



COMMUNITY ENGAGEMENT PROJECT

THE NIMHE MENTAL HEALTH PROGRAMME

**REPORT OF THE COMMUNITY LED RESEARCH PROJECT FOCUSING
on:**

THE MENTAL HEALTH SERVICE NEEDS OF CHINESE ELDERS IN
WESTMINSTER, KENSINGTON & CHELSEA AND BRENT

BY

THE CHINESE NATIONAL HEALTHY LIVING CENTRE
LONDON

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RESEARCH TEAM

The following researchers were involved in the development and delivery of this project:

Lucy Tran (Lead researcher and report author)

Lucy is Evaluation and Research Officer at the Chinese National Healthy Living Centre and lead the project from the outset. Lucy recruited and coordinated the community researchers and was involved in all aspects of the research.

Cary Wong (Community researcher)

Cary is a part time advocate and joined the research team to learn more about the Chinese community. Cary was involved in developing the research tools, translating them, conducting the focus group and some interviews, transcribing and analysing data. He enjoyed every minute of the research study.

Judith Yung (Community researcher)

Judith is a mother of two and works part time as a community worker at a Chinese Community Centre. She joined the project to learn more about mental health services for the Chinese community in order to benefit her work as well as her own personal development. She found the project very interesting: 'Studying and sharing mental health problems in communities is very useful and fascinating'. Judith was involved in developing the research tools, translating them and conducting some of the interviews.

Jenny Lam (Community researcher)

Jenny has been working with the Chinese community for the last 12 years and her experience has undoubtedly been an asset to the project. Although she has much experience working with elderly Chinese, she found interviewing Chinese people with mental health problems a real challenge. The project has given her an opportunity to learn more about mental health and the experiences and challenges faced by Chinese people with mental health problems.

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EXECUTIVE SUMMARY

Purpose of research

The Chinese National Healthy Living Centre (CNHLC) promotes healthy living and facilitates access to health services for the Chinese community in the UK. Language difficulties and cultural differences present major obstacles to many Chinese people accessing mainstream health and social care provision.

The Chinese population have been shown to consistently underutilise the National Health Service, including mental health services. The underrepresentation of Chinese psychiatric patients may be due to a lower prevalence of psychiatric morbidity or under-use of services. There is a dearth of research on the mental health of Chinese in the UK. However, the few pieces of existing research and our discussions with people in the community suggest that the mental health needs of the Chinese community are not being met by current service provision.

The purpose of this research project was to understand the barriers to access to mental health services for Chinese older people in Westminster, Kensington & Chelsea and Brent and to provide recommendations based on the findings of the research.

Background

This project was part of a national Community Engagement Programme that aimed to deliver on the Department of Health's *Delivering Race Equality in Mental Health Care (DRE)* five-year action plan. The three key aims of the action plan are equality of access, equality of experience and equality of outcomes for all people of black and minority ethnic status in mental health services in England. The project was funded by the National Institute for Mental Health in England and managed by the Centre for Ethnicity and Health at the University of Central Lancashire (UCLan).

Aims and objectives

This study aimed to answer the following questions:

What are the barriers to access to mental health services for Chinese elders?
What are the experiences of mental health services of Chinese elders?

The research questions of this study were:

What are the beliefs and understandings about mental health among Chinese elders?

What knowledge of and attitudes to mental health services do Chinese elders have?

What are the experiences of Chinese elders in mental health services?

Methods

Qualitative methodology was used to gather the views and experiences of Chinese people aged 55 or over in Westminster, Kensington & Chelsea and Brent. One focus group and 21 semi-structured interviews were carried out between December 2007 and February 2008. In total, the study sample consisted of 4 mental health service users, 1 carer and 24 non-service users (including the focus group participants).

Results and conclusions

This study has shown that cultural concepts of mental health and wellbeing are major factors in determining whether or not Chinese older people recognise mental health problems and subsequently seek help from the National Health Service. Chinese older people were unlikely to recognise the symptoms of mental ill health and also unlikely to perceive mental health problems as ailments that required medical attention.

Interpreting services were considered to be unreliable and unprofessional across the three boroughs. Thus, combined with language difficulties and the stigma of mental illness (being perceived as a lack of self-control and weakness), Chinese older people were less likely to access services for mental health problems.

In specialist mental health services, Chinese older people (and Chinese people in general) were underrepresented. In the context of *Delivering Race Equality*, provision of services across the three boroughs was far from being culturally-appropriate, especially in inpatient settings.

Recommendations

1. To support CNHLC in developing a mental wellbeing programme for Chinese people. The programme would focus on how to maintain good mental health and raise awareness about mental health and access to services.

2. To develop a Chinese-speaking health/mental health guide. This guide could be based with CNHLC and would signpost and support people in accessing health/mental health services.
3. Mental health professionals with language abilities should be made available across different PCT boundaries.
4. For CNHLC to work with Community Development Workers (BME) to develop and deliver an awareness training and mental health promotion programme to primary care workers.
5. To provide training for Community Mental Health Teams, Older People's Mental Health Teams and in-patient staff on Chinese culture and the local Chinese-specific resources that are available to link with.
6. For one team and/or in-patient ward to take a lead in developing expertise in working with Chinese community resources and to act as an advisor to other teams/wards.

This summary is available in Chinese (Appendix III).

1. INTRODUCTION

In December 2006, the Department of Health's Black and Minority Ethnic Mental Health Programme invited expression of interest from black and minority ethnic community groups and organisations for the provision of Community Engagement Projects that met the Government's *Delivering Race Equality in Mental Health Care (DRE; Department of Health, 2005)* five-year action plan. The Chinese National Healthy Living Centre (CNHLC) successfully tendered for a grant to provide a Community Engagement Project to explore the mental health service needs of Chinese elders in Westminster, Kensington & Chelsea and Brent. The project was funded by the National Institute for Mental Health in England and managed by the Centre for Ethnicity and Health at the University of Central Lancashire (UCLan). Eighty Community Engagement Projects have been funded nationally over three years. This project is one of 40 that have been funded in the final year of the mental health programme.

1.1. The Centre for Ethnicity and Health's Model of Community Engagement

1.1.1. Background to the community engagement model

We often hear the following words or phrases:

- Community consultation
- Community representation
- Community involvement/participation
- Community empowerment
- Community development
- Community engagement

Sometimes these terms are used inter-changeably; sometimes one term is used by different people to mean different things. The Centre for Ethnicity and Health has a very specific notion of community engagement. The Centre's model of community engagement evolved over several years as a result of its involvement in a number of projects. Perhaps the most important milestone however came in November 2000, when the Department of Health (DH) awarded a contract to what was then the Ethnicity and Health Unit at the University of Central Lancashire (UCLan) to administer and support a new grants initiative. The initiative aimed to get local Black and minority ethnic community groups across England to conduct their own needs assessments, in relation to drugs education, prevention, and treatment services.

The DH had two key things in mind when it commissioned the work; first, the DH wanted a number of reports to be produced that would highlight the drug-related needs of a range of Black and minority ethnic communities. Second, and to an extent even more important, was the process by which this was to be done.

If all the DH had wanted was a needs assessment and a 'glossy report', they could have commissioned researchers and produced yet another set of reports that may have had little long term impact. However this scheme was to be different. The DH was clear that it did not want researchers to go into the community, to do the work, and then to go away. It wanted local Black and minority ethnic communities to undertake the work themselves. These groups may not have known anything about drugs, or anything about undertaking a needs assessment at the start of the project; however they would have proven access to the communities they were working with, the potential to be supported and trained, and the infrastructure to conduct such a piece of work. They would be able to use the nine-month process to learn about drug related issues, and how to undertake a needs assessment. They would be able to benefit and learn from the training and support that the Ethnicity and Health Unit would provide, and they would learn from actually managing and undertaking the work. In this way, at the end of the process, there would be a number of individuals left behind in the community who would have gained from undertaking this work. They would have learned about drugs, and learned about the needs of their communities, and they would be able to continue to articulate those needs to their local service providers, and their local Drug Action Teams (DATs). It was out of this project that the Centre for Ethnicity and Health's model of community engagement was born.

The model has since been developed and refined, and has been applied to a number of areas of work. These include:

- Substance misuse
- Criminal justice system
- Policing
- Sexual health
- Mental health
- Regeneration
- Higher education
- Asylum seekers and refugees

New communities have also been brought into the programme: although Black and minority ethnic communities remain a focus to the work, the Centre has also worked with:

- Young people
- People with disabilities
- Service user groups
- Victims of domestic violence
- Gay, lesbian and bi-sexual and trans-gender people
- Women
- White deprived communities
- Rural communities

In addition to the DH, key partners have included the Home Office, the National Treatment Agency for Substance Misuse, the Healthcare Commission, the National Institute for Mental Health in England, the Greater London Authority, New Scotland Yard and Aimhigher.

1.1.2. The key ingredients of the model

According to the Centre for Ethnicity and Health model, a community engagement project must have the community at its very heart. In order to achieve this, it is essential to work through a host community organisation. This may be an existing community group, but it might also be necessary to set up a group for this specific purpose of conducting the community engagement research.

The key thing is that this host community organisation should have good links to the defined target community¹, such that it is able to recruit a number of people from the target community to take part in the project and to do the work (see section on task below).

It is important that the host community organisation is able to co-ordinate the work, and provide an infra-structure (e.g. somewhere to meet; access to phones and computers; financial systems) for the day-to-day activities of the project. One of the first tasks that this host community organisation undertakes is to recruit a number of people from the target community to work on the project.

The second key ingredient is the research task that the community undertakes. According to the Centre for Ethnicity and Health model, this must be something

¹ The target community may be defined in a number of ways – in many of the community engagement projects it has been defined by ethnicity. We have also worked with projects where it has been defined by some other criteria, such as age (e.g. young people); gender (e.g. women); sexuality (e.g. gay men); service users (e.g. users of drug services or mental health service users); geography (e.g. within a particular ward or estate) or by some other label that people can identify with (e.g. victims of domestic violence, sex workers).

that is meaningful, time limited and manageable. Nearly all of the community engagement projects have involved communities in undertaking a piece of research or a consultation exercise within their own communities. In some cases there has been an initial resistance to doing 'yet another piece of research', but this misses the point. As in the initial programme run on behalf of the DH, the process and its outcomes have equal importance. The task or activity is something around which lots of other things will happen over the lifetime of the project. Individuals will learn and new partnerships will be formed. Besides, it is important not to lose sight of the fact that it will be the first time that these individuals have undertaken a research project.

The final ingredient, according to the Centre for Ethnicity and Health's model, is the provision of appropriate support and guidance. It is not expected that community groups offer their time and input for free. Typically a payment in the region of £15-20,000 will be made available to the host organisation. It is expected that the bulk of this money will be used to pay people from the target community as community researchers². A named member of staff from the community engagement team is allocated as a project support worker. This person will visit the project for at least half a day once a fortnight. It is their role to support and guide the host organisation and the researchers throughout the project. The University also provides a package of training, typically in the form of a series of accredited workshops.

The accredited workshops give participants in the project a chance to gain a University qualification whilst they undertake the work. The support workers will also assist the group to form an appropriate steering group to support the project³.

The steering group is an essential element of the project: it helps the community researchers to identify the community they are engaging with, and can also facilitate the long term sustainability of the projects recommendations and outcomes. The community researchers undertake a needs assessment or a consultation exercise. However the steering group will ensure that the work that the group undertakes sits with local priorities and strategies; also that there is a mechanism for picking up the findings and recommendations identified by the research. The steering group can also support individuals' career development as they progress through the project

1.1.3. The community engagement team

² This is not always possible, for example, where potential participants are in receipt of state benefits and where to receive payment would leave the participant worse off.

³ Very often we will have helped groups to do this very early on in the process at the point at which they are applying to take part in the project.

The community engagement team comprises of senior support workers, support workers, teaching and learning staff, administration team and a communications officer. They work across a range of community engagement areas of specialisation, within a tight regional framework.

National Programme Directors			
Northern Team	Midlands Team	Southern Team	Senior Programme Advisors
Senior Support Worker		Senior Support Worker	
Support Workers	Support Workers	Support Workers	Drug Interventions Programme
			Citizen Shaped Policing
Teaching And Learning Team			
Administration Team			
Communications Officer			

1.1.4. Programme outcomes

Each group involved in the Community Engagement Programmes is required to submit a report detailing the needs, issues or concerns of the community. The qualitative themes that emerge from the reports are often very powerful. Such information is key to commissioning and planning services for diverse and 'hard to reach' communities. Often new partnerships between statutory sector and hard to reach communities are formed as a direct result of community engagement projects.

In 2005/6 the Substance Misuse Community Engagement Programme was externally evaluated. This concluded that:

- The Community Engagement Programme had made very significant contributions to increasing awareness of substance misuse and understanding of the substance misuse needs of the participating communities. It also raised awareness of the corresponding specialist services available and of the wider policy and strategy context.
- The Community Engagement Programme had enabled many new networks and professional relationships to be formed and that DATs appreciated the links they had made as a result of the programme (and the improvements in existing contacts) and stated their intentions to maintain those links.

- Most commissioners reported that they had gained useful information, awareness and evidence about the nature and substance misuse service needs of the participating organisations.
- All DATs reported positive change in their relationship with the community organisations. They stated that the Community Engagement Programme reports would inform their plans for the development of appropriate services in the future.
- A significant number of the links established between DATs and community organisations as part of the Community Engagement Programme were made for the first time.
- The majority of community organisations reported their influence over commissioners had improved.
- Training and access to education was successful and widely appreciated. 379 people went through an accredited University education programme.
- A third of community organisations in the first tranche reported that new services had been developed as a result of the Community Engagement Programme.
- The vast majority of participants and stakeholders expressed high levels of satisfaction with the project.

The capacity building of the individuals and groups involved in the programme is often one of the key outcomes. Over 20% of those who are formally trained go on to find work in a related field.

The views expressed in this report are those of the Chinese National Healthy Living Centre, and are not necessarily those of the Centre for Ethnicity and Health at the University of Central Lancashire.

1.2. The Chinese National Healthy Living Centre

The Chinese National Healthy Living Centre (CNHLC) is a registered charity and was founded in 1987 to promote healthy living and facilitate access to health services for the Chinese population in the UK. The Centre is situated in Soho, Westminster and serves the needs of Chinese across London and nationally.

Mental health has been a priority area for the Centre since its inception as a Healthy Living Centre. Over the years, a number of projects and services have been delivered to meet the mental health needs of Chinese. These have included, for example, a counselling service for Chinese youths in Birmingham and a national piece of research on the mental health needs of Chinese in England. Currently, the Centre provides a Chinese-speaking counselling service

and a Chinese Mental Health Advocacy and Support Service. The Centre has also trained 20 mental health advocates to London Open College Network level 3.

Little research has been carried out regarding mental health in the Chinese community, and even less of this has focussed on older people. In the 2007 *Count me in* census of mental health inpatients in England and Wales, approximately 30% of Chinese people in the census were aged 50 or over. This study focuses on Chinese older people for three reasons: they are under researched; the Chinese population resulting from the major waves of migration (see 1.3 below) is now reaching old age; older people were a priority group of the NIMHE.

1.3. Chinese settlement in the UK

In order to provide context to the experiences of Chinese older people in the UK, the history of settlement and demographics of the national Chinese population is described here.

A timeline

<u>Late 19th century</u>	The first Chinese to arrive in Britain were the seamen employed on British merchant ships in the late 1860s. By the late 19 th century, they had settled in ports such as Limehouse in London and Liverpool.
<u>1950s – 1960s</u>	Land reforms and the collapse of the agricultural industry in Hong Kong resulted in a second wave of migration as farmers left to seek work in the UK. The 1948 British Nationality Act that gave New Commonwealth citizens the right to live and work in Britain made this possible. This Act also opened the door to arrivals from former British colonies, such as Malaysia and Singapore, who brought with them specialist skills, such as nursing.
<u>1970s – 1980s</u>	The end of the Vietnam War marked another phase of Chinese immigration with ethnic Chinese forming nearly 80% of the Vietnamese refugee community in Britain.
<u>1990s – present</u>	The return of Hong Kong to China on 30 th June 1997 also led to further migration of Hong Kong Chinese to Britain while recent years have witnessed a rapid increase in the number of mainland Chinese, especially from the Fujian province, seeking economic freedom in Britain.

Population characteristics

In 1991, the National Population Census recorded ethnicity for the first time and put the figure for ethnic Chinese in Britain at 164,667 (ethnic group data were not collected on the Northern Ireland Census). By 2001, this figure had climbed to 247,403, making ethnic Chinese the 6th largest non-white minority ethnic group in the UK and forming 0.4% of the total population. However, these figures are likely to be underestimates as the Census would not have included those who were illiterate, those who were in the process of applying for asylum or irregular migrants. Mid-year population estimates by the Office for National Statistics suggest that the number of ethnic Chinese in England stood at 312,400 in 2004. The growth in the Chinese population is largely attributable to net international in-migration. Chinese community representatives believe that this growth is being led by students and economic migrants from mainland China (London Chinese Community Network, 2005). Data from the Higher Education Statistics Agency estimates the number of students from China, Taiwan, Hong Kong, Macao, Malaysia, Singapore and Vietnam to be around 83,000 in 2005/06, giving a proxy estimate for the number of Chinese students in higher education in the UK (HESA, 2007). Estimates suggest that as many as 80,000 work here illegally, with the pace of new arrivals largely explaining why more than 60% of the population cannot speak fluent English (The Sunday Times, January 22 2006). China's rapid economic expansion is also predicted to have a sizeable impact on the UK Chinese population and its dynamics in the near future.

Geographically, the Chinese population is the most dispersed ethnic minority group in the UK. Although Chinese population density remains highest in the major urban areas, with 80,206 in London (Census 2001), there are significant numbers outside of these areas. This pattern of settlement has come about largely through the movement of restaurateurs and takeaway owners away from concentrations of Chinese people in order to reduce competition, resulting in social isolation, especially amongst the elderly. The catering trade remains the largest industry for Chinese people (Census 2001), although this is likely to change as second and third generation UK-born Chinese assimilate into mainstream society, taking up different roles. The number of 'high street' Chinese medicine shops is also growing rapidly and fast becoming the second largest industry for Chinese according to unofficial sources.

1.4. Underrepresentation of Chinese in mental health services

There is evidence for underrepresentation of Chinese people in services across the NHS including GP and secondary care services (Smaje & Le Grand, 1997) and this pattern does not exclude mental health services – studies have shown that Chinese psychiatric patients are underrepresented in the NHS (Wong &

Cochrane, 1989; Li, 1991). The first *Count me in* census of mental health inpatients in England and Wales in 2005 showed that Chinese men and women were also significantly underrepresented in rates of admission to inpatient facilities. This trend was repeated in the two subsequent annual *Count me in* censuses (Commission for Healthcare Audit and Inspection, 2005, 2007, 2007) which again showed that rates of admission to mental health inpatient facilities in England and Wales were lower among the Chinese population compared to the national average.

1.5. Prevalence of mental health disorder in the Chinese population

The underrepresentation of Chinese in mental health services has prompted the question of whether or not the prevalence of mental health disorder is lower in the Chinese population compared with other ethnic groups.

Some studies have suggested a lower prevalence of mental health disorder in the Chinese population, both within the UK and in Taiwan and China (Sproston *et al.*, 1999; Weissman *et al.*, 1994; Weissman *et al.*, 1996; The WHO World Mental Health Consortium, 2004). In the UK, psychological well being was measured using a Chinese Health Questionnaire (developed to account for cultural differences in the reporting of psychological well-being) to detect possible psychiatric morbidity (Sproston *et al.*, 1999). In the sample of 910 Chinese men and women aged 16-74, 7% met the threshold score indicative of the possible presence of a psychiatric disorder. This proportion was under half that found among people in the general population (17%) using the equivalent General Health Questionnaire. However, the complexities in perceptions, expression and diagnosis of mental health disorder, especially in anxiety and mood disorders, cross-culturally mean that this type of data is difficult to interpret.

In psychotic illness, such as schizophrenia where there is a suspected genetic component to aetiology, there is a lack of epidemiological data in relation to the Chinese. Cross-national comparative analysis of prevalence studies of schizophrenia are also subject to difficulties in interpretation due to differences in diagnostic standards, life expectancy, course and prognosis (Torrey, 1987). Lower prevalence rates have been reported in 'least developed' countries compared with 'emerging' or 'developed' countries, with a more benign course of illness in less developed countries suggested to produce the lower prevalence rates (Torrey, 1987; Saha *et al.*, 2005).

In the UK, the Chinese population might be expected to have a higher prevalence of mental health disorder as immigrant populations have been shown to be at higher risk (King *et al.*, 1994). On the other hand, prevalence rates might be lower due to differences in expression of problems i.e.

expression in behavioural or somatic terms. While these theories serve to highlight the limitations of prevalence studies, estimating the proportion of a population affected by a certain disease is central to health service planning. These theories also make generalisations about a population that is heterogeneous in nature. Understanding the needs of subgroups within the Chinese population is crucial to providing efficient and effective services.

1.6. Barriers to access

In light of the lack of good epidemiological data, it is not known whether underrepresentation in mental health services is due to a lower prevalence of psychiatric morbidity or an underutilisation of services. However, CNHLC's national survey (Li & Logan, 1999) and experiences of working with the Chinese population suggest that language and cultural appropriateness of services present barriers to access for Chinese people. The older generation are more likely to experience barriers to access as they are often first generation immigrants who have roots in their native languages and cultures.

In 1999, CNHLC published *The Mental Health Needs of Chinese in England: A Report of a National Survey* (Li & Logan, 1999). The study surveyed 401 Chinese people in England and 86 (21.4%) screened positive for past or current mental health disorder. Seventy one of these agreed to be interviewed. The interview data showed that

- 74.3% of the interviewees had encountered difficulties with seeking help
- Of 50 interviewees who had a current mental health disorder, 36.8% given a diagnosis did not know what that diagnosis was
- No one was given counselling, psychotherapy or ECT, which meant that drug therapy was the only option
- 40.8 % and 56.1% had had negative experiences with their GP or psychiatrist, respectively.

The Government's response to the independent inquiry into the death of David Bennet and the resulting *DRE* action plan acknowledge that there is inequality and discrimination, both direct and indirect, in mental health care (Department of Health, 2005).

1.7. Aims of the study

This study aimed to answer the following questions:

What are the barriers to access to mental health services for Chinese elders?
What are the experiences of mental health services of Chinese elders?

Objectives

The research questions of this study were:

What are the beliefs and understandings about mental health among Chinese elders?

What knowledge of and attitudes to mental health services do Chinese elders have?

What are the experiences of Chinese elders in mental health services?

1.8. Delivering race equality

The *DRE* action plan is designed to deliver on three key aims:

- Equality of access
- Equality of experience
- Equality of outcomes

The programme of change is founded on three building blocks:

- **more appropriate and responsive services** - achieved through action to develop organisations and the workforce, to improve clinical services and to improve services for specific groups, such as older people, asylum seekers and refugees, and children.
- **community engagement** - delivered through healthier communities and by action to engage communities in planning services, supported by 500 new Community Development Workers.
- **better information** - from improved monitoring of ethnicity, better dissemination of information and good practice, and by improving knowledge about effective services. This includes a new yearly census of ethnicity of mental health patients.

Within the context of the *DRE* action plan, the findings of this study aimed to allow service developers to:

- Create an environment where there is better understanding of and subsequently less fear of mental health services. This would lead to improved accessibility to services and allow Chinese people to obtain the help they need

- Develop services that are more appropriate and responsive to the needs of Chinese older people through better understanding of their beliefs and needs
- Increase user satisfaction and improve experiences and outcomes for patients by providing culturally sensitive care
- Increase the number of Chinese older people reaching self-reported states of recovery by improving user satisfaction and user experiences and outcomes
- Provide a more balanced range of effective therapies, including peer support services, psychotherapeutic and counselling treatments based on identified needs
- Engage with the Chinese community and sustain the links created by this project to allow Chinese people to influence planning and provision of services

2. METHODS

The CNHLC lies within the boundaries of the Central and North West London NHS Foundation Trust (CNWL). Three boroughs served by CNWL were selected for study based on mid-year population estimates. Westminster (400), Kensington & Chelsea (200) and Brent (300) had the highest proportions of Chinese people at or above retirement age (60 for females and 65 for males; Table 1).

Table 1. Estimated resident population of Chinese people (total and aged 60+ (female) or 65+ (male) in CNWL boroughs, mid-2004 (Office for National Statistics, 2006, experimental statistics)

Borough	Chinese population*	Total population	% Chinese	Chinese aged 60/65+	Total aged 60/65+	% Chinese
Westminster	7,400	230,000	3.2	400	29,300	1.4
Kensington & Chelsea	5,200	184,100	2.8	200	25,100	0.8
Brent	3,300	267,700	1.2	300	36,600	0.8
Harrow	2,700	211,200	1.3	200	35,100	0.6
Hillingdon	2,700	248,700	1.1	200	39,100	0.5

* These figures are likely to be underestimates as they will not include the recent growth in overseas Chinese students or irregular migrants.

2.1. The Community Engagement Model

Recruitment of community researchers began in May 2007 through advertisement on CNHLC's website, press releases in Chinese newspapers and word-of-mouth. Three researchers of Chinese ethnic origin and who combined could speak Cantonese, Mandarin and English were recruited. These researchers attended a 7-day training course on community-based research and mental health provided by UCLan. Unfortunately, one of the researchers left the project after completing the training due to personal circumstances. The role was filled by a member of the CNHLC staff.

In order to ensure sustainability of the project (sustained links between the community and service providers; and mechanisms to carry forward recommendations), a steering group composed of key stakeholders in service delivery was formed. The steering group was composed of:

Carsten Bruggemann, Deputy Manager, West End Locality Community Mental Health Team

Cecilia Ko, Marlborough Family Service psychotherapist and CNHLC counsellor
David Truswell, FIS Manager, CNWL Mental Health Foundation Trust
Erzsebet Pek, Head Occupational Therapist, Older Adult Services, South K&C
and South Westminster
Imran Mirza, UCLan Support Worker
Karen Brown, Community Services Manager, Older Adult Services, South K&C
Mental Health Centre
Mike Jones, Commissioning Manager, Joint Mental Health Services,
Westminster City Council and Westminster Primary Care Trust

The project was unable to obtain representation from Brent although invitations were offered.

2.2. Research design

The study used qualitative methods to explore the views of the following groups:

- i) Older Chinese mental health service users (*service users*)
- ii) Carers of service users (*carers*)
- iii) Older Chinese not using mental health services (*non-service users*)

A *service user* was defined as someone currently using services or had used services within the last 5 years. A *carer* was defined as a person providing unpaid, regular and substantial care to a *service user*. A *non-service user* was defined as someone who was not using or had not used mental health services in the last 5 years.

Although the primary aim of including carers in the study was to identify the needs of service users, carer needs were also explored.

A focus group was initially conducted with non-service users (8 participants) with representation from all 3 boroughs (Westminster 4, RBKC 1 and Brent 3) to identify potential areas of interest. The focus group topic guide (Appendix I) was first piloted in a semi-structured interview with a Chinese elder to ensure cultural and linguistic sensitivity and comprehension. The broad themes of the topic guide were:

1. Understanding of mental health
2. Getting help
3. What could be done to improve services?
4. Cultural appropriateness of services

A total of 21 in-depth semi-structured interviews were then conducted to gather the views and experiences of non-service users (16), service users (4) and carers (1) across the 3 boroughs. Interview schedules for each group are

attached in Appendix I. The focus group topic guide and all interview schedules were translated into Chinese to ensure consistency across interviewers.

2.3. Sample selection

Participants were selected using the criteria described in Table 2.

Table 2. Participant selection criteria

	Service users	Carers	Non-service users
Ethnicity	Chinese	Any	Chinese
Age	55 or over	17 or over	55 or over
Borough of residence	Westminster, Kensington & Chelsea or Brent	Westminster, Kensington & Chelsea or Brent	Westminster, Kensington & Chelsea or Brent

Although NHS older adult services serve the population aged 65 or over, the age criterion for this study was based on the perceptions of Chinese people of age – many Chinese consider themselves as ‘old’ after the age of 55.

2.4. Sample recruitment

2.4.1. Non-service users

Advertisements were placed in local Chinese community organisations, local faith groups and Chinese newspapers. Focus group participants were recruited from the CNHLC service user pool. Snowball sampling was used to recruit further participants for the semi-structured interviews. No response was generated by the advertisements. Outreach to local community groups (Chinese Community Centre, Age Concern Covent Garden Day Centre, North London Chinese Association) generated the majority of the participants. The Westminster Chinese Domiciliary Care Service generated one participant. No one was turned away from the study.

2.4.2. Service users

Service users and carers were recruited through service providers in the CNWL Mental Health Foundation Trust. Letters were sent to service providers in December 2007 describing the study and requesting that a covering letter and information sheets be sent to users who fulfilled the selection criteria for participation in the study. This did not generate any response. Four service users were eventually recruited to the project. Involvement of steering group members in providing contacts yielded three service users. The fourth service user was already known to the CNHLC.

All participants of the study were offered £15 to take part.

2.5. Data collection and analysis

Interviews and focus group were conducted in the language of preference of the participants (Cantonese or Mandarin), voice-recorded and fully transcribed in Chinese. The transcripts were separately analysed by two members of the research team by inductive thematic analysis. The data were coded manually according to emerging themes (recurrent topics that were present in the data). The themes arrived at were cross-checked between the two coders and the final themes translated into English and agreed on by the research team. Data were collected between December 2007 and February 2008.

2.6. Ethics

NHS ethical approval was obtained from the Harrow Research Ethics Committee in December 2007. Ethical approval was also obtained from the UCLan internal ethics committee. Research and development approval was obtained from Westminster City Council Research Steering Group and Royal Borough of Kensington & Chelsea Social Care Research Steering Group. Approval was not required from Brent Council.

Information sheets in English and Chinese were prepared for the focus group and individual interviews. Participants had at least 24 hours to decide whether or not to take part. Signed consent was taken prior to taking part in the focus group or interview. Strict participant confidentiality and data protection codes were adhered to at all times.

As a requirement for ethical approval, the study did not include people who did not have capacity to give consent or people with dementia.

2.7. Limitations of the study

The non-service user sample consists only of individuals who access local Chinese community organisations and might not be representative of the older Chinese population as a whole.

While the service user sample is limited in size, it does represent services across the three boroughs (although service users were resident in only two of the three boroughs, see section 3.1.1). However, as a qualitative study, the interview data were intended to provide rich, phenomenological data that allowed deeper understanding of the interviewees' experiences.

2.8. Mapping of service-use across Westminster, Kensington & Chelsea and Brent

An attempt was made to map the use of services across the three boroughs in order to identify the pool of potential participants. Difficulties were encountered in i) identifying the appropriate contacts within organisations and ii) lack of response. Thus, the picture is incomplete.

2.8.1. Mental health services

Data collected on services provided by the Central and Northwest London Mental Health Foundation Trust (CNWL) to Chinese patients are presented here.

Chinese representation in Adult and Older Adult services across all CNWL boroughs during 2006/2007 are shown in Table 3.

In the adult population, 1.49% of the total population in the boroughs served by CNWL were Chinese in the 2001 Census, while in the adult inpatient population in 2006-2007, 0.67% of the population were Chinese.

In the older adult population, 0.8% of the total population in the boroughs served by CNWL were Chinese in the 2001 Census, while in the older adult inpatient population in 2006-2007, 0.16% of the population were Chinese.

Brent

In the 2007/08 financial year, there were no Chinese inpatients aged 55 or over in Brent (February 2008). There was one younger Chinese patient. Ten patients of Chinese ethnicity aged 55 or over were seen in a community contact by Brent teams in the 2007/08 financial year (March 2008).

Kensington & Chelsea and Westminster

Across the two boroughs, a total of 5 current Chinese service users across all CNWL services aged 55 or over were identified in January 2008. In April 2008, 5 current Chinese service users aged 55 or over were identified in Westminster.

The above data were extracted by service managers from the Epex database used by CNWL. The database has been described as unreliable by a number of CNWL staff, and a new system is being put in place at the time of writing this report. The primary aim of this exercise was to identify the potential pool of service user participants and these data provide a good indication of the representativeness of the service user sample.

Table 3. Services provided by the Central and Northwest London (CNWL) Foundation Trust to Chinese adults (16-64) and older adults (65 or over) from 1 April 2006-31 March 2007. Figures are for full year so users who are in inpatient population will also appear in community population. Patients may be 'open' in more than one service so open community episodes do not equate to the number of Chinese patients using services during that year.

Service	Number of inpatient admissions	Number of open community episodes
Westminster Adult	11	67
Kensington & Chelsea Adult	10	29
Brent Adult	5	27
Harrow Adult	3	3
Hillingdon Adult	3	4
Older Adults (all boroughs)	2	10

2.8.2. Social care services

Data for social care services were obtained for Westminster only (source: Strategy and planning, Westminster City Council, January 2008) although attempts were made to obtain data for all three boroughs.

25 adults aged 55 or over, whose ethnicity was recorded as Chinese, were supported in the community with ongoing community services commissioned or provided by Westminster Adults Services. This represented 0.8% of the total number of people supported who were aged 55 or over. For comparison, the estimated population of Chinese people aged 60/65 or over was 1.4% of the total population aged 60/65 or over in Westminster in 2004 (Office for National Statistics, 2006).

Of the 25 adults currently receiving support

- 14 were receiving support from the Chinese Domiciliary Care team
- 1 was in residential care outside Westminster boundaries
- 2 were in nursing home care, with one within Westminster boundaries
- None were in Westminster extra care housing

2.8.3. Other services

In December 2007, various services across the 3 boroughs were contacted to identify current Chinese users who might be potential participants. In total, 12 day centres, 8 voluntary sector services and 11 residential, nursing or extra care homes were contacted (Appendix II). Three of the services had current Chinese users: Age Concern Westminster – Covent Garden Day Centre (Chinese Information and Advice Service); Age Concern Westminster – Leonora Day Centre (Chinese service users under age 55); Age Concern Brent (drop-in advice service).

Chinese community centres

The Chinese Community Centre in Chinatown, Westminster, provided current membership data to date for the 2007/2008 financial year (Table 4; February 2008).

Table 4. Number of current members of The Chinese Community Centre in Chinatown residing in Westminster, Kensington & Chelsea or Brent (2007/08)

Borough	Number of current members	% of total membership
Westminster	266	16.9
Kensington & Chelsea	18	1.2
Brent	49	3.1
Total	1580	21.2

3. RESULTS

3.1. Sample statistics

The total sample comprised of 8 participants of the focus group (non-service users) and 21 interviewees (4 service users, 1 carer and 16 non-service users).

3.1.1. Borough distribution

Borough	Service users	Carers	Non-service users	Total
Westminster	2	1	10	13
Kensington & Chelsea	0	0	4	4
Brent	2	0	9	11
Other	0	0	1	1
Total	4	1	24	29

3.1.2. Core demographic data

Age $n=28$ (not including carer)

Age	n	%
55-59	2	7.2
60-64	2	7.2
65-69	5	17.9
70-74	3	10.7
75-79	8	28.6
80-84	5	17.9
85-89	2	7.2
90-94	1	3.6

Age $n=28$ (not including carer)

Mean	74
Median	76
Mode	79
Range	55-91

Gender $n=29$

Gender	n	%
Male	15	51.8
Female	14	48.3

Ethnicity $n=29$

Chinese	100%
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Place of birth $n=29$

Place of birth	n	%
China	16	55.2
Hong Kong	11	38.0
Malaysia	1	3.5
Vietnam	1	3.5

Years in the UK $n=29$

Years in the UK	n	%
<1	0	0
1-5	0	0
6-10	1	3.5
11+	28	96.6

Years in the UK, 11+ years $n=28$

Mean	32
Median	31
Mode	30
Range	11-60

Citizenship $n=29$

British citizen	100%
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First spoken language $n=29$

First spoken language	n	%
Cantonese	25	86.2
Mandarin	3	10.4
Chiu Chow	1	3.5

First written language $n=29$

First written language	n	%
Chinese	16	55.2
None	13	44.8

Other fluent languages $n=30$

Other spoken language	n	%
Hakka	5	16.7
Mandarin	4	13.3
English	2	6.7
Cantonese	1	3.3
Wei Tao	1	3.3
Vietnamese	1	3.3
None	16	53.3

Religion $n=29$

Religion	n	%
None	15	51.7
Buddhism	6	20.7
Christianity	4	13.8
Ancestor/deity worship	2	6.9
Not answered	2	6.9

Sexuality $n=29$

Heterosexual	100%
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Self-reported disability $n=29$

Self-reported disability	n	%
Yes	3	10.4
No	26	89.7

3.2. Non-service users

Non-service users in this study were defined as people who were not using or had not used mental health services in the last 5 years. Non-service users were consulted on their beliefs and understandings about mental health and their experiences of other services; in particular GP services (GP services being the first point of access to most NHS services).

3.2.1. Experiences of services

Participants had used or were currently using:

- GP services
- Chinese community organisations including
 - Chinese National Healthy Living Centre
 - Chinese Community Centre (Chinatown)
 - Camden Chinese Community Centre
 - North London Chinese Community Association
 - Age Concern Westminster - Covent Garden Day Centre Chinese Information and Advice Service
- Westminster Chinese Domiciliary Care Service
- Hospital services

Chinese community organisations were perceived to fill an important gap in service provision in terms of providing assistance to access health services and in providing social activities.

'For us older people – it's just hospitals and interpreters – someone to read our letters, make sure we know when the appointment is and make sure there will be an interpreter there.' *Int10*

The majority of participants lived alone or with one other person (a partner or adult child).

Language and interpreting services

When asked about health [GP and hospital] services, the availability of interpreters was at the forefront of most of the participants' minds. The fact that interpreters were not always available and sometimes failed to show up was a source of worry for most. However, upon receiving care, all participants thought services were good.

'[Interpreters] are mostly not available – that means your condition gets worse because the doctor doesn't understand what you are saying.' Int1

'It would be best if there was an interpreter for every Chinese older person [in hospital] so that when we get there, for balloon angioplasty or whatever, we know what is happening. If there was no interpreter people would just sign their name [to give consent] anyway, just really scared.' Int2

'The interpreter didn't turn up so I didn't get to see the doctor. I had to book another appointment. This has happened twice already.' Int11

GP appointment systems

Participants also faced difficulties at the point of booking GP appointments.

'The receptionist asks lots of questions when it is obvious that I can't speak English.' Int1

Although appointment-booking systems varied from practice to practice, many of the participants were not satisfied with:

- The need to make an advanced appointment (lack of emergency or walk-in surgeries)
- The waiting times to see a GP, usually one week or more (this was put down to GP opening hours being too short and therefore generating long waiting lists; more time being required to find an interpreter)

Suggestions for improvement?

Participants wanted to see:

- A reliable, professional interpreting service
- Automatic booking of interpreters for Chinese older people
- A Chinese-speaking doctor - *'The best thing would be to have a Chinese doctor.'*
- Extended GP opening hours and emergency/walk-in surgeries
- Routine health MOTs for older people – *'Prevention is better than cure'*

3.2.2. Understanding of mental health

Lack of concept of 'mental health'

When participants were asked about their understanding of mental health, the majority responded with accounts of their physical health. With prompting and

further explanation, participants were able to share their understanding of mental health.

'Don't think too much'

Knowledge and understanding of mental health and illness varied among the sample. However, nearly all participants thought that good mental health could be attained by 'not thinking (worrying) too much' and controlling your emotions.

'If you think too much – about who's been bad to you in the past – this will give you schizophrenia. Don't think – just clear your mind.' Int15

'For good mental health you need to sleep early, control your emotions, don't lose your temper so easily.' Int7

Perceptions of mental health and ill health

Mental health was intrinsically linked with physical health – maintaining good physical health would naturally lead to good mental health. Mental ill health was not perceived to be an illness.

'Chinese people don't think that mental illness is an illness. Chinese people can take more pressure than other ethnic groups.' Int17

Given the above perceptions around mental health, participants thought that mental health problems could be prevented by taking actions to keep themselves occupied and relaxed through socialising at Chinese community centres, listening to music, taking walks and doing exercise to stay physically healthy.

3.2.3. Getting help

Everyone sampled knew that the GP was the first point of contact for health problems and would refer to the appropriate services. All but two of the 16 interviewees said that they would go to the GP if they thought that they or a family member had a mental health problem. The two interviewees who wouldn't go to the GP thought that the GP could not help with mental health problems.

'You have to rely on yourself, not to think too much.' Int2

In the focus group, there was uncertainty about whether the GP would refer to mental health services – mental health services seemed to be separate from other health services. With the need for interpreters, the focus group participants also thought that it would be difficult to convey complex thoughts and feelings to the GP in the time allotted.

None had used mental health services before and the majority did not know what services were available but the majority also said they would use mental health services if they needed to.

'I don't know what the GP can do [for mental health problems]. I have never asked my GP before. When us older people go to the doctor, if we ask too much I am afraid he'll think I'm rambling.' Int2

Social stigma

Most participants said that they would talk about mental health problems with 'close friends' as they might learn useful information from them. However, there was stigma attached to mental health problems that also prevented people from talking about it.

'You should ask the 40-50 year olds about that. No, we don't talk about these things; we don't like to talk about these things.' Int10

'People will talk negatively about you if you have a mental illness. One person will tell 10 and 10 will tell 100. In the end everyone will know about it – so people don't talk about it. They will only tell people like interpreters or doctors – people that can help them.' Int7

Not getting help

Three interviewees were suspected to have depression but had not sought help as they felt that these types of problem could not be resolved.

'I'm always tired. I can't sleep. I haven't been able to sleep [for the past few months].... I'm very sad, when I think about things. My husband died [a long time ago] and left me by myself. I cry everyday. [Have you been to see your GP about this?] No, how can he help?' Int3

3.2.4. Cultural appropriateness of services

Participants felt that language was the main barrier to services being able to provide culturally-sensitive care. As older people, many participants' concerns were around the care they would receive should they need to stay in hospital or in nursing/care homes.

'I can't speak English so if I needed to stay in hospital, what would the food be like, I wouldn't be able to speak to the nurses, I would be very scared.' Int19

'Sometimes, my heart feels very heavy, I feel very troubled. I wake up in the middle of the night, I don't know what the future will be like, the children do not live nearby.... If I had to stay in a nursing home, I hope that there would be one or two Chinese people there to look after me.' Int11

Some participants expressed a wish for supported housing schemes that catered specifically for Chinese people that would overcome language difficulties and combat social isolation.

3.3. Service users

Service user	Diagnosis
SU1	Schizophrenia
SU2	Schizoaffective disorder?
SU3*	Schizophrenia
SU4 (support worker present at interview)	Schizoaffective disorder/bipolar disorder

*the support worker was interviewed with the service user's consent

Presentation to the system

All service users had presented to the system through violent/unusual behaviour and all have been admitted under a section of the 1983 Mental Health Act.

Assimilation/cultural conflict as causal factors?

'According to the history that I have it was because the mother was Catholic trying to convert [SU3] from Buddhism to Catholicism and he wouldn't have any of it. That is what they said started it.' SU3

'My son was taken from me by an English woman – that's how it all started.' SU2

Medication and psychological therapies

- ¾ did not like taking medication as they did not believe they were ill (common in people with schizophrenia/schizoaffective disorder).
- One was receiving fortnightly depot injections.

- There was poor understanding of medication/treatment.

'I think having injections is torturous. I have been having injections for 20 years and I still have to have them – it means that the medication is not effective not effective.' SU4

- One was receiving psychotherapy in addition to medication but this was not through referral by the GP/psychiatrist.

In hospital

- One interviewee had had negative experiences.

'...the nurses would come in and huy huy huy pointing this way and that they didn't treat the patients like human beings there was a nurse who treated you as if you weren't a human being' SU4

- Cultural isolation

'I don't talk with [the staff or other patients]. I talk very little. There are no other Chinese patients here. ... I just want to leave hospital. This is an environment for English people.' SU1

- Meals

All 3 interviewed were dissatisfied with meals:

'I like rice. Here they give rice but it is different – Caribbean – it is not the same as ours.' SU1

'...eating the food there made me really thin. I said can I go home to make soup and eat and then come back...' SU3

'The food was not right. I was half hungry.' SU4

Isolation

Two of the interviewees lived alone, one lived with a spouse and one in a nursing home. All had limited contact with family.

Contact with Chinese community

For all, contact with the Chinese community was an inherent part of their lives – Chinese supermarkets, Chinese community centres, Chinatown, Chinese restaurants and Chinese media.

Language

All could speak basic English which meant that interpreters were only available when seeing the GP/psychiatrist. Regular meetings with support workers/social workers did not have interpreters. One interview was conducted in the presence of the interviewee's support worker for ethical and safety reasons. It was apparent at this meeting that there were communication difficulties between the support worker and interviewee and that this impacted on the wellbeing of the interviewee.

3.4. Carer

One carer – a Chinese woman caring for her husband who has schizophrenia – was interviewed in this study.

Financial difficulties

The carer responsibility and inability to communicate in English meant that getting paid employment was difficult. Benefits were being paid to the caree by direct debit into his bank account and this was sometimes difficult for the carer to access. The carer was not receiving the appropriate benefits and did not receive support to learn English which was a wish expressed in the interview.

Support in caring role

Supervising the caree to take medication was difficult as he often refused to take it. The interviewee expressed a need for support at these times.

Seeking help

The interviewee had not sought help when she first became aware that her husband had a mental health need. He eventually came to the attention of the police and was admitted to hospital.

'I knew something was wrong, he had delusions that there were waves tracking him, following him.... I knew something was wrong but he wasn't a danger to anyone so I just let it be.'

4. DISCUSSION

Within the context of the *DRE* action plan, this study aimed to understand the beliefs and understanding about mental health and the experiences of mental health services of Chinese elders in relation to service needs.

This study found underrepresentation of Chinese across all services – mental health, social care and mainstream voluntary services – in the 3 boroughs studied. Our findings are consistent with other studies which suggest that inequity of access to services in relation to mental health needs is due to a number of factors (Green *et al.*, 2002; Kung, 2004).

4.1. Language

In this study, language was perceived as a difficulty that would hinder communication of complex mental health matters to GPs and might therefore delay help-seeking and appropriate detection of mental health problems by health professionals. Across all boroughs, interpreting services were deemed unreliable and sometimes unprofessional, leading to feelings of anxiety and disappointment. As the gateway to most other services, the process of making an appointment to see the GP was considered bothersome and difficult. While these problems might delay help-seeking, they were not alone sufficient to prevent participants from seeking help if they felt they had a mental health need.

The widespread availability of interpreting services in London has to some extent diminished the language barriers experienced by the older Chinese people sampled. However, this is not likely to be the case for all Chinese: interpreting services are not available throughout the country and are particularly scarce in rural areas; many new arrivals to the country are not aware of the availability of interpreting services. There is much scope for improvements to be made to interpreting services – a recent report by Kensington & Chelsea and Westminster's Black & Minority Ethnic Health Forum '*Primary Concern*' makes comprehensive recommendations towards achieving better interpreting services (BME Health Forum, 2008).

4.2. Culture and tradition

Chinese belief systems are based on the 'great tradition' (a system of philosophies, religions and theoretical principles) which is rooted in Confucianism, Taoism and Buddhism (Shih, 1996). These belief systems form the basis of Chinese people's concepts of health and illness. In this study, concepts of mental health and ill health were major contributing factors in determining whether or not participants would present to primary care services with mental health needs.

Recognition of need

- Traditional Chinese theories of medicine did not consider mental health separately from physical health (Chang and Kleinman, 2002). Treatment focussed on restoring physiological function and balance. This concept is apparent in our sample and could perhaps lead to somatisation.
- The participants who were suspected to have mental health needs did not identify their symptoms (sleeplessness, depression) as mental health-related; neither were these symptoms perceived as ailments that required medical attention. A previous study has shown that symptoms potentially indicative of mental ill health in Western biomedicine were less likely to be medicalised by the Chinese (Prior *et al.*, 2000).
- There were concepts of mental health problems being a result of loss of self-control of thoughts and emotions, and perhaps being a sign of weakness.

Coping strategies

- Participants would employ passive coping strategies, such as avoidance and minimising the problem, to deal with mental health needs. This is not more apparent than in the case of the carer interviewee, who did not seek help for her husband who was suffering from paranoid delusions.

The factors listed above were pervasive in this sample of elderly Chinese. However, these and other factors, such as denial, have also been reported in the Chinese population as a whole (Green *et al.*, 2002; Kung, 2004). In a health needs assessment of Chinese in Shropshire County (Tran, 2006), similar concepts were found among the study sample – ‘Mental health problems aren’t really health problems – you just deal with it’.

It is conceivable that in the case of less severe mental health problems, these cultural concepts mean that problems remain hidden in the community. In the case of more severe illness, the seeking of appropriate help or treatment would be delayed and patients would eventually present through admission to hospital or sectioning, as observed in this study. These cultural barriers would be compounded by language difficulties encountered in accessing services.

There is evidence that earlier diagnosis leads to better outcomes for patients and these findings are pertinent to the three key outcomes of the *DRE*: equality of access; equality of experience and equality of outcomes.

It is also important to note that the majority of the sample in this study did not belong to any religion but had strong cultural beliefs. Thus, culture and tradition are distinct from religion and assumptions cannot be made based on a person’s religion.

4.3. Social isolation

In this study, the majority of the participants lived alone or with a spouse and did not have the support provided by extended families as is commonly believed. Although this group of people may be more likely to make use of Chinese community centres, the main source of participants in this study, a lack of family support was also found to be the case in Li & Logan's study (Li & Logan, 1999). Contact with the Chinese community was important for both the non-service users and service users in this study.

This breakdown of the extended family was a cause of distress among the elderly sample leading to proposals from some participants for communal housing facilities for Chinese elders. In London, only one housing scheme exists that caters specifically for Chinese and this only has capacity for 5-7 individuals. The lack of facilities for Chinese older people has given rise to an initiative (lead by the CNHLC) to establish the first extra care home for Chinese people in London, although this is in its early stages.

In Manchester and Birmingham, Chinese housing schemes have been set up that provide varying levels of support to residents. The Tung Sing Housing Association in Manchester, founded in 1984, was the first registered Chinese housing association in Britain and was originally established to provide affordable housing to the Chinese community in Manchester. In Birmingham, two housing schemes cater for Chinese older people and adults with mild learning disabilities or mental health needs and provide models of good practice (see Box 1).

4.4. Knowledge and awareness

Given the conceptual beliefs of Chinese older people around mental health, much work is needed to raise the level of knowledge and awareness of mental health and mental health services. For Chinese elders, this must be done in a way that is inclusive of people who are illiterate – 45% of the sample in this study was unable to read or write in any language.

Although some headway has been made in tackling the stigma attached to mental illness, it still exists widely in the community. The intense stigma attached to mental illness means that there is fear of 'losing face' if mental illness is made known to the community. Chinese culture emphasises family and collective responsibility and the shame extends beyond the individual to the family (Hong *et al.*, 2001). The stigma is due in part to attribution of mental illness to flaws in character and to 'bad genes' (Kung, 2004).

As part of the *DRE* action plan, 500 Community Development Workers (CDWs) were to be commissioned nationwide by March 2008⁴ to engage communities in service planning. The role of CDWs in engaging communities will be vital to promoting mental health awareness and combating stigma in ethnic minority communities.

Box 1. A sketch of the Trident Chinese supported housing schemes in Birmingham (information provided by the Operations Manager and Assistant psychologist)

Trident Housing Association provides two housing schemes in Birmingham specifically for Chinese people in the West Midlands area. The two schemes house 134 people in total and cater for older people and adults with mild learning disabilities or mental health needs. One of the schemes provides sheltered housing (68 units) while the other provides supported housing (45 units). The schemes provide on-site support with a Chinese assistant psychologist and Chinese support workers. The support workers are also receiving training in mental health support. There is a Community Development Worker for Chinese on the premises who helped to secure funding from the local authority to provide a Chinese counselling service (1 day/week) that started in January 2008. While the counselling service is on-site and accessible to the residents, it is open to all Chinese in Birmingham.

Of residents aged 55 and over, there are currently 10 diagnosed with mental health illness (Table 4), while many show signs of loneliness and depression. 'Many enter the schemes with physical health problems or have been bereaved and this affects their mental state' (Manager).

Table 4. Number of service users in the Trident Chinese housing schemes who have diagnosed mental health needs

	Under 55	55 and above
Dementia	0	6
Schizophrenia	1	1
Personality disorder	0	2*
Anxiety disorder	1	1
Carer (of service user who has schizophrenia)	0	1

* 1 of these cases is suspected, no formal diagnosis has been given as the service user has refused treatment

The schemes help to overcome the cultural isolation felt by many Chinese people as well as language difficulties. 'There are younger residents with

⁴ The original target for recruitment of these CDWs was 2006; this was subsequently extended to 2007 and then 2008.

mental health problems who choose to stay here as it meets their cultural needs – they can speak English’ (Assistant psychologist). With their cultural background and language skills, the team are also able to get the residents’ families involved. This is considered crucial in the treatment and recovery process.

4.5. Service user experiences

The preliminary mapping exercise carried out in this study demonstrated low service uptake across mental health services, social care services and mainstream voluntary services across the three boroughs studied (section 2.7). The small number of service users recruited to this study reinforces previous studies finding underrepresentation of Chinese in mental health services. Nonetheless, the data collected here are valuable in understanding the current experiences of Chinese people in mental health services.

It is important and encouraging to report that, overall, interviewees were satisfied with the care they were receiving, although this was not drawn out by thematic analysis due to different services being used and the small sample size. In the *DRE* context, it is not possible to comment on the prevalence of the provision of psychological therapies in this small sample. However, of relevance is the fact that one of the interviewees was using an NHS Chinese-speaking psychotherapy service in Westminster. Given the language and cultural differences experienced by many Chinese, the need for care provision, especially in mental health, from providers of the same ethnic background has been recognised to some extent. Westminster has the highest percentage of Chinese of all London boroughs (3.2% of the population are Chinese, mid-2004 experimental statistics, ONS) and provides a Chinese Domiciliary Care Service as well as a Chinese GP in its West End ward (which has the highest population of Chinese of all Westminster wards (4.6% of the population are Chinese, Census 2001). However, much more needs to be done to ensure that services are more responsive and appropriate to Chinese people’s needs in Westminster and other boroughs.

The results of this study highlight a need for culturally-appropriate inpatient care. Patients admitted under a section of the Mental Health Act may stay in hospital for between two weeks and six months. In this study, participants who had extended stays in hospital mental health wards experienced intense isolation. Culturally-appropriate food options were also not available and caused considerable distress to participants. Overall, the conditions experienced by inpatients were not conducive to mental well-being or recovery. Negative experiences of services, if prevalent in a community, might also have a negative impact on access to and engagement with services for that community.

5. CONCLUSIONS

Whether or not there is a difference in prevalence of mental health disorder in the Chinese population, this study has shown that cultural concepts of mental health have a significant bearing on whether or not Chinese older people recognise mental health problems and subsequently seek help from the National Health Service. Combined with language difficulties and the stigma of mental illness (being perceived as a lack of self-control and weakness), this meant that Chinese older people were less likely to access services for mental health problems. In specialist mental health services, Chinese older people (and Chinese people in general) were underrepresented in the three boroughs studied: Westminster, Kensington & Chelsea and Brent. In the context of *Delivering Race Equality*, provision of services across the three boroughs was far from being culturally-appropriate, especially in inpatient settings.

6. RECOMMENDATIONS

These recommendations are aimed at service commissioners, local service delivery stakeholders and potential future funders of CNHLC services. They form a programme of actionable targets that can only be achieved with full commitment and extra resource input from service commissioners and effective partnership working between service providers and CNHLC.

1. To support CNHLC in developing a mental wellbeing programme for Chinese people. The programme would focus on how to maintain good mental health and raise awareness about mental health and access to services.
2. To commission a Chinese-speaking health/mental health guide. This guide could be based with CNHLC and would signpost and support people in accessing health/mental health services.
3. Mental health professionals with language abilities should be made available across different PCT boundaries.
4. For CNHLC to work with Community Development Workers (BME) to develop and deliver an awareness training and mental health promotion programme to primary care workers.
5. To provide training for Community Mental Health Teams, Older People's Mental Health Teams and in-patient staff on Chinese culture and the local Chinese-specific resources that are available to link with.
6. For one Community Mental Health Team and/or in-patient unit to take a lead in developing expertise in working with Chinese community resources and to act as an advisor to other teams/wards.

7. OTHER OUTCOMES

A number of outcomes have arisen as a result of conducting this study:

- The Care Services Improvement Partnership London Development Centre funded the lead researcher of this project to undertake the Mental Health First Aid Instructor Training course.
- The Chinese National Healthy Living Centre has developed links with the West End Community Mental Health Team.
- A number of the participants of this study are now receiving support from the Chinese National Healthy Living Centre.

8. REFLECTION

The project has been an invaluable vehicle for establishing links with key stakeholders in mental health service delivery. Without the impetus provided by the *DRE* for PCT/mental health trust participation, this project would not have been as successful. However, this does not mean that difficulties were not encountered during the project. While it is recognised that time and resources in the NHS are limited, the lack of representation/contribution from certain boroughs means that the results presented in this report are not as complete as they could have been. The process also highlighted the difficulty in obtaining ethnicity data from the NHS and local authorities.

It was necessary to obtain approval from several authorities in order to undertake this Community Engagement Project – the local NHS research ethics committee and two of the local authorities concerned. The process delayed the commencement of the project and reduced the time available for data collection. This had a negative impact on the service user sample size which could have been larger had time permitted further fieldwork.

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APPENDIX I. Focus group topic guide and interview schedules

Focus group topic guide

1. Understanding of mental health

- How would you recognise mental health problems?
- Is it easy to talk about MH problems? Why (not)?

2. Getting help

- Where would you go to for help, in the first instance, if you thought you had a MH problem? Or if you thought a relative or friend had a mental health problem? Why?
- Do you know what sort of help you can get from MH services?
- Would you use these services?
- In what ways do services work well?
- Are there any difficulties that would prevent you from using these services? If yes, what do you think these would be? How would you rank these barriers?

3. What could be done to improve services?

- What is lacking?
- What improvements can you suggest?

4. Cultural appropriateness

- As an older Chinese person, how do you think services could be changed to make them more suitable for your needs? In terms of
 - knowledge about services
 - access
 - the service itself

CEP Interview – non-service user

1. Your experiences of using services

- Do you live alone? Do you get support on a regular basis? Who from?
- What other help/support do you get? (from GP, psychiatrist, CPN, Chinese community centre, domiciliary care)
- Tell us more about this. What's good and what's bad?
- Can you suggest any improvements?
- What else would help?

2. Understanding of mental health

- What do you understand by 'mental health'?
- What do you know about MH problems?
- How would you recognise mental health problems?
- Is it easy to talk about MH problems? Why (not)?
- On a scale of 1-10 (1 being very poor, 10 being very good), how would you rate your mental health?
- What should mental health services be like?

3. Getting help

- Where would you go to for help, in the first instance, if you thought you had a MH problem? Or if you thought a relative or friend had a mental health problem? Why?
- What other services are there that are for mental health problems?
- How would you access these?
- Do you know what sort of help you can get from MH services?
- Would you use these services?
- In what ways do services work well?
- Are there any difficulties that would prevent you from using these services? If yes, what do you think these would be? How would you rank these barriers?

4. Cultural appropriateness

- As an older Chinese person, how do you think services could be changed to make them more suitable for your needs? In terms of
 - knowledge about services
 - access
 - the service itself

CEP Interview – MH service user

4. Your experiences of using services

- Do you live alone? Do you get support on a regular basis? Who from?
- What other help/support do you get? (from GP, psychiatrist, CPN, Chinese community centre, domiciliary care)
- Tell us more about this. What's good and what's bad?
- Can you suggest any improvements?
- What else would help?

5. Treatments [if in receipt of]

- Are you taking medication for your MH problem? What are your feelings about taking medication?
- What other treatment (e.g. counselling, psychotherapy) are you receiving? What are your feelings about receiving these treatments?
- Do you have a diagnosis?

6. Hospital stays

- Have you ever had to stay in hospital for your MH problem? Which hospital?
- Tell us more about it. What was good and what was bad?
- How could your stay in hospital have been improved?

7. Getting help

- How did you first realise that you had this MH problem?
- Who did you go to for help when you first experienced these problems?
- Was it easy to get help when you first found out you had a problem? (in recognising need for help and in accessing services)
- How long did it take from first recognising the problem to actually getting professional help?
- Have you at any point found it difficult to access any of the services you have used? (Please tell us more about this.)

8. Appropriateness of services

- Do you think your experiences of mental health services would have been different if you were not Chinese?
- Do you think your experiences of mental health services would have been different if you were not an older person?
- As an older Chinese person, how do you think services could be improved to make them more suitable for you?

CEP Interview - carers

5. Understanding of mental health

- What do you understand by 'mental health'?
- What do you know about MH problems?
- How would you recognise mental health problems?
- Is it easy to talk about MH problems? Why (not)?

6. Your caring role

- Who do you care for?
- How much time do you spend in your caring role?
- What do you do in your caring role?
- How do you feel about being a carer?

7. Services for carees

- What services does the person you care for use?
- What do you think about these services?
- What improvements can you suggest?
- What else would help?
- How do you think services could be improved to make them more suitable for their needs as Chinese elders?

8. Services for carers

- Do you get paid?
- Do you get any state benefits for your caring role?
- What support do you get?
- What else would help you as a carer?

APPENDIX II. Services in Westminster, Kensington & Chelsea and Brent contacted by telephone in December 2007

Westminster

Voluntary Sector Services		
Age Concern Westminster – Covent Garden Day Centre	020 7240 5733	Chinese information and advice service on Mondays, 2-4pm
Age Concern Westminster – Elgin Day Care Centre	020 7286 2043	0 Chinese
Age Concern Westminster – Leonora Day Centre	020 7286 0386	2-3 Chinese, all under 55
Age Concern Westminster – Sherborne Day Care Centre	020 7834 0064	0 Chinese
Age Concern Westminster – Pullen Day Care Centre	020 7932 0140	0 Chinese
Church Street Drop-in Centre	020 7723 1104	0 Chinese
St Margarets Drop-in Centre	020 7821 1621	1 Chinese, now housebound, no details available
Westminster Mind	020 8969 2434	0 Chinese
Capio Nightingale Hospital (for adult psychiatric and neuropsychiatric problems)	020 7535 7700	0 Chinese
Residential and Nursing Homes		
Greathed Lodge Residential Care Home	020 7624 9173	0 Chinese
Norton House Residential Care Home	020 7976 7681	0 Chinese
St George's Nursing Home (private)	020 7821 9001/2	0 Chinese

Royal Borough of Kensington and Chelsea

Voluntary Sector Services		
Age Concern Kensington & Chelsea Dementia Service	020 7471 5557	0 Chinese
Forward Project (for	020 7381 8778	0 Chinese

people from ethnic minorities with mental health problems)		
Day Centres		
The Quest Day Centre (dementia)	020 7792 8434	0 Chinese
Edenham Day Centre (dementia)	020 8960 1301	0 Chinese
Kensington Day Centre	020 7727 7337	0 Chinese
EPICS, the Westway Centre	020 7598 4600	0 Chinese
Gertrude Street	020 7598 4747	0 Chinese

Brent

Voluntary Sector Services		
Age Concern Brent – advice, advocacy, outreach	020 8965 7711	2-3 Chinese people using drop-in advice service
Asian Community Care Services	020 8459 1030	
Day Centres		
Dollis Hill Day Centre (frailty, physical disability)	020 8450 7237	0 Chinese
Westbrook Day Centre (dementia)	020 8961 8831	0 Chinese
Residential and Nursing Homes		
Knowles House Residential	020 8961 9563	Currently 0 Chinese. Had 2 Chinese residents over one year ago. One had passed away; one is now in a nursing home.
Lonsfield Nursing Home	020 8830 4290	0 Chinese
Birchwood Nursing Home	020 8385 1115	0 Chinese
Middlesex Manor Nursing Home	020 8795 4442	0 Chinese
Extra Care Homes		
Tulsi House	020 8908 4650	0 Chinese
Tower House	020 8933 7203	0 Chinese
Craven House (Supported Housing)	020 8838 5302	0 Chinese
Hanover Road (Supported Housing)	020 7451 6325	0 Chinese

APPENDIX III

西敏市、肯盛頓與切爾西和布蘭特區內的 華人長者心理健康服務需求調查

內容提要

調查目的

語言障礙與文化上的差異成為許多居英華人未能懂得使用主流保健與社會護理服務的主要原因。全國華人保健中心 (CNHLC) 致力於促進健康生活，讓英國華人社區更容易使用國民保健服務。

有研究調查顯示，英國華人持續未能善用國民保健服務，當中包括心理健康服務。英國華人心理病患者使用服務率較低，可能包括華人心理病發病率較少或公眾未有善用心理健康服務的緣故。然而，以往數個調查及為華人社區所作的討論表明英國的主流保健與社會護理服務並未能切合華人心理健康的需求。

本調查計劃的主要目的是為要了解居住在西敏市、肯盛頓與切爾西和布蘭特區內的華人長者在心理健康服務上所遇到的困難和障礙，並希望能提供改善華人長者使用英國心理保健服務率的建議。

背景

本計劃是全國社區參與計劃的其中之一項目，旨在履行對衛生局所發表的「種族平等心理健康護理」(DRE) 為期五年的行動計劃。這個行動計劃的三個主要目標是為在英國的黑人和少數族裔在心理健康服務上促進平等的使用途徑、平等的實踐經驗和平等的最終結果。此項計劃是由英國國家心理健康研究院贊助，並由中蘭開夏大學 (UCLan) 監督管理。

宗旨和目標

本研究旨在回答下列問題：

華人長者在接觸心理健康服務時曾遇上什麼樣的障礙？

華人長者在心理健康服務時有什麼經驗？

本研究的調查項目

華人長者對心理健康有什麼信念，而對心理健康又有多少認識和了解？

華人長者以什麼態度面對心理健康服務？

華人長者對心理健康服務有什麼經驗呢？

研究方法

此項研究採用定性方法作調查。樣本收集包括居住在西敏市、肯盛頓與切爾西和布蘭特區，年滿 55 歲或以上的華人長者。一個專題小組與二十一次的個人面談討論於 2007 年 11 月到 2008 年 2 月期間開設。其中邀請了四個心理健康服務使用者、一個護理者與二十四個非服務使用者 (包括專題小組討論參與者) 來參與討論，搜集他們的意見和經驗。

結果和結論

這項研究顯示華人長者對心理健康的文化概念是一個很重要取決他們能否識別心理病和會否從國民保健服務尋求幫助的主要原因。研究發現，一般華人長者未必能識別心理病的症狀。以致當他們心理健康欠佳時也不察覺到這是需要看醫生的病徵。

研究顯示，橫跨三區的華人長者一致認為傳譯服務不可靠也不專業。語言溝通的困難再加上心理病的恥辱 (被視為缺乏自制力和懦弱) 令華人長者很多時未能在心理有問題時獲得適合的服務。

總括而言，華人長者 (已及一般華人) 在專科心理健康服務的使用率被發現為偏低。此發現表明了西敏市、肯盛頓與切爾西和布蘭特這三區的「種族平等心理健康護理」(DRE)行動計劃均未能為華人提供及配合其適當文化的環境 - 特別是住院設置的服務。

可行建議

1. 支持 CNHLC 為華人開辦一個心理健康活動。該活動將集中教育華人如何保持心理健康，提高華人對心理病的認識與接受服務的機會。
2. 建立一個用中文講解的保健 / 心理健康指南。該指南在全國華人保健中心提供的指引下，清楚列明服務使用者能獲得的保健 / 心理健康服務。
3. 懂多種語言的心理健康專業人員應該提供跨區服務。
4. CNHLC 與社區發展工作者 (黑人與少數族裔) 合作，為基層醫療服務人員開發和提供一個提高對心理健康認識的訓練和心理健康促進計劃。
5. 為社區心理健康小組、長者心理健康小組及駐院工作人員提供有關華人資源及中國文化認識的培訓。
6. 其中一專責小組或一個住院病房可帶頭與華人社區在工作上發展專業知識，並為其它小組 / 病房擔當顧問工作。