareness of palliative care and services available for use. However, minority ethnic elders expressed a keen interest in increasing their awareness and knowledge about what is available
- There is a low uptake of palliative care services as a result of lack of awareness and of accessible information
- Minority ethnic elders prefer to talk about delicate issues such as death, dying, resuscitation etc, through the medium with which they are most comfortable and able to express themselves in their own languages, i.e., community organisations.
- Language is one of the biggest barriers to accessing information and engaging with palliative care services
- Minority ethnic elders felt that using an independent interpreter was to be preferred to using family members as interpreters. It was felt that this is not the best way of communicating as sensitive and difficult information may not be relayed accurately or in full to 'protect' loved ones
- Most minority ethnic elders are unlikely to use bereavement counsellors as the family/community is usually leaned on for support. For some, using counsellors is seen to be disrespectful to family, and taboo at the same time
- Religion and spirituality is an important aspect of the last stage of a person's life, especially for the South Asian participants, and would be a large consideration in making preparations for death
- The preparation of food in a culturally and religious sensitive manner is important. Participants from both South Asian and Chinese communities emphasised that home-made food is preferred as it is 'authentic' and 'spicy' and what they are used to - food prepared by the hospice kitchens is not authentic enough
- There are few volunteers from minority ethnic backgrounds in palliative care, which affects the perceived adequacy of such services for minority ethnic elders.
- The specific point was made that women from a minority ethnic background needed to be specifically included to ensure that any cultural bias does not affect the service available for women
- It was felt that the best outlets for disseminating information were community organisations; producing information leaflets and DVDs in various languages; GP surgeries. The Chinese participants emphasised that openly discussing death and dying is seen as bad luck, hence displaying information in open spaces is not a good idea

6 Managing Long Term Conditions Health Notebook

6.1 Introduction

NHS Scotland defines a long term condition as “a condition that requires ongoing medical care, limits what one can do and is likely to last longer than one year” (NHS Scotland, 2005).

Long term conditions, which are also referred to as chronic diseases, severely limit the activity of the individual suffering from the illness. S/he requires constant and ongoing care/treatment for a condition such as diabetes, for example. 60% of deaths worldwide are attributed to a long term condition, and thus managing long term conditions is seen as the greatest challenge to and strain on health care systems (*Preventing chronic diseases: a vital investment*, World Health Organisation, 2005). In the UK, around 80% of all GP consultations are with those who are suffering from a long term condition, who are likely to stay in hospital much longer and who make up over 60% of bed stays. It is estimated that around one million people in Scotland have one long term condition (*A health and well-being profile of Scotland*, NHS Scotland, 2004). It has been noted that the prevalence of long term conditions increases with age, and with the projected rise of the population aged 75 over, this places a strain and urgency on ensuring that measures are in place to cope with the rise.

Key points regarding policy on long term conditions are:

- Better Health, Better Care was launched in 2007 as the Scottish Government’s strategy for a healthier Scotland. The Action Plans central tenets are patient participation, improved healthcare access, improving Scotland’s health and tackling

health inequalities

- Delivering for Health is a programme of action for NHS Scotland (based on the ‘Kerr Report’: A national framework for service change in the NHS in Scotland: Building a health service fit for the future, Scottish Executive Health Department, May 2005) which emphasizes providing care as locally as possible. The focus is on improving health, reducing health inequalities, reducing hospital admissions and providing sufficient support for people suffering from long term conditions.
- “Our National Health, a plan for action, a plan for change” highlighted that the health of older people will be a priority for NHS Scotland.

6.2 Background to the Notebook

The rates of certain types of long term conditions are more prominent in minority ethnic elders, for example diabetes and heart problems in South Asian communities (NHS/British Heart Foundation (2004), *Heart Disease and South Asians: Delivering the National Service Framework for Coronary Heart Disease*). In addition to the high rates, there is also a trend of early onset of long term conditions in BME communities.

Due to language barriers, lack of information and awareness and specific cultural needs minority ethnic elders experience difficulties in managing long term conditions by themselves. Very often family members will become involved in looking after the elderly as carers in the BME communities. However, the carers have little information on how to manage the conditions or on what preventive measures are appropriate.

It was intended that the health notebook

would be a self-help tool for minority ethnic elders and their families and carers to assess the conditions that they have experienced at home and receive early intervention. In addition, the aim was to enable older people to manage these situations by themselves or feel confident about contacting a health care professional for help and support. It was intended that the notebook would also assist health care professionals, through its clear and structured format, in getting to know minority ethnic elderly patients in terms of their experience at home and what measures they have taken. It was felt that the notebook would help to prevent non-scheduled admissions by promoting early intervention, and, if there was an emergency admission, the health notebook could also be used as an important tool for clinicians to understand what the older person had experienced prior to admission.

In designing the notebook it was hoped that certain outcomes would be achieved. Firstly, that minority ethnic elders would have better control over managing long term conditions by themselves. Secondly, that the health care professionals would find the notebook useful for providing better health care services to minority ethnic elders; and that it would help to break down some barriers in communication by providing information on what the elderly have experienced.

In setting up this project, SCEES worked with health boards in Glasgow, Lothian, Forth Valley, Ayrshire and Arran to identify minority ethnic elders suffering from long term conditions and not managing well at home. A letter with guidelines and agreement was given to older people through health care professionals.

The pilot began in September 2007 and ended in April 2008. This included an evaluation of the notebook by the minority ethnic elders using it. No personal data was collected and all evaluations were anonymous.

A total of 62 people (30 South Asian; 32 Chinese) participated in the pilot. At the evaluation stage, 27 out of the 32 Chinese

people and 26 out of the 30 South Asian participants agreed to participate in the evaluation of the notebook by means of a short questionnaire (see Appendix 2).

6.3 Evaluation

There was a clear difference between South Asian and Chinese participants over how effective and useful the notebook was in their daily lives.

Participants were asked how easy they found the notebook to use. 45 respondents (76%) indicated that the notebook was easy to use. However, there was a difference between ethnic groups: all the South Asians thought the notebook easy to use but only 50% of the Chinese thought it easy to use. 35 (66%) indicated that they thought the notebook was easy to fill out. A similar difference by ethnic group applies here, with all the South Asians finding the notebook easy to fill out but only one-third of the Chinese finding it easy to do so.

The comments by the Chinese respondents show that those who did not find the notebook easy to use could not read or write in either English or Chinese. Although the notebook contained Chinese characters, they could not understand the questions and were given help in filling in the questionnaire. Those who could read/write in their own language had no problems in completing the notebook.

Respondents were asked if they would continue to use the notebook in the future. 9 (33%) of the Chinese respondents said they could continue to use it and 24 (92%) of the South Asian respondents said they could continue to use it.

The respondents who felt the notebook was useful and easy to use felt it would facilitate better communication with their doctor, and would be a good tool in the case of an emergency.

The comments from some of the Chinese respondents indicate that, because of literacy and language problems, they had failed to

understand the purpose of the notebook and felt that when they went to see the doctor they could rely on family and friends acting as interpreters.

Summary

- Although the notebook was extensive, a large number of minority ethnic elders completed the information required. This suggests that elders' are motivated to establish their own self awareness and represents an important consideration in developing appropriate interventions
- There is also the issue that 'too much information' is recorded and what to do with that. The project length did not allow for further assessment and this is

something that should be considered further

- There was a clear difference in experiences between the Chinese and South Asian participants
- South Asian participants found the notebook easier to use as they had ongoing support from the community organisation. The Chinese respondents especially those with literacy problems had a less favourable view of the notebook and many failed to understand its purpose
- That self awareness of health conditions is important to elders but their capacity to engage with tools is determined by the levels of literacy and knowledge of how effectively the information can be used

7 Conclusions

7.1 Active Ageing

The study shows that the aims and objectives of the service providers are consistent with Scottish Government policy and that the organisations are seeking to address many of the issues covered in that policy. These include helping people to enjoy more years of healthy living; enabling them to manage long term health conditions; helping older people to participate in learning activities for both vocational and personal development; enabling older people to volunteer in the way that best suits their capacities; recognising their contribution; making authoritative, up-to-date sources of advice and information accessible to older people; ensuring access to people-centred, good quality services that are appropriate to their needs. The BME voluntary organisations which took part in the Active Ageing Programme were proactive in all these areas and clearly were important providers of advice and information to facilitate access to mainstream services.

The study revealed that the skill base needed to set up a BME voluntary organisation providing services/activities is quite complex, often requiring great dedication and determination of both groups and individuals. The skills required include obtaining funding, finding premises, engaging and employing staff, planning, financial management and budgeting, recruiting volunteers, promoting awareness of the need for the organisation, hence marketing skills, dealing with political issues surrounding its work, and sometimes opposition to it.

There were two key areas where the services provided by the organisations produce benefits for their members and users. These are health and socio-cultural benefits. With regard to health, the organisations promote healthy lifestyles; educate their members on health issues and how to access services; improve quality of life; engage their members in physical activities; help elders cope with

long term conditions such as diabetes, heart disease and arthritis; help address some mental health issues such as depression and stress; and provide some useful health-related services such as regular health checks and chiropody. On the socio-cultural side, the organisations provide community cohesion, offer care and support for elders and their families, help elders maintain their independence; reduce isolation, help elders understand and act on their rights; bring people together regularly for social interaction and education; and promote/celebrate the culture of service users.

It was apparent from the research that funding was a crucial issue. For many of the organisations, survival depends on securing funding, preferably on a more stable, longer term basis. Many of the organisations have ideas on how to expand their services to meet the needs of their service users and provide additional activities. Funding was the main issue preventing expansion of services (this was mentioned by nine organisations).

From the elders' survey, it was apparent that there was a high level of participation in groups and group activities, both in the frequency and the range of activities. This suggests that there is a high level of demand for the type of services offered by BME voluntary organisations and, as indicated, there are many benefits for the participants in this kind of engagement with services.

For those who do not take part, the main reasons were that travel and distance were a problem. The language barrier was also frequently mentioned, which suggests that elders were not aware of culturally tailored services in their area. Another frequent comment was the need to be taken to such activities. This may derive either from the difficulty of actually travelling alone, to and from the centre, or from a wish not to engage on their own without someone to introduce

them to the service. Overall, one extremely positive outcome is the high level of interest among elders in keeping fit and maintaining a healthy lifestyle.

It is worth bearing in mind that this level of interest in a healthy lifestyle is found in a group with a high rate of long term illnesses. Common problems amongst the sample included high blood pressure, arthritis, diabetes and heart disease. The desire for a healthy lifestyle was also confirmed by the commitment to eating foods such as fruit and vegetables daily and using oil for cooking rather than saturated fat products.

The primary aim of the Champions' Training Programme was capacity building to empower them both as individuals and as a group so that they are able to play an active part in BME voluntary organisations, promoting healthy living and active ageing in their communities. Many of the elders were already involved in a wide range of activities. The training sessions conveyed much valuable information to participants but discussions also highlighted many issues of interest or of concern. Briefly, some of the issues raised were:

- Lack of interpreters in the community, especially Cantonese
- Lack of awareness of services for older people, in comparison to working-age adults and children
- An interest in upgrading/up-dating skills and knowledge
- Barriers to accessing fitness services include: health, motivation, lack of companionship, time, transport, cost
- Desire for fitness activities in their community that were culturally sensitive – e.g. for women only

The participants had positive views about the training sessions, including increased confidence and self-esteem and raised interest in volunteering.

For example, the evaluation of the Chinese participants revealed that all the respondents thought they had benefited from the training programme. Some of the issues to come out

of the evaluation were:

- **Engaging in the Community:** Sessions provided useful information about events and services. Take-up subsequently was hindered by the language barrier; most preferred events specifically for their community and would only attend activities with other BME groups if interpreting services were available. However, some had attended activities within the broader community, which had helped improve their language skills and which had better resources, with most activities were free
- **Food and Nutrition:** The session was beneficial and the practical demonstrations very helpful. There was a strong preference for food from participants' own cultures rather than "western" type food
- **Physical Activities for Older People:** Since the training session, an exercise group had been set up in Edinburgh which was welcomed by participants, who expressed a positive attitude towards exercise
- **Mental Well-being:** None of the attendees had had occasion to use mental health services although they felt better informed on them after the session. There was still a taboo about discussing mental health issues; one respondent felt it would be preferable to use mainstream services rather than any specific to their own community because of the potential for gossip in a small community
- **Being Mature:** Most participants felt their views on being mature had not become more positive. Seven were doing volunteer work in the Elderly Support Association in Edinburgh (but more of them had been volunteers previously)
- **Volunteering and Action Plan:** Participants generally felt that they had more knowledge of volunteering work and wider opportunities after the training session, but some felt they lacked confidence due to their level of language skills

7.2 Palliative Care

Six Palliative Listening events were held for the Chinese and South Asian communities from Edinburgh, Glasgow and the Forth Valley. The events were intended to raise awareness and understanding of palliative care in the community and proved a milestone development in raising awareness among members of the BME community. In addition, the Palliative Care Team was able to discover some of the concerns of attendees.

The events demonstrated that there are many doubts among BME communities about using palliative care services and especially hospices. These revolve round the cultural and religious aspects of death and dying, and also, closely related, social aspects such as the role of the family and friends in caring for the individual concerned. There are also gender issues about mixed/separate facilities.

Panel members were able to ask specific questions concerning cultural and religious practices apposite to the end stages of life; the involvement of family/friends and others; and methods of disseminating information about palliative care. The South Asians thought that language support was vital and

that services should not rely solely on family members or friends to convey distressing medical information. This is emotionally difficult for other family members who may well not want to convey such truths to the terminally ill patient; or may not understand or be able to translate the correct medical terms and diagnosis.

7.3 Long Term Conditions Health Notebook

The Managing Long Term Conditions Health Notebook was well received by the South Asian participants but less so by the Chinese. The main reason is that many of the Chinese participants in the pilot could not read or write in either English or their own language although there is some possibility that the way the project was administered may have influenced this. It is believed that the South Asians were given more support from the Dixon Community Centre in maintaining the notebook. It appears to be important that, in a pilot of this nature, participants need, in advance, a clearer understanding of its nature and purpose and that the language issue needs to be addressed.

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Appendix 1

Professional Questionnaire

A. ACTIVITIES/SERVICES – ORIGINS and USAGE

1. Please state the aims of your organisation/project?
2. Please describe your user group/s: (options given)
3. Do you organise any specific activities/services for your users, e.g. with reference to the cultural needs, health needs and physical needs? Yes No
4. If Yes, please list the activities/services and details, e.g. nature, times and frequency
5. When did the activity(s)/service(s) begin?
6. How did the activity/service begin?
7. Who took the lead in developing the activity/service? Did that person have particular qualities or qualifications e.g. language skill, previous experience, knowledge in working with BME communities.
- 8a. What facilities do you have, such as fully accessible venue, IT equipments, language support?
- 8b. Can you rate the facilities suitability? (options) If more than one please list all the activities/services and rate accordingly
9. How many people attend the activity/service?
- 10a. Is the activity/service aimed at a specific ethnic group? (If yes, please specify)
- 10b. Do you think the cultural aspect of the activity/service attracts more people?
- 10c. What made you decide on this type of activity/service in particular?
- 11a. What age range is the activity/service aimed at? (options given)
- 11b. What age range does it mainly attract?

B. ACTIVITIES/SERVICE – FUNDING

- 13a. What kind of funding did your project receive/Who funds the project?

- 13b. How long is the funding for?
- 14a. How is the activity/service managed?
E.g. In-house staff or contracted external specialists
- 14b. Are there any advantages/disadvantages in the way that the activity/service being managed?
14. If the activity/service isn't funded how do you cover the costs?
15. Do you charge participants?
16. Do you receive any support from other agencies, e.g. funding, resources?
17. Do you have any volunteers? How many?
18. What costs were involved in setting up the project, financial and time costs?
19. What problems, if any, did you face any problems in setting up the activity/service to date?
20. Do you foresee any problems in the future?

ACTIVITIES/SERVICE – IMPACT

21. Is the activity aimed at improving/reducing any specific health conditions; long term conditions, break down, isolation, mental well being, health in later life etc.
22. Please list any higher incidence of any particular health conditions within the communities that your project aimed at?
23. What do you see as the main benefits of the project, e.g. health benefits, social benefits, improve quality of life, respite for carers etc.
24. Are you considering expanding your range of activities/service? If yes, please provide details?
25. How would you expand the range of activities/services?
26. What will prevent you from expanding?
27. Do you think showcasing such work will help increase the uptake of BME users?
28. How will increasing in BME users be beneficial to your project? (e.g. increase funding opportunities, mainstreaming the service)

Appendix 2

Managing Long Term Conditions Health Notebook Evaluation Form

1. How long have you been using the notebook?
2. Did you find the notebook easy to use?
Yes No
2a. Why not?
3. Did you find the content of the notebook easy to fill out? Yes No
3a. How can the notebook be improved?
Can you suggest ways in which to make it better?
4. Did you have help in filling out the notebook? Yes No
4a. Please specify: (options given)
5. Would you continue to use the notebook after this trial has finished? Yes No
5a. Why not?
6. Any Other Comments?

9 Black and Minority Ethnic Elderly: Perspectives on Long-Term Care

Extract from published report by the Royal Commission on Long Term Care for the Elderly, *WITH RESPECT TO OLD AGE – RESEARCH VOLUME 1*, HMSO 1999 which involved elders, carers and managers of community organisations in Scotland, September 1998. Full report downloadable at www.priae.org

‘Having crossed so many continents to settle in Glasgow, we still have time and energy left to develop the recommendations of your report.’

(A 91-year-old elder at the PRIAE-CRE Seminar)

Executive summary

(p.g 257-261//333)

1. Summary

The seminar findings reflect the patterns generated in research studies of the past 15 years. Progress in day care, housing and effective assessments for some in the post-community care era cannot be denied. For those unfamiliar with the subject, the expressions of elders and carers at the seminars may seem no different to those of white elders who also express dissatisfaction with social care, health service and housing. So where is the distinctiveness? The answer lies in the source of supply of care, the level of developments in care and a constant existence on the margins.

We analysed empirical studies in the 1980s and reached several conclusions, one of which concerned the centrality of minority ethnic organisations in the supply of care. We said then that assessing the evidence, such organisations were acting as ‘primary

providers’ (substituting mainstream services) rather than acting as ‘complimentary providers’ to mainstream health, social and housing services (Patel 1990).

In the late 1990s, the Government’s own inspection survey (Murray and Brown 1998), point to the inadequacies of mainstream providers and the compensatory effect of minority ethnic organisations who continue to act as ‘primary providers’ in the post-community care era. Given this *continuity* of mainstream neglect and/or indifference, we can state that this constitutes *de facto* racism. In other words, the mainstream services *by default* are structuring the segmentation of care to minority ethnic elders into a long-term solution. Our concern here is not that the location of services are in BEM elder care centres. Rather that such location tends to be inadequately supported, maintained nor expanded.¹ This makes the development of comprehensive services and an ability to reach all sections of BEM elders (disabled, frail for example) problematic. Moreover, as Table 1 indicates, the current number of minority ethnic older people (i.e. 65+ years) stands at 3.7% or 4.2% of the ethnic minority population (depending on under-remuneration) with the increase to come in the approaching old age category (13.6% in the 45-64 years of age). The current lack of a foundation or low level of service developments will be dramatically felt in the next decade or two for the latter group as there will be a larger share of minority ethnic elderly population (1.3% currently of the 65+ compared to 4% of 45-64 years).

It is in this context that people at the seminar were vexed by the question of funding for care and alternative models of

care: as they said they have already had to manage in the absence of both appropriate and effective mainstream provision. We also need to emphasise the recurrent point in all the seminars concerning the heterogeneity of BEM2 elder population. Like the elders from majority group, not all BEM elders require the range of services recommended nor face the issues of disadvantage, discrimination and experience effects of ageing to the same degree. The recommendations are fully provided in the text in Section 3. For the purpose of the Executive summary, we have identified under each question a key recommendation which gives a 'theme' to those explained in detail in Section 3. The delegates had emphasised the importance of the implementation of these recommendations by the Government via the Commission's Report since they felt: *'we have had too much discussion, action is overdue.'*

2. Recommendations

2.1 The appropriateness of current models of care

(a) Where mainstream services have effectively engaged with 'different needs', (re: changes in communication, design, planning, assessment, staffing and delivery where the definition of 'culturally appropriate' is broader than mere technical aspects), BEM elders, carers and professionals express satisfaction with choice and standard of care.

(b) Where the local market of care is already characterised by BEM elder Centres, the direction, shape and take up of services is already mapped out. In the 1990s we have several examples of 'what works' in housing, health and social care concerning BEM elder care. There are also several areas that remain unexplored. The capacity and method of services provided by such centres need to be examined as part of investment strategies.

Recommendation 1a

BEM elder care centres should therefore be strengthened, expanded to meet growing demands and regarded as primary providers of care rather than as an alternative to

the mainstream. Commissioning and Funding bodies need to seriously examine their knowledge base and act in a non-stereotypical way in support of this.

Recommendation 1b

Mainstream health, housing and social care organisations need to urgently examine (and consequently act upon) on why they continuously appear to have difficulties in effectively responding to BEM elders and their carers' ordinary not special, needs. If they continue with the present approach of 'ad hoc, patchy and piecemeal developments', they will by default, have structured BEM elder centres into segmented long-term care solution on marginal resources, endorsing de facto racism in a modern society as we approach the 21st century. BEM elders' settlement in concentrated areas present planners with less difficulty in implementing the proposals.

Recommendation 1c

The relevant Government departments need to urgently take a proactive approach to stimulate the necessary action to prevent the structuring of the above scenario which can have serious social and race relations policy implications.

2.2 Accessing Services

The delegates spoke cogently about why in the 1990s it was so difficult to establish what was available, where and how to access basic information on services. Research studies which we have cited all point to lack of knowledge and information on social care, primary and secondary health services ('going beyond visits to the GP and the hospital') among BEM elders and carers.

Recommendation 2a

The 'hush-hush' system to information on services needs to now be vocalised with a planned strategy in marketing of services. Here good quality translated leaflets are only one part of the communication programme.

Recommendation 2b

Barriers relating to information, choice, culturally responsive care and underlying

discriminatory processes which affect assessments need to be eliminated. The elders of tomorrow will demand an equal but perhaps different service and the authorities need to be prepared for this as well as be flexible in their approach to care.

2.3 Planning and Paying for Long-Term Care

The question of affordability, ability and willingness to pay for care received a mix of reactions. There was a feeling that equitable treatment is easily dispensed with when it comes to payment but not so when receipt of effective care is called upon. Most delegates emphasised the context of employment, discrimination and disadvantage in the working period as well as sustained effects of long-term unemployment. The continuation of this cycle for the elders of tomorrow was also expressed. The particular effect on specific minority ethnic older women and carers who have remained outside of the formal employment needs to be recognised. The research we have cited in Section 1 provides empirical evidence for such views.

Recommendation 3a

The following principle expressed by an 86-year-old elder was supported in all three seminars. That,
‘those who have means must pay those who have no means must be provided for without hesitation nor humiliation.’
(Person Z)

It should be noted that the former sentence is relative: in the discussion it referred to those who ‘were very well off!’ The emphasis was on generating economic independence and not structuring dependency on various sources, should care be required.

Recommendation 3b

Carers’ informal role should be recognised in monetary terms for the care they provide and the savings they generate for the state. Their improved income base may not only help them and the family but may contribute to greater economic independence in their own old age.

2.4 Reducing Dependency: what alternative models of care are being considered currently for the future?

The discussions and proposals can be grouped as those relating to:

- (i) personal ageing and well being;
- (ii) specific developments to promote healthy and independent ageing; and
- (iii) transfer learning and changing of roles.

Recommendation 4a

Support and strengthen the BEM elder Centre base, particularly day care. Elders can remain at home and yet activate social contact at the day centres. Initiate, fund and direct work aiming at healthy independent ageing, with positive mind and body in BEM elder Centres.

Recommendation 4b

New roles (e.g. volunteering, short-term employment) of elders should be encouraged to break social distance between the young and old, thereby creating a better view on the ‘value’ of older people in society.

Recommendation 4c

The new Parliamentary bodies in Wales, Scotland and Northern Ireland have an excellent opportunity to build in at the outset the arrangements which will support effective care and independent ageing for BEM elders and carers in collaboration with BEM elder bodies in each area.

2.5 Future Model of Care

Recommendation 5

Mainstream authorities and funding bodies need to be guided to enact the elders’ consistent recommendation in all three seminars – that the future model of care should attempt to cater for all minority ethnic groups ‘under one roof’, but still catering to specific person-centred requirements. This would enable the individual to receive culturally sensitive care and enable greater understanding between communities and foster good community and race relations.

We at PRIAE have termed this as the ‘Pomegranate’³ model exemplifying the principle of ‘unity in diversity’.

Seminar at Edinburgh City Chambers, 11th September 1998 in association with VOCAL

Organisation	Managers' Group	Elders' Group	Carers' Group
Aberdeen Chinese Elders Assoc.	Gregory Poon		
Age Concern Scotland	Helena Scott		
Bharatiya Ashram	Mr Jyoti Hazra	Mrs Helen Hazra	
Chinese Elderly Initiative	Mrs Li Fang Lamb	Mr Wong	Mrs Lou
	Mr Noor Mohammed		
Dixon Carers Centre	Julie Young	Jasbir Kaur	
Dostana Association	Iftikhar Chaudhary	Mr Barkat Ali	Mr Sultan M Anwer
Edinburgh Chinese Elderly Support Assoc.	Ben Yuen	Mr I S Tang	
Glasgow Multicultural Health		Sheem Gill	
Mel Milap Centre		Mr S S Kohli	
			Mr O P Bakshi
Minority Ethnic Carers of	Sharmila Sockhoe		Ms Arifa Aziz
Older People Project	Eliza Leung		Mrs Sharif
			Ms Rose Tibi
Shanti Bhavan	Kavita Agarwal	Mr J R Chadha	Mrs Leela Sethi

Speakers, Staff and Interpreters

Sir Stewart Sutherland, Chairman, Royal Commission on Long Term Care for the Elderly

Alan Davey, Secretary, Royal Commission on Long Term Care for the Elderly

Marion Morton, Councillor, Chair of Race Equality Forum, Edinburgh City Council

Naina Patel, Mick Convoy, Suzanne Munday, Jeanice Callendar, Kiran Duggal and Maqsood Ahmad

Also invited

Leith Sikh Community Group; Multicultural Elderly Day Care Centre; Pius Nyiam Africa Centre, Scotland; Milan Senior Welfare Council; San Jai Chinese Project; Mental Health Framework Project; and Wing Hong.

PRIAE-CRE warmly acknowledge the help and support of Suzanne Munday, (VOCAL), Edinburgh Unit for facilitating the arrangements and Edinburgh City Council, Leeds City Council and staff at the CRE, London for hosting the Royal Commission Seminars.

Note: We recognise that, in the process of seminar attendance and delegate changes, some names of delegates may have been omitted and/or misspelt.

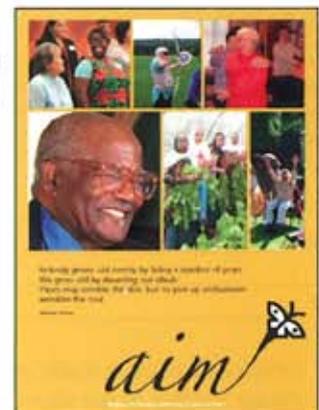
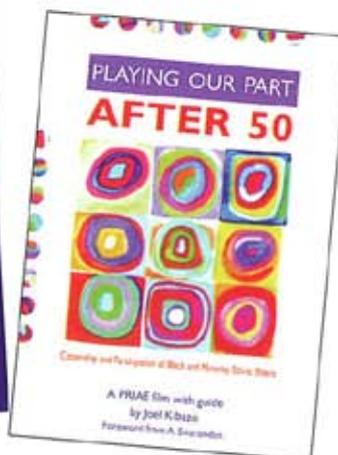
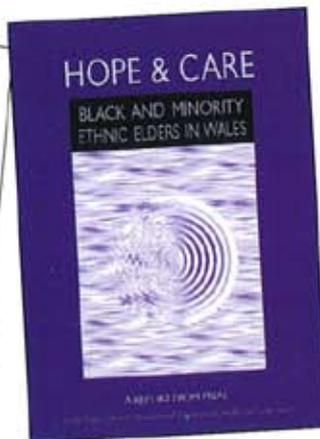
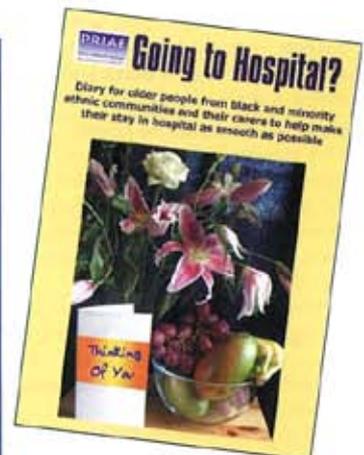
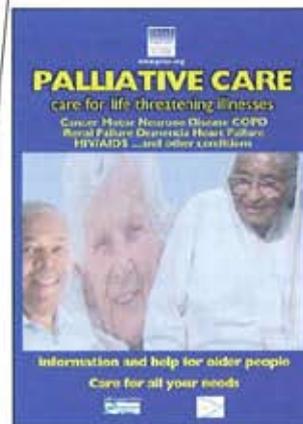
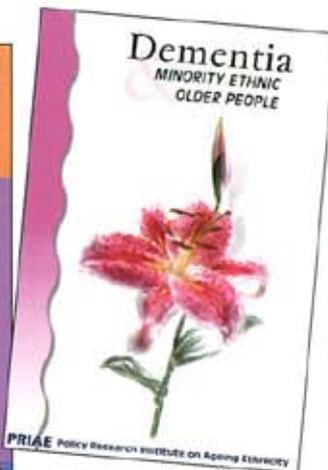
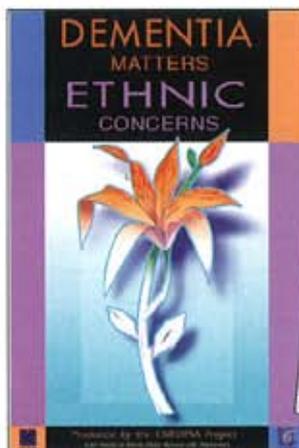
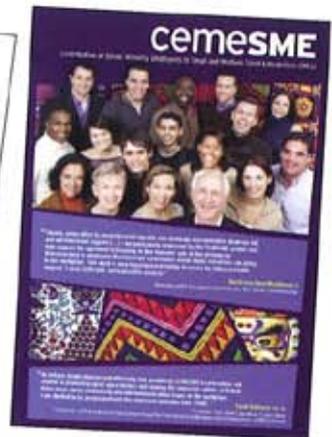
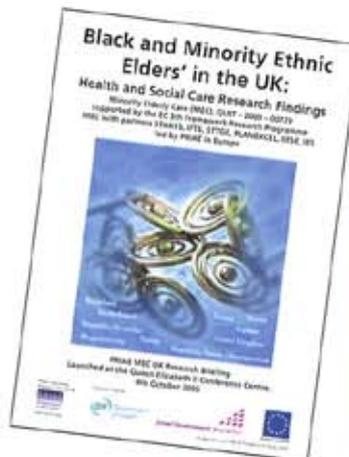
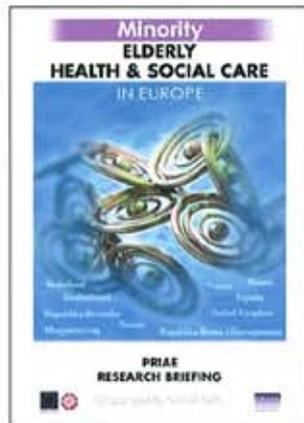
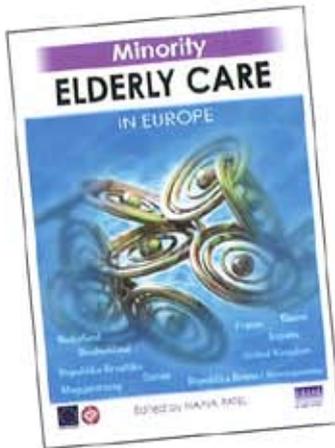
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SCEES Steering Group Members

Professor Sashidharan, PRIAE trustee;
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Ayrshire & Arran; Samantha Coope Social
Inclusion: Tackling Poverty Team; Brian
Dornan and Neil Langhorn, Former Heads of
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Team Scottish Executive; Alastair Pringle,
Patient Focus Manager SEHD; Pek Yeung
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Hazra, Elder Representative; Eleanor
McKnight, Head of Equalities Support, NHS
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