

**COMMUNITY ENGAGEMENT PROJECT  
NIMHE Mental Health Programme**

Report of the Community led research project focussing on:  
**The Needs of Chinese Older People with Dementia  
and their Carers**

**Wai Yin Chinese Women Society**

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Wen Li Ho  
Connie Jung  
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Improvement Partnership, managed and supported by  
The Centre for Ethnicity and Health, University of Central Lancashire.



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

### **Profiles of the researchers**

**Nancy Chan** – came to England 26 years ago and has four grown up children. Most of her time was dedicated to being a housewife, looking after her four children. Nancy also was employed in different jobs such as working in take-away shops, as a cleaner and a driver. She was a volunteer at Care and Repair after she completed her DIY course. With her skills, she has personally helped a lot of older people.

**Dorothy Ho** –is 45 years old. Dorothy is a married housewife with two children. She has three and half years experience working in a nursing home. Now that Dorothy's mother is reaching the age of 83, she fully understands what dementia means to her. This project not only provided her with the knowledge to deal with dementia, but gave her a more positive attitude towards people suffering from dementia. She would like to help those in need and to serve the community.

**Wen Li Ho** –is a housewife and likes to make new friends. The involvement of this project has increased her awareness of the host society and given her more understanding about Chinese living in England. Her participation in volunteer work has had an important effect on Wen Li – making her life more meaningful. Her greatest achievements from this project were to enhance her confidence, to improve her knowledge and to meet a group of supportive volunteers, and to help others.

**Connie Jung** –is over 50 years old, married with three children. She is a part-time receptionist at Wai Yin. She has experience of working in a nursery. She would like to develop her skills through the involvement of this project. She would like to be able to help people with dementia in the future.

**Kwai Fong Lau** – is a housewife with two children, a carer and works part time an assistant in a takeaway shop. She became involved with the project to learn more about mental health, and to increase her knowledge and confidence. By taking part in the project she has a better understanding of the issues that carers face.

**Sophie Lau** –is 50 years old. Sophie is a housewife, married with four grown up children. She likes to make good use of her time and enjoys doing the DIY course. Participating in Wai Yin volunteer work has given her a chance to learn new things and make a lot of friends.

**Sau Wan Li** –is 56 years old. She is a care worker and a carer herself. Initially the purpose of her involvement was to obtain more information and knowledge about dementia. During her participation in this project, she needed to find extra

time to manage her tight time schedule for trainings and meetings, as well as her work. Although she finds the project is very stressful, she feels that she has learnt a lot from this project. Her greatest achievement is to make new friends from the group, who are sympathetic, patient and supportive.

**Kim M. Mak** – is 49 years old, and joined this Project as a volunteer researcher. Formerly he was a catering/construction/legal worker. Now he is an interpreter/customer service officer. Participation in this Project has greatly helped him understand community research and mental health issues.

**Emily Ngai** - is 54 years old. She spent almost 30 years working at home, looking after her children and her family. She could not find any spare time for involving herself with volunteer work in the past. Her close friend has dementia, and she is so pleased that that she is able to participate in this project at her age and has learnt a lot about dementia from the training sessions.

**Xing Chan Shen** – was a teacher in China. She has been involved as volunteer since she settled in England a few months ago. Although she is struggling to find time managing her settlement in England, looking for jobs and the involvement of this project, she finds that the volunteers in this project are very helpful and she had learnt a lot from this project. She would like to develop her skills in this area and be able to serve the Chinese community in the future.

**Liping Wen** – is 26 years old. She settled in England five years ago. Liping has a 3 year old daughter and she is a full time student. Her experience gained from this project has not only increased her knowledge about mental health issues but also to enjoy the mutual support from the other group members. She finds the group members are very kind and helpful.

**Sau Wah Chan Wong** – also known as Ping is 50 years old. After working in a commercial establishment for many years, she is ready for a career change. Joining the project has been a chance to explore new areas of work. She finds the UCLAN Community Engagement model fascinating and the Wai Yin project well coordinated. Apart from gaining new knowledge and understanding on mental health policy and practice, Ping has experienced personal growth through her involvement with other volunteers. She is particularly delighted to see that others in the group have also undergone some personal growth through their participation. Ping hopes that the research findings would help to improve the access, experience and beneficial outcomes of Chinese mental health service users.

**Susan Yip** –is over 40 years old. When she joined this project, her business had come to the end. The project gave her an opportunity to learn a lot about mental health and research and involved her with volunteer work, from which she was able to widen her career prospective. It also gave her a better understanding about Chinese older people in Manchester and would like to practice what she had learnt from this project.

**Louise Wong** –is just over 50 years old. She has been working as a Mental Health Development Worker since the Kwan Wai project was established in 1999. She is a mother of two grown up children, with nursing and health studies background. The project has given her an in-depth knowledge of mental health in relation to Chinese older people and a full picture of the cultural clash among the immigrants and their adaptation to social change over a period of time.

**Mark Greenwood** –is nearly 50 years old. He is a qualified psychiatric nurse with over 25 years experience working in the NHS, supported housing and voluntary sectors. He has managed the Kwan Wai (Mental Health) Team for the last six years. Mark used to be Chair of the Manchester Alzheimer's Society, so he has a particular interest in issues relating to dementia.

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# **CONTENTS**

I

	<b>Page</b>
<b>Profiles of the researchers</b>	<b>2</b>
<b>Acknowledgements</b>	<b>5</b>
<b>List of Tables and Figures</b>	<b>7</b>
<b>Executive Summary</b>	<b>10</b>
<b>Introduction</b>	<b>13</b>
<b>Background Information</b>	<b>18</b>
<b>The focus of this report</b>	<b>19</b>
<b>Methodology</b>	<b>20</b>
<b>Results</b>	
<b>Section 1 Profile of the respondents</b>	<b>23</b>
<b>Section 2 Daily life needs</b>	<b>31</b>
<b>Section 3 Dementia Awareness</b>	<b>36</b>
<b>Section 4 Family Doctor</b>	<b>50</b>
<b>Section 5 Health and Social Care need</b>	<b>61</b>
<b>Section 6 Discussion</b>	<b>71</b>
<b>Section 7 Recommendations</b>	<b>84</b>
<b>Appendix 1 Focus group interview questions</b>	<b>86</b>
<b>Appendix 2 Questionnaire Chinese version</b>	<b>87</b>
<b>Appendix 3 Questionnaire English version</b>	<b>102</b>
<b>Appendix 4 Occupation of the respondents</b>	<b>118</b>
<b>References</b>	<b>119</b>

## LIST OF TABLES AND FIGURES

			<b>Page</b>
Section 1		Profile of the respondents	
	Chart 1.1	Gender of the respondents	21
	Chart 1.2	Age range of the respondents	21
	Chart 1.3	Respondents' first language	22
	Chart 1.4	Language profile of the respondents	23
	Chart 1.5	Religion	23
	Chart 1.6	District of residency	24
	Chart 1.7	Accommodations	24
	Chart 1.8	Housing Circumstances	25
	Chart 1.9	Country respondents came from	25
	Chart1.10	The length of stay in the U.K.	26
	Chart1.11	Reasons for settled in the U.K.	27
	Chart1.12	Education	27
	Chart1.13	Retirement	28
	Chart1.14	Disability	28
Section 2		Daily Life Needs	
	Chart 2.1	Thing makes respondents happy	29
	Chart 2.2	Concept of mental health	30
	Chart 2.3	Problems Chinese older people encounter to	31
	Chart 2.4	Respondents have the same problems	31
	Chart 2.5	Respondents' seek help pattern	32
	Chart 2.6	Seek help from family members	33
	Table 2.1	Seek help pattern	32
	Table 2.2	Seek help from family members	33
Section 3		Dementia Awareness	
	Chart 3.1	Respondents heard of dementia	34
	Chart 3.2	Respondents attended dementia talks	34
	Chart 3.3	Description of dementia	36
	Chart 3.4	Behaviour change of people with dementia	38
	Chart 3.5	Cause of dementia	40
	Chart 3.6	Dementia is a mental illness	40
	Chart 3.7	Dementia can be cured	41
	Chart 3.8	Respond to dementia	41
	Chart 3.9	Respondents willing to pay for treatment	42
	Chart 3.10	Place where people with dementia should stay	43
	Chart 3.11	Chinese community respond to people with dementia	44
	Chart 3.12	Dementia can be prevented	45

			<b>Page</b>
	Table 3.3	Description of dementia from the respondents	36
	Table 3.4	Respondents think changes might happen to a person with dementia	38
	Table 3.5	Respondents think the cause of dementia	39
	Table 3.6	Chinese community respond to people with dementia	44
	Table 3.7	Activities that could reduce the chance of having dementia	45
	Table 3.8	The fears that stopping older Chinese people accessing the mainstream or mental health services	46
	Chart 3.14	Fears of using mental health services	46
<b>Section 4</b>		<b>Family doctor</b>	
	Chart 4.1	Language used to communicate with the GP	48
	Chart 4.2	Understand doctor's prescription	49
	Chart 4.3	Understand side-effects	49
	Chart 4.4	Need accompany to visit GP	50
	Chart 4.5	Someone went with the respondents to see doctors	50
	Chart 4.6	Accompany with respondents to see doctors	51
	Chart 4.7	Need interpreter during consultation	52
	Chart 4.8	Interpreting for respondents during consultation	53
	Chart 4.9	Satisfaction of the interpreting services	54
	Chart 4.10	Memory problem	54
	Chart 4.11	Memory problem consult with GP	55
	Chart 4.12	Supported by carer	
	Chart 4.13	Carer offered a carer assessment	
	Chart 4.14	Respondents are carers	
	Chart 4.15	Carers offered assessment	
	Table 4.1	Members accompany with respondents to see doctor	51
	Table 4.2	Members interpreting for the respondents during consultation	53
	Table 4.3	Problems consult to doctor and referral was made to health services	55
	Table 4.4	Carer referral services and rating of satisfaction of the services	58

			<b>Page</b>
<b>Section 5</b>			
	Chart 5.1	Children unable to help	59
	Chart 5.2	Heard of the benefits	62
	Chart 5.3	Apply for DLA	62
	Chart 5.4	Apply for AA	63
	Chart 5.5	Apply for Carere Allowance	63
	Chart 5.6	Apply for Income Support	64
	Chart 5.7	Apply for Pension	64
	Chart 5.8	Apply for Pension Credit	65
	Chart 5.9	Apply for Direct Payment / Individual Budget	65
	Chart 5.10	Require a carer	66
	Chart 5.11	Services suggested by respondents	67
	Table 5.1	Children unable to help means not show filial piety	59
	Table 5.2	Reasons of children should filial piety to parents	60
	Table 5.3	Reasons for children unable to offer help	61
	Table 5.4	Respondents had heard of the benefits	61
<b>Section 6</b>			
		Discussion	
	Chart 6.1	Accommodation	69
	Chart 6.2	Living on their own and age group	70
	Table 6.1	Live in Manchester and age group	69
	Table 6.2	Respondents living on their own and housing	70
	Table 6.3	Age 50-64 age group and occupation	71
	Table 6.4	Language profile of the respondents	71

## EXECUTIVE SUMMARY

According to the 2001 census, there are 250,000 Chinese people in the UK. It is estimated that there are 30,000 Chinese in the Greater Manchester area. During the 1950s and 1960s, many young Chinese came to work in the UK, the vast majority of whom set up businesses and raised their families here. This generation is now in their 70s and 80s and, inevitably, many have become frail, both in mind and body.

Research (Jones and Lam 2004) on service usage among Chinese older people showed that they have great difficulty in accessing health services. This is especially difficult for people suffering from dementia and their families. The Chinese community is not prepared for the expected rise in the number of people suffering from dementia. The opportunity presented by the Community Engagement Programme was timely and essential to address these needs.

Thirteen volunteers were recruited and trained to carry out this research project. The project aim was to explore the needs of Chinese older people with dementia and their carers in Greater Manchester. One to one interviews were conducted in different Chinese communities within the Manchester area. 72 people completed questionnaires; 28 males and 44 females respondents, aged between 50 and 87. All are immigrants; 75% of them came from Hong Kong and almost 75% respondents are Manchester residents and have lived in the UK for over 20 years.

20% of the respondents are living on their own. Those living on their own are more likely to rent from a housing association in Manchester. The language barrier was singled out as the major difficulty that the Chinese older people encounter in their daily life. However, almost 33% of them thought that Chinese older people need some one to look after them and they found that cultural differences make it difficult to adapt and integrate in the UK's lifestyle. Chinese older people also feel isolated as a result of declining physical health and a social environment that restrains their mobility. In consequence about 75% of Chinese older people are heavily reliant on support from their family members, especially their children. It is a Chinese tradition that children are obliged to look after their parents. In addition, due to language barrier, they are more likely to seek help and support from the Chinese communities rather than Government services.

Over 80% of respondents had heard of dementia and over half of them were aware that dementia is related to memory lost. In addition, they believed that dementia is related to the person's thinking and that people with dementia appear to be 'dull witted'. The person with dementia will have memory loss, and problems associated with their mobility and speech. The cause of dementia is due to aging, excessive stimulation (unexpected shock), brain disease or isolation. This description of dementia is widely believed by people within the Chinese community.

There was mixed feelings about whether dementia should be called a mental health problem. Just over half of them thought that it is a mental illness; about 33% of them thought that it is not, and less than 20% of them were not sure whether or not it is a mental illness. The findings also revealed their helplessness when they or their family member suffer from dementia. Seeking help from their GP seems to be the

only option to seek help from. However, due to the language barriers most of the Chinese older people think having dementia is due to old age and nothing can be done about it. Few of them were referred to carry out an assessment about their memory loss.

In addition, there is a strong stigma attached to people with mental health problems and the fear of “losing face” also stops them gaining access to mental health services. Whether or not they are willing to seek help and advice outside the family, will depend on their knowledge and attitudes towards people with dementia. Therefore, it is crucial to provide adequate knowledge and information of dementia for the service users and the carers.

Furthermore, the findings show that Chinese older people have a strong wish to maintain their independence and dignity; to be able to have choice of treatments and services and to be less reliant on their children. However, Chinese older people feel that as there is a lack of available information, they would not know what to do or where to seek help, if a family member suffers from dementia. Therefore, it is important to provide individual and family support for the people with dementia and their carers to link up with the existing services and to develop services which are culturally appropriate for Chinese older people. In order to do this, it is important to develop a workforce through continuous training and encourage service users and carers to become actively involved in the development of mental health policy and in the planning and provision of services.

### **Key recommendations**

1. Establish a partnership with the Alzheimer’s Society to use their expertise and skills in challenging ignorance and stigma about dementia within the Chinese communities. This will lead to a reduction in fear about mental health services amongst Chinese communities
2. Fund, recruit and sustain a Dementia Outreach Worker who will work with sufferers and their carers to help them access services which are culturally competent
3. Establish a more balanced range of therapies for Chinese dementia sufferers. This includes a support group for carers, a be-friending scheme run by volunteers, a Chinese counselling service and research partnerships with universities in China and Hong Kong.
4. Develop the existing volunteer researchers and recruit more volunteers to take an active role in training of professionals, in the development of mental health policy and in the planning and provision of services.
5. To establish a workforce capable of delivering appropriate and responsive mental health services. To set up a culturally appropriate home support service which is capable of working with the Chinese communities in the Greater Manchester area

## **Wai Yin Chinese Women Society**

This Dementia Project was carried out by staff and volunteers of The Wai Yin Chinese Women Society (known as Wai Yin). Wai Yin was founded twenty years with the clear mandate to help and support Chinese women in the Manchester area. At the time, many women could not speak English and were having many problems such as domestic violence and difficulties with parenting children. Wai Yin's philosophy has always been that women need to empower themselves through education, financial independence and mutual self-help. Over the last twenty years, Wai Yin has developed many projects ranging from child-care, youth, elderly, mental health, education, job preparation and welfare/tax support. There are over 500 members and all the services are open to men and women, Chinese and non-Chinese.

## **INTRODUCTION**

### **The Centre for Ethnicity and Health's Model of Community Engagement**

#### **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.

### **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 community<sup>1</sup>, 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 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 researchers<sup>2</sup>. 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.

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<sup>1</sup> 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).

<sup>2</sup> 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.

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 project<sup>3</sup>.

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

### The community engagement team

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			

### 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:

<sup>3</sup> 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 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 the report are those of the group that undertook the work, and are not necessarily those of the Centre for Ethnicity and Health at the University of Central Lancashire.

## **Background Information**

According to the 2001 census, there are 250,000 Chinese people in the UK. It is estimated that 30,000 Chinese people live in the Greater Manchester area alone. There are two distinct Chinese communities in Manchester – Cantonese and Mandarin speaking. Those who speak Cantonese are from Hong Kong or the neighbouring province of Guangdong. The majority of older Chinese people came from Hong Kong New Territories and Hakka is their mother tongue. However, most of them have a good understanding of Cantonese.

Throughout the 1950s and 1960s, young Chinese men (followed later by their wives) came to live in Manchester and bought existing fish and chips restaurants to cater for the growing English taste for Chinese food.

In recent years, a newer Chinese community has developed, coming from mainland China (People's Republic). This community is separate from the older more established Hakka and Cantonese community. Since most of them have come as students, it is a much younger community.

The generation that came in the 1950s and 1960s have become elderly and some have become frail and housebound. Research on service usage by Chinese older people in 2004 shows that Chinese older people in Manchester have great difficulty in gaining access to health services, and there is no accurate information recorded about their use of Primary Care Services (Jones and Lam, 2004). From anecdotal experience, we estimate that there has been a rise in the number of people experiencing dementia within the Chinese community. The Chinese community is not prepared for this rise in people suffering from dementia and their families are finding it very hard to access appropriate support and help.

## **The Focus of This Report**

Since 2000, over 200 community groups have taken part in one or other of the Centre for Ethnicity and Health's Community Engagement Programmes.

Wai Yin Chinese Women Society was one of 40 community groups who took part in the National Institute for Mental Health in England's Community Engagement Programme between 2006 and 2007.

The objectives of the programme were to improve equality of access, experience and outcomes for Black and minority ethnic mental health service users by:

- Building capacity in the non-statutory sector
- Encouraging the engagement of Black and minority ethnic communities in the commissioning process
- Ensuring a better understanding by the statutory sector of the innovative approaches that are used in the non-statutory sector
- Involving Black and minority ethnic communities in identifying needs and in the design and delivery of more appropriate, effective and responsive services
- Ensuring greater community participation in, and ownership of, mental health services
- Allowing local populations to influence the way services are planned and delivered
- Contributing to workforce development, and specifically the recruitment of 500 Community Development Workers

(DoH) 2005

**The focus of our work was:**

**The needs of Chinese older people with dementia and their carers**

### **AIMS AND OBJECTIVES**

- To gain insight into the lived experience of dementia within the Chinese community
- To identify the needs of older Chinese people with dementia and their carers in the Manchester area
- To develop tailor-made services for Chinese older people with dementia and their carers
- Raise awareness of dementia among Chinese older people
- Promote positive attitudes towards Chinese older people with dementia
- Awareness of the availability of support and services for people with dementia and carers both from the statutory services and voluntary organisations
- Capacity building of the research team
- To look at the cultural needs of the older people with dementia and their carers such as treatment, respite care and support services.

## **METHODOLOGY**

### **Volunteer researchers**

13 volunteer researchers were recruited in this project. The group of volunteer researchers consisted of carers, mental health service users, care workers and Wai Yin volunteers. All of them were actively involved with the mental health project and Wai Yin's other projects.

The training was provided both from Wai Yin and UCLAN. At the beginning of the project, two mental health workshops were delivered by UCLAN to provide an overview of national mental health policies, and 5 research workshops. These workshops were followed by three dementia awareness training sessions, delivered by Wai Yin to offer different perspectives on dementia to the volunteer researchers; Dementia awareness; Dementia in Hong Kong and Caring for People with Dementia.

Moreover, in order to provide volunteer researchers with a wider view of health and social care services related to dementia, Wai Yin also organised a training session on health services for older people in Manchester and a session on benefit awareness.

For most of the volunteer researchers, English was a second (or third) language. There was a key issue of language barriers when attending workshops and training and an interpreter was arranged by UCLAN for the workshops and training. The Project Co-ordinator and the Kwan Wai (Mental Health) team provided language support for each support worker visit and other training.

Some volunteers struggled with childcare arrangements and time management for their work and study. With support from Wai Yin, volunteer researchers were able to receive childcare during the training sessions and meetings. However, as the group developed, mutual support was provided between members to ease the tensions between their work and study. Research budgets need to include childcare and dependent care budgets.

The volunteer researchers were involved with each stage of the research project. This included the design of the project, methodology used, data collection and data analysis. In addition, their enthusiasm for this project and for working in the community also put what they had learnt into action. The most important task was to raise awareness about our project and to collect information from older Chinese people about their views on dementia.

A dementia awareness talk was delivered on the 8<sup>th</sup> October 2006 to a group of Chinese older people at a World Mental Health Day Event. The Wai Yin Community Engagement Project also presented to the Chinese community and the Primary Care team in Belfast. The group visited Belfast on the 30<sup>th</sup> November 2006. The Chinese community in Belfast are the largest ethnic minority in Northern Ireland, but remain isolated from other Chinese communities in the rest of the UK.

## **The Steering Group**

The Steering group was set up in May 2006 and held monthly meetings. The steering group consisted of a service user, volunteer researcher, local Trust outreach worker, an Admiral Nurse, a member of The Alzheimer's Society, the Chair of Primary Care Trust in Salford and lecturers from Salford University and Manchester Metropolitan University. The aim of setting up the steering group was to provide support and guidance to the research project. It had responsibility for helping the project manage the ethical issues, giving advice and training on potential ethical issues that might occur. The project also obtained support from the Regional Race Equality Lead CSIP North West via the north west community engagement network and meetings where based in Manchester.

## **Research Ethics**

All the volunteer researchers involved with interviewing participants had to attend the research workshops. They are all aware of the importance of informing the respondents about the purpose of the project and obtaining consent from them.

All respondents participated on a voluntary basis. Due to the nature of the project and the target group which included vulnerable adults, it was important to inform all respondents about our project and obtained consent from them before the interviews were carried out. All respondents were made aware that they had the right to withdraw at any point during the interview. Moreover, the respondent's name was not to be recorded on the questionnaire. However, if the respondents wished to obtain further mental health information or the final report, they could leave their name and contact address on a separate sheet so that we could contact them in the future for this purpose.

## **Methods**

For the purpose of this research, the term "older people" is defined as anybody aged over 50. However, the target group we focused on was aged over 65. A one to one semi-structured questionnaire was used in this research project. However, it was important for the researchers to obtain some background knowledge about Chinese older people in Manchester and to design an appropriate questionnaire for this research project. A focus group interview was conducted for this purpose.

Two focus group interviews were carried out in October 2006 at the Sheung Lok Day Centre, (Wai Yin's elderly luncheon club). The themes we focused on were; how do people seek help, knowledge and understanding about dementia, what and where the support needs among the Chinese older people and carers (see Appendix 1). A questionnaire was developed for the members of the Chinese community in Manchester (see Appendix 2 and 3).

Permission was obtained from Chinese respondents to carry out the research in their own premises. All interviews were conducted within the premises of the local Chinese Community services: Wai Yin Centre, Wai Yin Elderly Day Centre, Buddhist Light Temple, the Chinese Christian Church and Tung Sing Housing Association.

The questionnaires (see Appendix 2 and 3) combines with both quantitative and qualitative data. SPSS statistics programme was used to analyse quantity data, in addition, in regarding qualitative data collected from the open questions, all response was written down by the researchers and thus the recurring themes were identified.

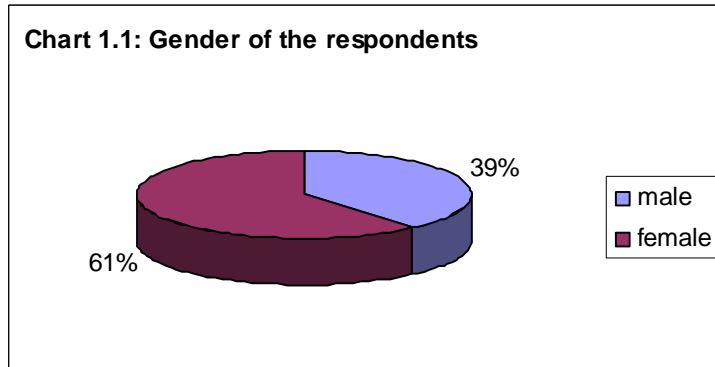
# RESULTS

## Section 1 : Profile of the respondents

A total of 72 respondents completed the questionnaire.

### 1.1 Gender

Among the 72 respondents, 28 (39%) were male and 44(61%) female. (see Chart 1.1)

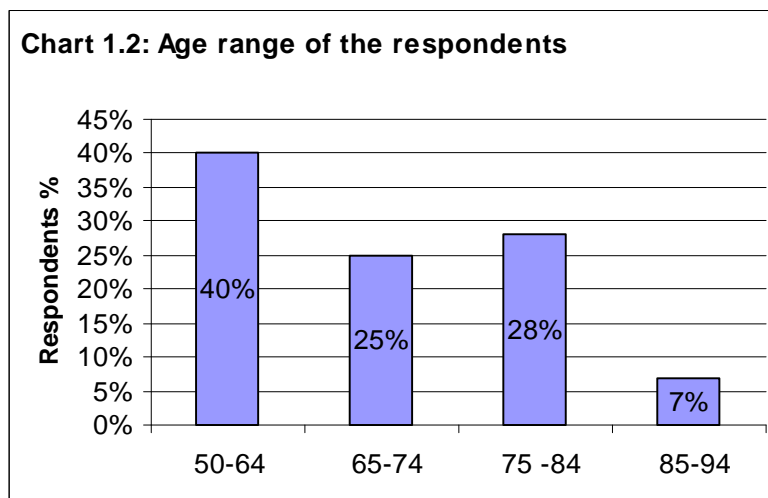


61% were female and 39% were male. 48 are heterosexual and 24 did not wish to answer their sexual orientation

### 1.2 Age

Their age range is between 50 and 87. The last birthday of the respondents (see Chart 1.2):

29 (40%) aged between 50-64 years old  
18 (25%) aged between 65-74 years old  
20 (28%) aged between 75-84 years old  
5 (7%) aged between 85-94 years old



### 1.3 First Language :

#### Written Chinese

17 (24%) of them do not understand written Chinese at all.

55 (76%) of them have different level of understanding of written Chinese.

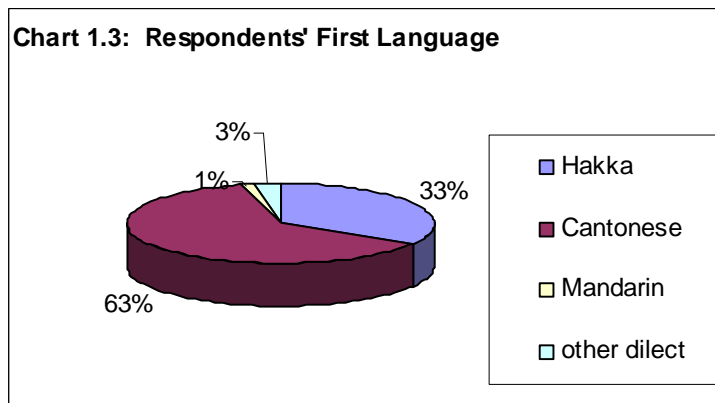
#### First Language

45 (63%) of the respondents their first language is Cantonese

24 (33%) their first language is Hakka

1 ( 1%) speaks Mandarin

2 ( 3%) speak other dialects (see Chart 1.3)



### 1.4 Language profile

#### 1.4.1 English

23 (32%) of them do not understand English at all

39 (54%) of them understand a little English

10 (14%) they speak fluent English.

#### 1.4.2 Mandarin

27 (38%) of them do not understand Mandarin at all

34 (47%) of them understand a little Mandarin

11 (15%) of them speak fluent Mandarin

#### 1.4.3 Cantonese

All respondents understand Cantonese, among them

5 (7%) understand a little Cantonese

67 (93%) of them speak fluent Cantonese

#### 1.4.4 Hakka

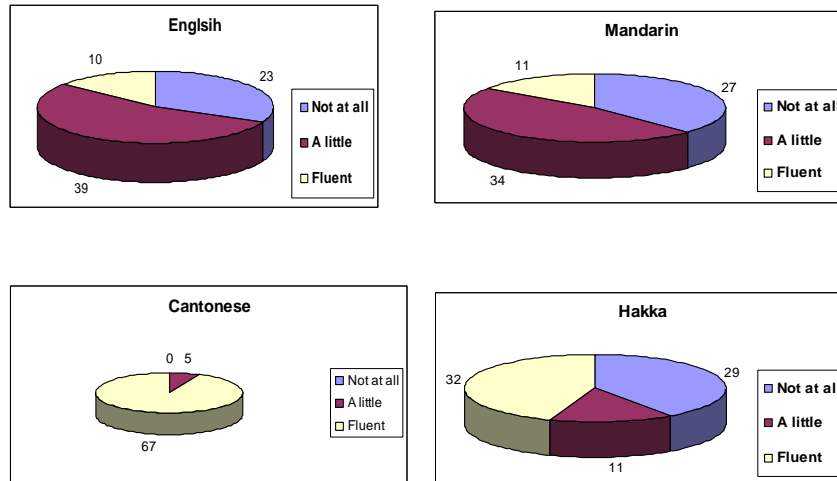
29 ( 40%) of the respondents do not understand Hakka

11 (15%) understand a little Hakka

32 (45%) speak fluent Hakka

(see Chart 1.4)

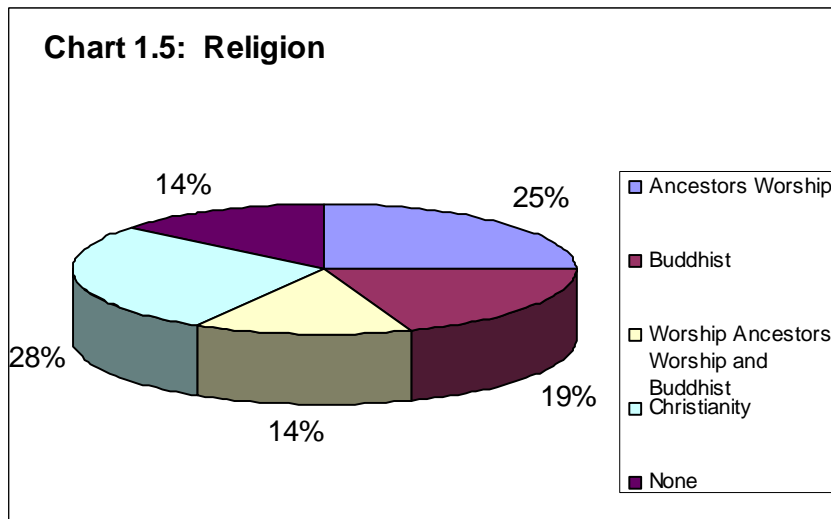
**Chart 1.4 Language Profile of the Respondents**



### 1.5 Religion

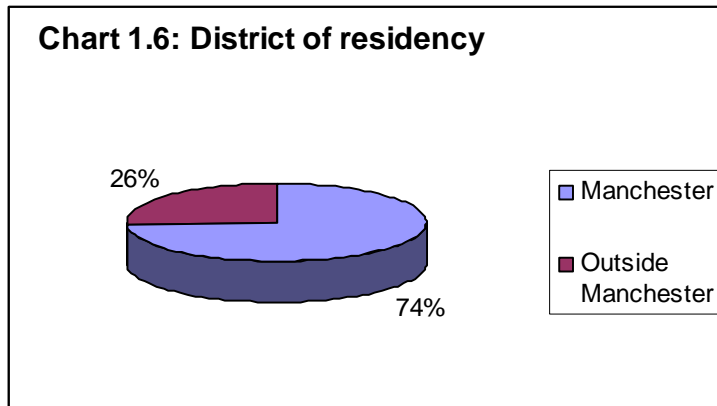
- 18 (25%) of the respondents are Ancestors Worship
- 14 (19%) are Buddhist
- 10 (14%) practice both Ancestors Worship and Buddhist
- 20 (28%) practice Christianity
- 10 (14%) has no religious faith
- (see Chart 1.5)

**Chart 1.5: Religion**



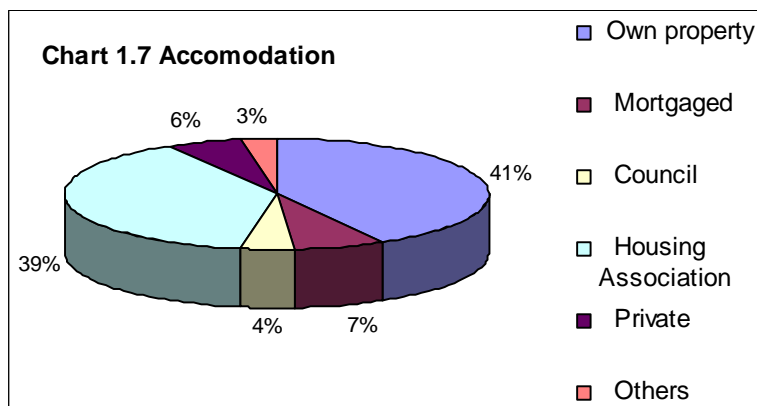
## 1.6 District of residency

53 (74%) of the respondents live in Manchester  
19 (26%) live outside Manchester.  
See Chart 1.6



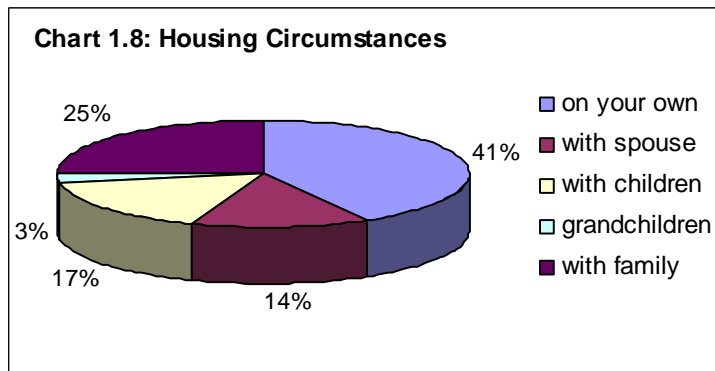
## 1.7 Type of accommodation

30 (42%) live in their own house  
5 (7%) live in their house with mortgage  
3 (4%) rent from Manchester City Council  
28 (39%) rent from Housing Association  
4 (6%) rent from private housing  
2 (3%) housing provided by others  
(see Chart 1.7)



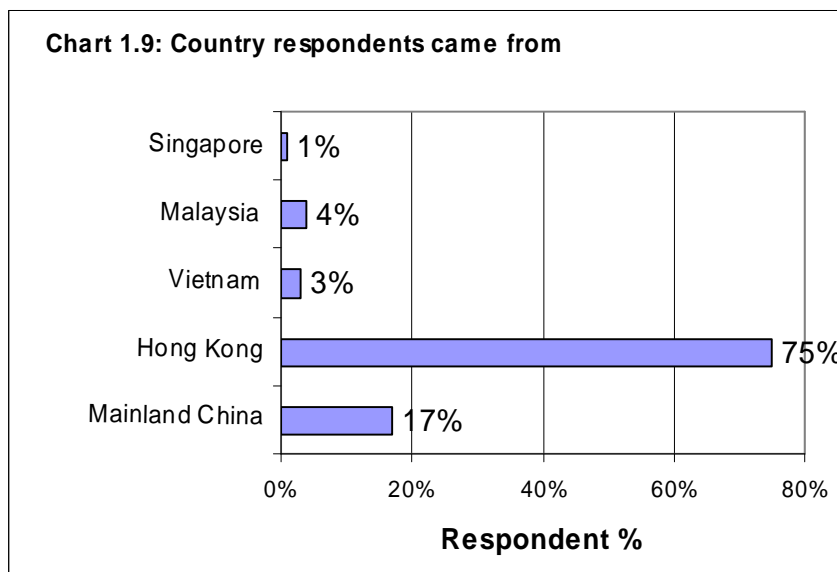
## 1.8 Living Circumstances

30 (41%) of the respondents live on their own  
10 (14%) live with spouse or partner  
12 (17%) live with their children  
2 (3%) live with their grandchildren  
18 (25%) live with their family  
(see Chart 1.8)



## 1.9 Country of Origin

54 (75%) of the respondents came from Hong Kong.  
12 (17%) came from mainland China;  
3 ( 4%) came from Malaysia  
2 ( 3%) came from Vietnam  
1 ( 1%) came from Singapore. (See Chart 1.9)

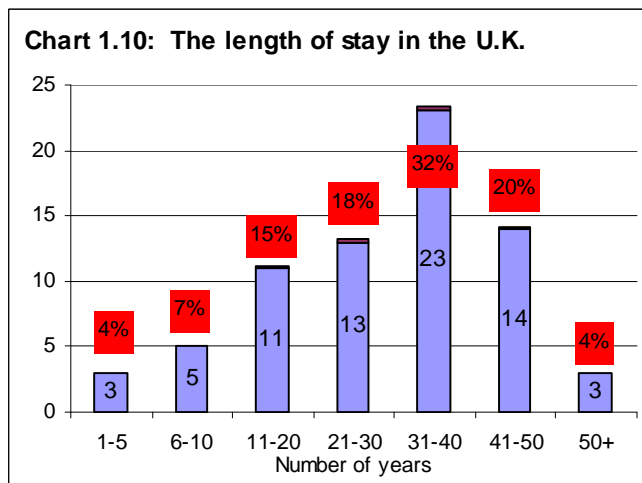


### 1.10 Born in the U.K.

None of the respondents were born in the U.K.

3 ( 4%) of the respondents live in the UK between 1-5 years  
5 ( 7%) of them 6-10 years  
11 (15%) of them 11-20 years  
13 (18%) of them 21-30 years  
23 (32%) of them 31-40 years  
14 (19%) of them 41-50 years  
3 ( 4%) of them over 50 years

(see Chart 1.10)



### 1.11 Citizenship

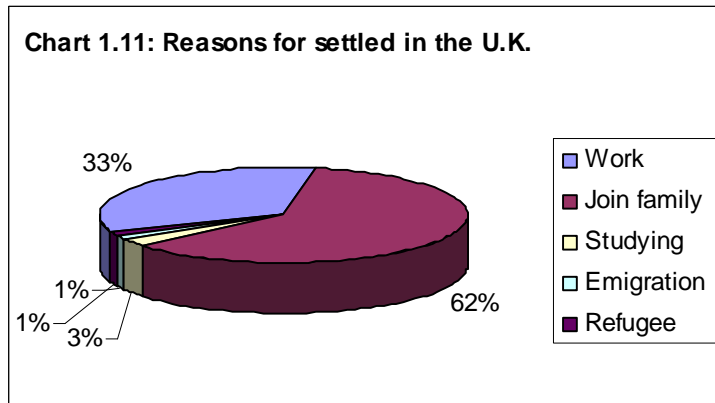
69 (96%) of the respondents are British citizens (3 refused to answer this question).

### 1.12 Ethnicity

All of the respondents said that they are Chinese although they came from different countries.

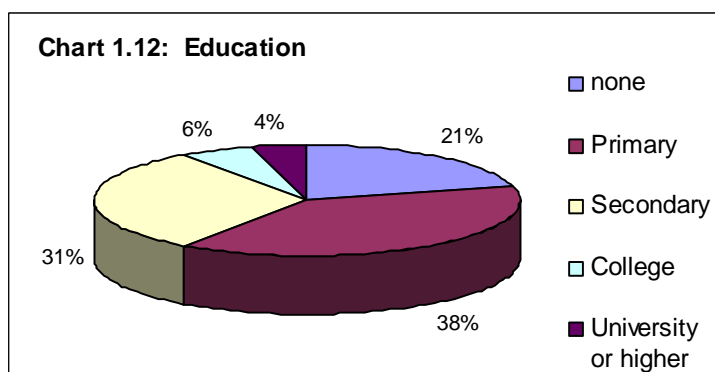
### 1.13 Reasons for coming to the U.K.

44 (60%) of them came to join their families  
24 (33%) were came for work  
2 (3%) of them came for studying  
1 (1%) was a refugee  
1 (1%) came for emigration  
(see Chart 1.11)



### 1.14 Education Attendance

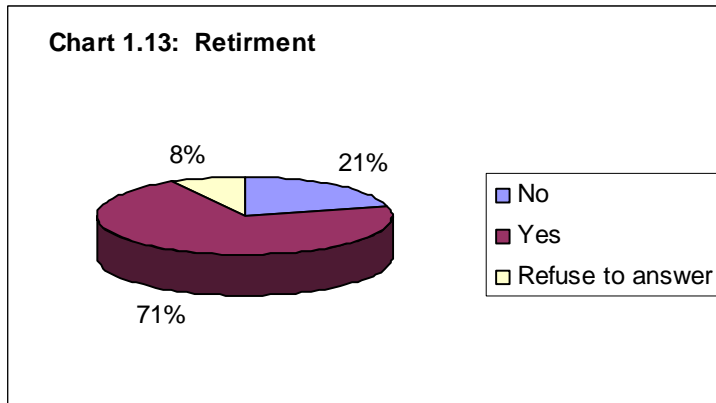
15 (21%) of the respondents had not received any education  
28 (39%) received primary schooling  
22 (31%) received secondary schooling  
4 (6%) received up to college education  
3 (4%) received university or higher education



### 1.15 Profession

51 (71%) respondents said they had retired, while 15 (21%) said they are not retired ; 6 (8%) did not wish to answer this question (see Chart 1.13).

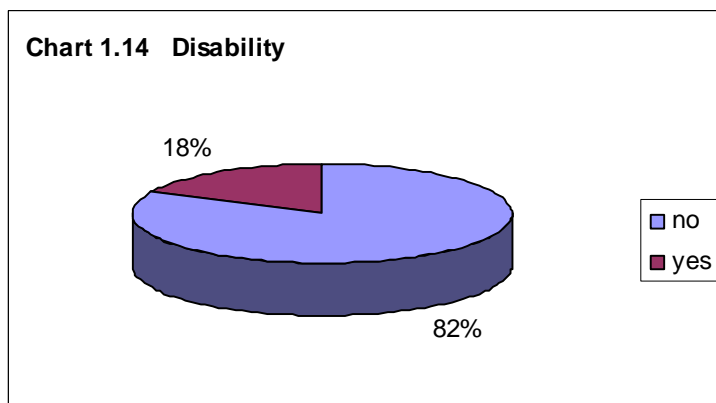
Respondents also stated their occupation (see Appendix 4)



### 1.16 Disability

13 (18%) of the respondents state that they had a disability

59 (82%) said that they were not a disabled person (see chart 1.14)



## Section 2 Daily Life Needs

### 2.1 Respondents were asked about things that make them happy.

14 (19%) of them said if family could always gather together, and grandchildren where around that will make them happy

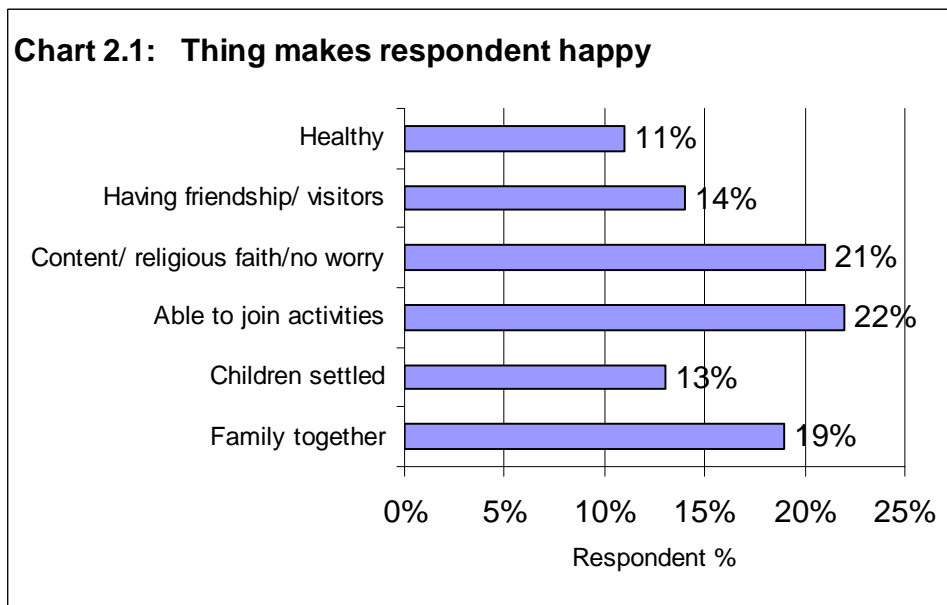
9 (13%) said if they could see children all settled down with their own families that will make them happy.

16 (22%) of them said if they could move around, able to keep up with their hobbies and activities such as going to the luncheon club or work that will make them happy.

15 (21%) said that being content with their circumstances, not to worry too much and have religious faith that will make them happy.

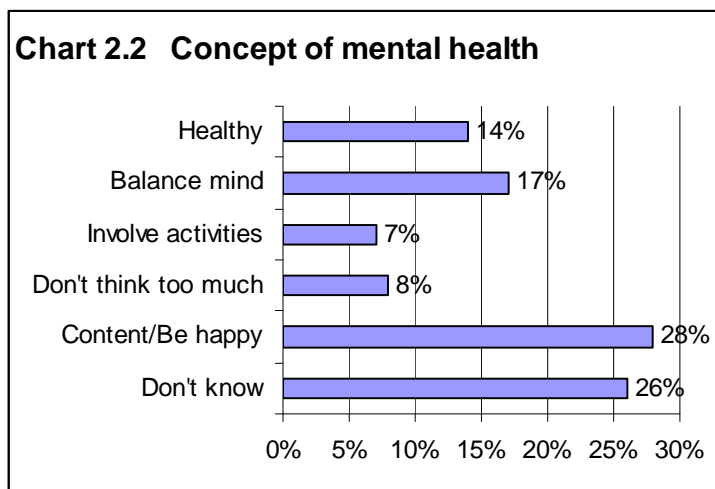
10 (14%) said having friends or visitors come around or someone to talk to that will make them happy.

8 (11%) said keeping oneself healthy, no illness or pain is happiness (see Chart 2.1)



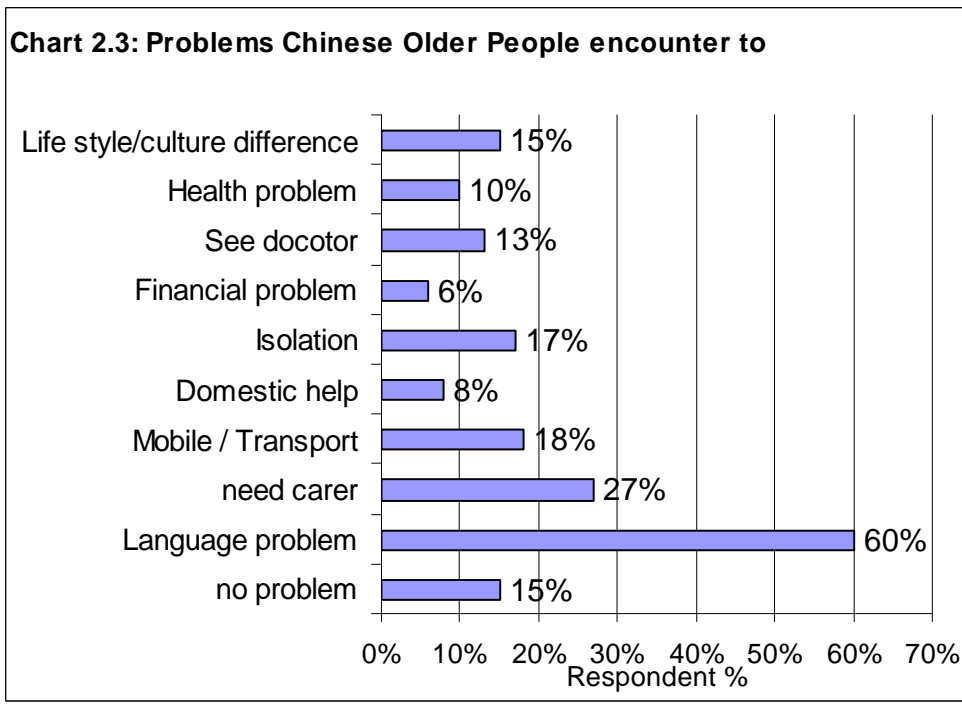
## 2.2 Respondents were asked what they think mental health means.

19 (26%) do not know what mental health is  
20 (28%) said that if everything is fine, be content with their own circumstances, then the person will always be happy and not worry.  
6 (8%) of them said not thinking too much is mental health  
5 (7%) of them said the person must able to engage him/herself in activities, more exercises - that is mental health  
12 (17%) said having a 'balanced mind' is mental health, so that the person is able to think positively  
10 (14%) said that mental health means the person is in good health, both physically and mentally (see Chart 2.2)



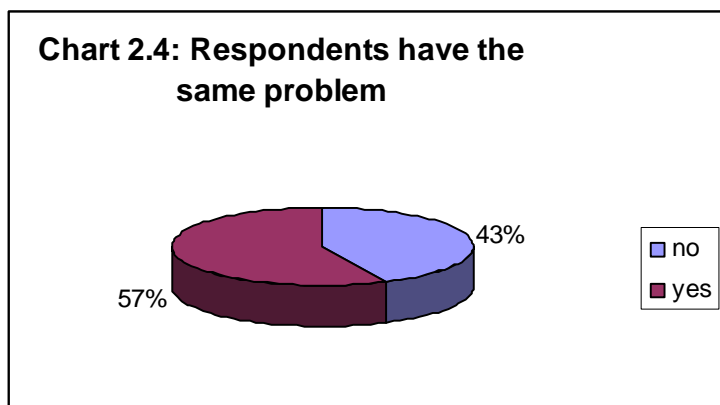
## 2.3 Respondents were asked their views about the difficulties that older Chinese people face in their daily life.

43 (60%) of the respondents said Chinese older people have a language barrier and have difficulties communicating in English  
14 (27%) of them said their difficulty is they are unable to look after themselves and need someone to help them.  
13 (18%) said Chinese older people have mobility problems or transport problems to help them get around  
6 (8%) of them said the older people find difficulties in doing their shopping or cooking  
12 (17%) said that older people are isolated, their children are unable to help them and they do not know how to seek help.  
4 (6%) said that the older people have financial problems  
9 (13%) said that the Chinese older people have problems seeing doctors  
7 (10%) of them said Chinese older people have health problems.  
8 (15%) said that are facing a culture difference from the country they came from, they need to adapt to the changes of the society.  
11 (15%) said that they Chinese older people have no difficulties in their daily life. (see Chart 2.3)



**2.4 Respondents were also asked whether or not they face similar difficulties.**

31 (43%) of them said they do not have any problem  
 41 (57%) of them said they have the same problems  
 (see Chart 2.4)



## 2.5 Seek help pattern

The respondents were asked who they would turn to if they encountered any difficulties in their daily life;

52 (72%) of the respondents said that they would seek help from a family member;

23 (32%) said that they would ask help from a neighbour;

14 (20%) said they would seek help from a warden

25 (35%) said they would ask their friends to help them

32 (45%) would go to Chinese community centres

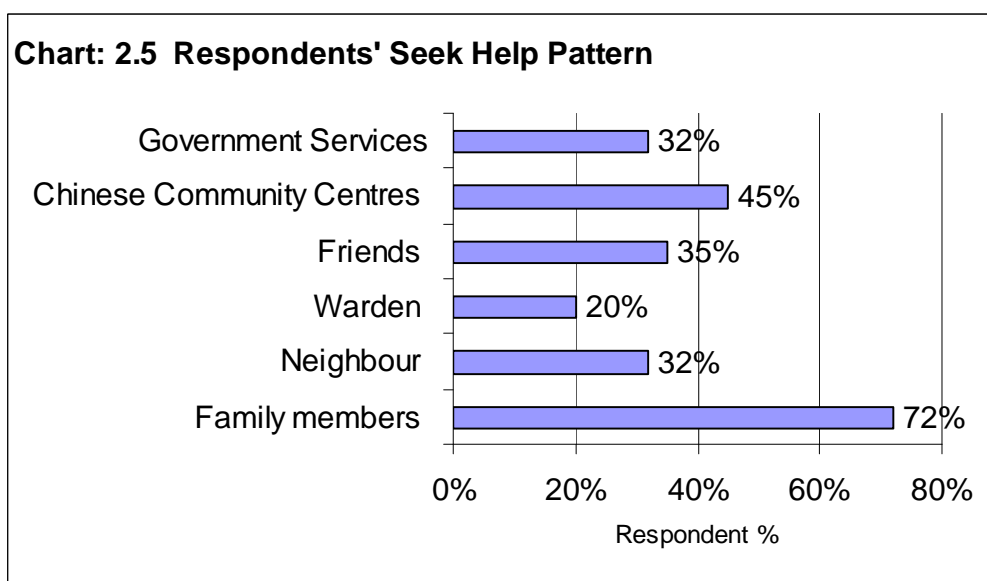
23 (32%) would rely on Government services

(see Table 2.1 and Chart 2.5)

**Table 2.1: Seek Help Pattern**

Seek help from	No. of Responds	Percent
Family members	52	72%
Neighbour	23	32%
Warden	14	20%
Friends	25	35%
Chinese Community Centres	32	45%
Government Services	23	32%
Total responses	169	236%

**Chart: 2.5 Respondents' Seek Help Pattern**

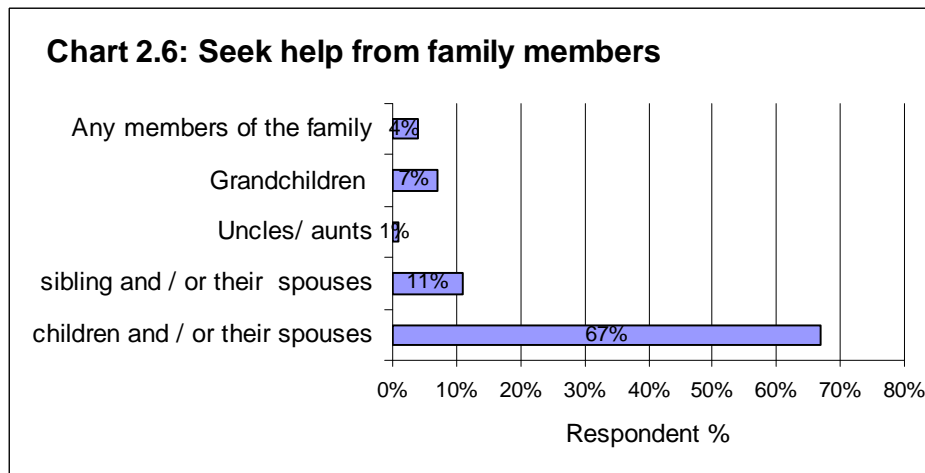


For those respondents who said that they would seek help from family members, they were then asked which family members that they would turn to when they need help

- 48 (67%) said that they would rely on their children or their spouses
- 8 (11%) said they would asked help from their siblings or their spouses
- 1 (1%) said they would consult their uncles and aunts
- 5 (7%) said that would asked help from their grandchildren
- 4 (4%) said they would seek help from any members within the family

**Table 2.2: Seek help from family members**

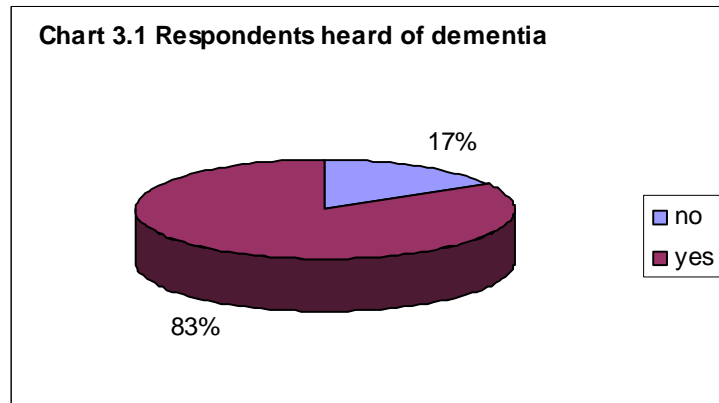
	No. of Respondents	Percent
children and / or their spouses	48	67%
sibling and / or their spouses	8	11%
Uncles/ aunts	1	1%
Grandchildren	5	7%
Any members of the family	3	4%
Total responses	65	90%



### Section 3 Dementia Awareness

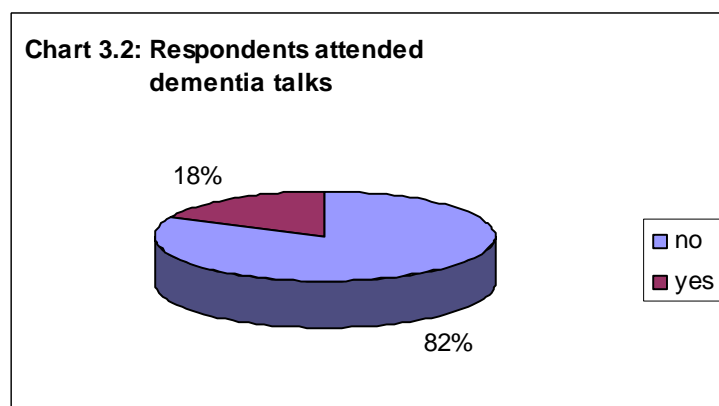
#### 3.1 Respondents were asked whether or not they heard of dementia

60 (83%) of the respondents said that they had heard of dementia  
12 (17%) said they had not heard of dementia  
(see Chart 3.1)



#### 3.2 Respondents were also asked whether or not they had attended dementia talks

59 (82%) said they had attended dementia talks;  
13 (18%) said they had not attended any dementia talk.  
(see Chart 3.2)



### **3.3 Respondents were asked what they think dementia is. They are free to give their views in this aspect.**

7 respondents said they do not know or did not respond to this question.

38 said dementia is memory loss;

11 said dementia is the problems of the person's thought, such as: thinking too much, thinking nonsense, thinking slow, no creation, unable to think clearly or the mind had gone;

8 said dementia is being dull and dim witted;

7 said dementia is when the person has a problem with his/her speech. The person speaks incoherently, not clearly, talking to his/herself, forgot what he/she had said or unable to talk;

7 said dementia is a problem with orientation so that the person will not be able to find his/her way home;

6 said dementia is the degeneration of the brain, the brain is not in balance or is brain damage;

6 said dementia is when the person not happy or lonely, stressed or anxious and when the person has no one to talk to;

5 said dementia is simply that the person is not normal, and that can be seen obviously

4 said dementia is just about ageing;

4 said dementia is about the person being unable to recognise people, even his/her close relatives;

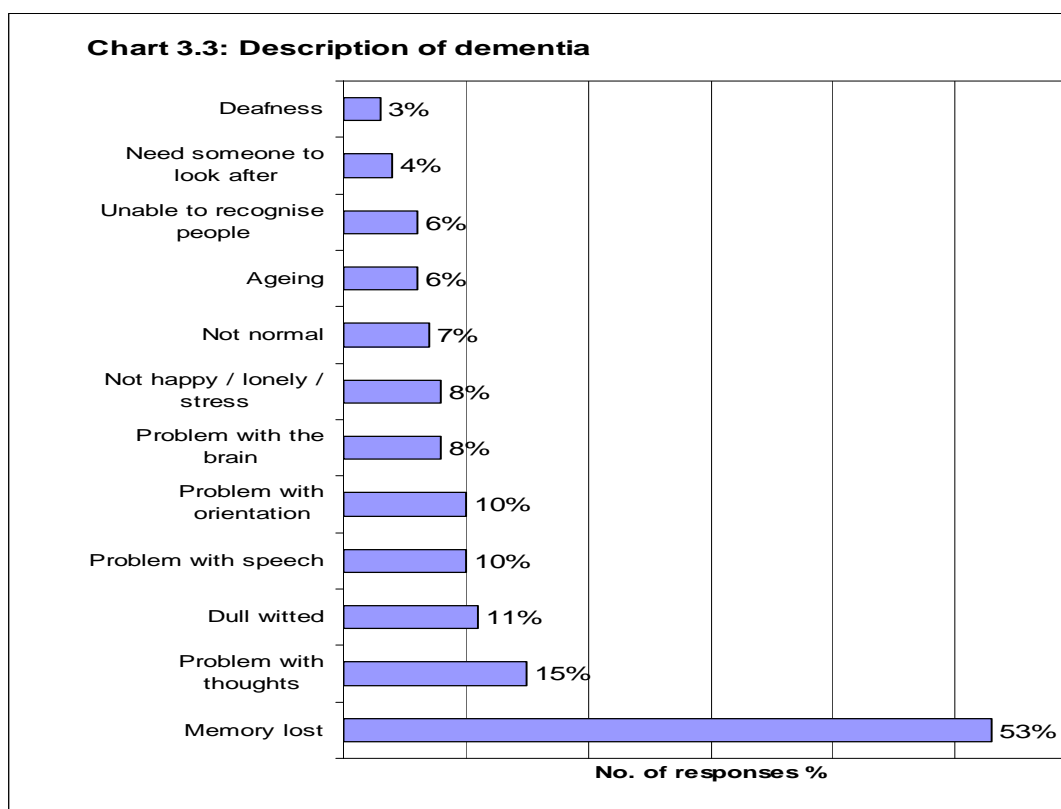
3 said dementia is the person needs someone to look after;

2 said dementia is deafness

(see Table 3.3 and Chart 3.3)

Table 3.3 Description of dementia from the respondents

Description of dementia	No. of responses	
Memory lost	38	53%
Problem with the person's thought	11	15%
Dull witted	8	11%
Problem with the speech	7	10%
Problem with orientation	7	10%
Problem with the brain	6	8%
Not happy / lonely / stress	6	8%
Not normal	5	7%
Ageing	4	6%
Unable to recognise people	4	6%
Need someone to look after	3	4%
Deafness	2	3%
Don't know / no response	7	10%
Total response	101	141%



Description of the person with dementia from the respondents as follows:

*'The person can remember things in the past, but forget things just had happened, for example the person forgets that he/she had just eaten and keeps on eating not know when is full.'*

*'the person is much to be pitied. No one will like him /her. He/she is very dirty, and is not knowing when and how to go to the toilet.'*

*'Dementia is deafness; they make no response to other people.'*

### **3.4 They were asked what changes might happen to a person with dementia**

17 (24%) of the respondents said that they did not know or not sure what the changes are

Respondents expressed that people with dementia will have the following changes:

14 (19%) said they have memory loss

11 (15%) said they have mobility problems, that they move very slowly and repeat doing the same thing.

10 (14%) said people with dementia they speak abnormally, they speak slowly, incoherently, and repeat what they had said and are unable to speak clearly.

9 (13%) said they have problems with thoughts that the person may be thinking too much or thinking nonsense; thinking slowly, unable to think clearly, confused and irrational thinking.

7 (10%) said they have problem with orientation that they are not able to find their way home.

6 (8%) said they are dull witted and unable to understand other people

6 (8%) said they have personality change, that the person is inward looking and unable to socialise, behave strangely, stressed and anxious

5 (7%) said they are not able to recognise people or close relatives

5 (7%) said they have a bad temper and shouting at people

3 (4%) said their appearance is not normal, they are dirty and not aware what they had done

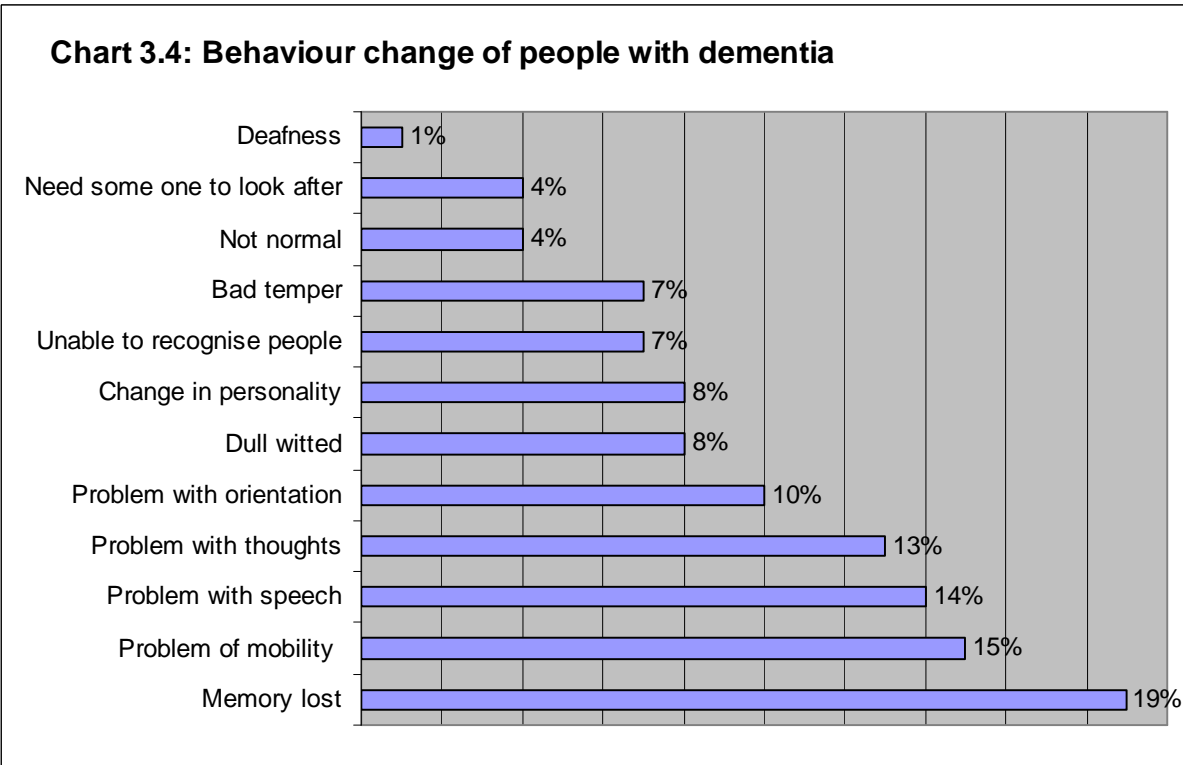
3 (4%) said they need someone to look after

1 (1%) said the person would be deaf or has no response to other people

(see Table 3.4 and Chart 3.4)

Table 3.4 Respondents think changes might happen to a person with dementia

Changes may happen to the person with dementia	No. of respondents	
Memory lost	14	19%
Problem of mobility	11	15%
Problem with speech	10	14%
Problem with thoughts	9	13%
Problem with orientation	7	10%
Dull witted	6	8%
Change in personality	6	8%
Unable to recognise people	5	7%
Bad temper	5	7%
Not normal	3	4%
Need some one to look after	3	4%
Deafness	1	1%
<b>Don't know / not sure</b>	<b>17</b>	<b>23%</b>



### 3.5 Respondents were asked their opinions about how people might get dementia.

16 said that dementia is due to ageing

13 said that 'stimulation' – unexpected shock to the person; or the person is depressed, unhappy or has a bad experience in the past. These emotional disturbances could be the cause of dementia.

6 said that the person has brain illness or degeneration of the brain which are the causes of dementia

6 said that the person isolates him/herself, or doesn't socialise with other people is the cause of dementia

5 said dementia is inherited; it is a genetic disease

3 said dementia is due to the surrounding environments, such as air pollution or even food poisoning. (Check again)

2 said it is due to due to the person having mental illness

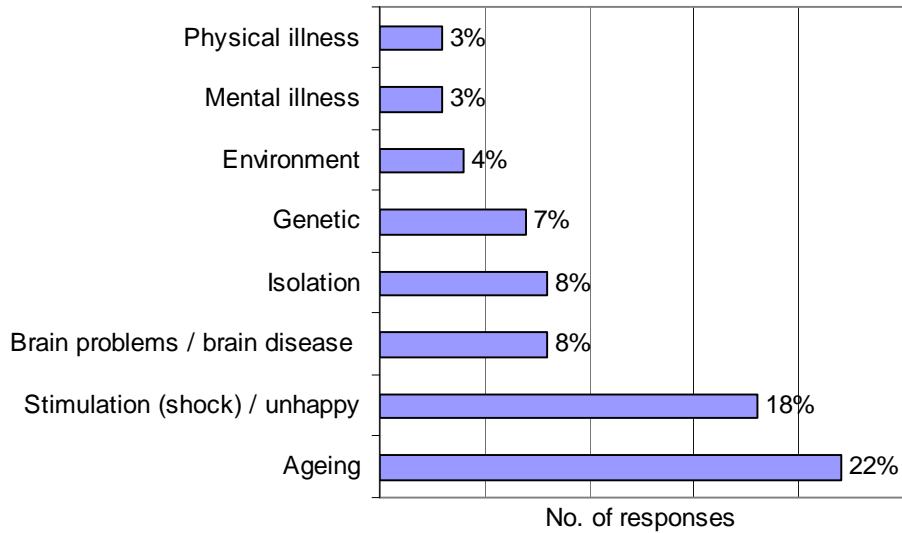
2 said it is due to the person having physical illness.

(see Table 3.5 and Chart 3.5)

Table 3.5 Respondents think the causes of dementia

Cause of dementia	No. of respondents	
Ageing	16	22%
Stimulation (shock) / unhappy	13	18%
Brain problems / brain disease	6	8%
Isolation	6	8%
Genetic	5	7%
Environment	3	4%
Mental illness	2	3%
Physical illness	2	3%
<b>Don't know</b>	<b>31</b>	<b>43%</b>

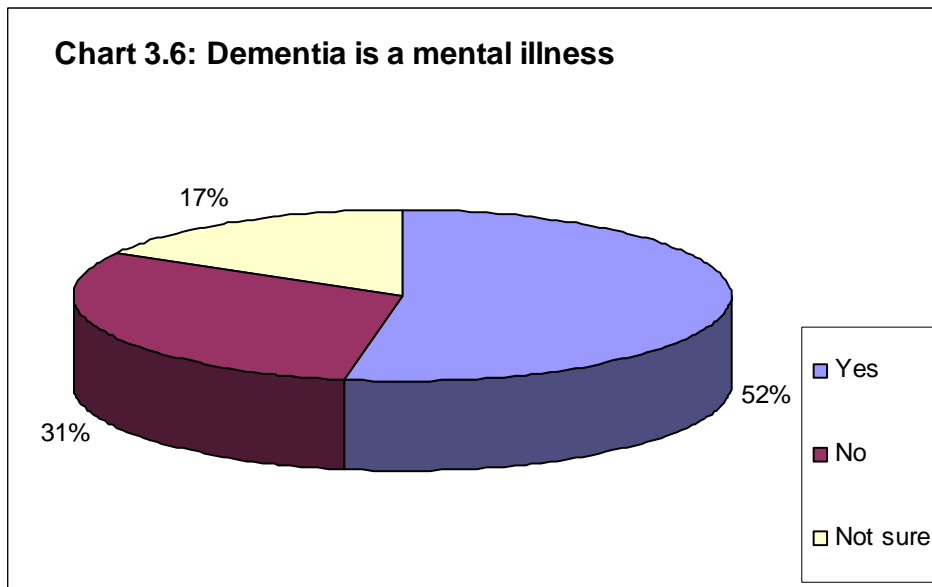
**Chart 3.5: Cause of dementia**



**3.6 Respondents were asked their views of whether or not dementia is a mental illness.**

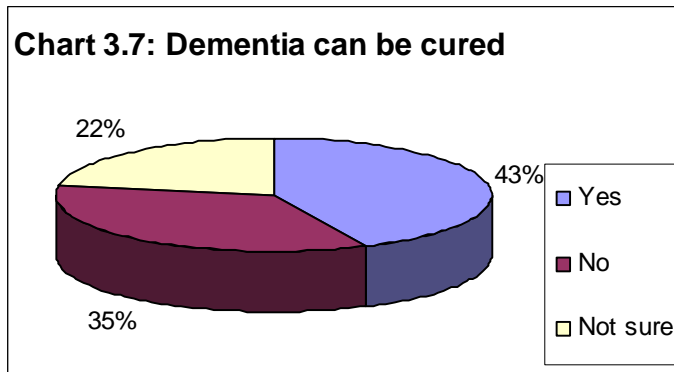
38 (53%) respondents said mental illness is a mental illness;  
22 (31%) said dementia is not mental illness;  
12 (16.7%) of them not sure (see Chart 3.6)

**Chart 3.6: Dementia is a mental illness**



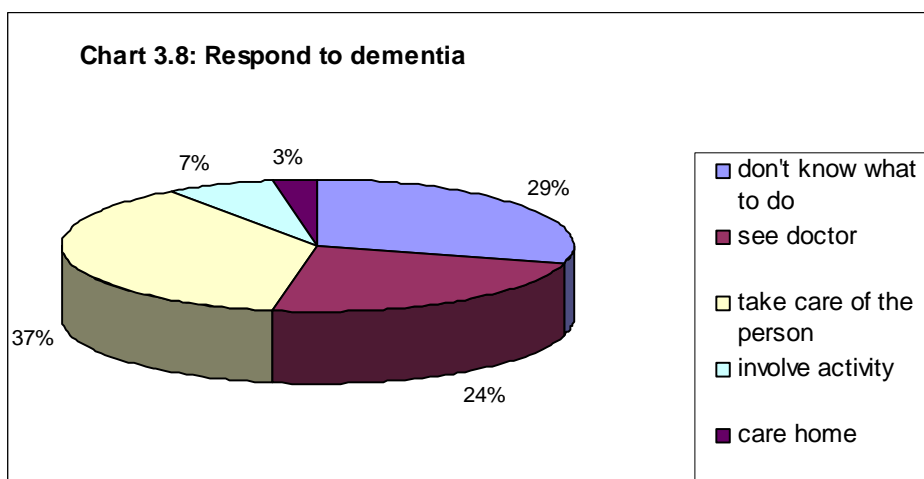
### 3.7 They were then asked whether or not dementia can be cured

31 (43.1%) said dementia can be cured;  
25 (34.7%) said it cannot be cured;  
16 (22.2%) said they are not sure whether it can be cured or not  
(See Chart 3.7)



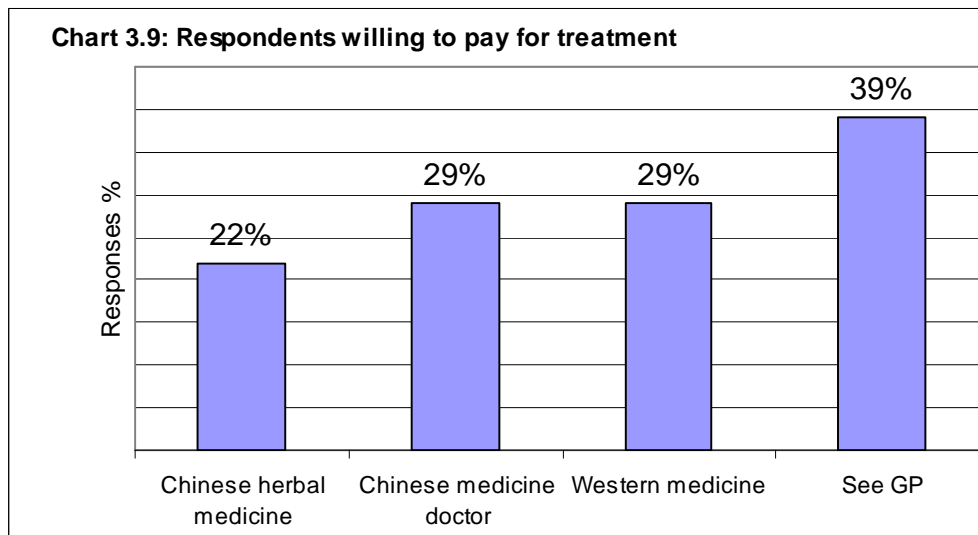
### 3.8 An open question were asked to the respondents what they would do if they or their family member has dementia

21 (29%) said they would not know what to do or did not respond to this question;  
27 (37%) said that it needs to take care of (looking after) the person with dementia;  
17 (24%) said the person needs to seek help from doctors;  
5 (7%) said the person should be involved with and participating in activities;  
2 (3%) said the person should be placed in a care home.  
(see Chart 3.8)



**3.9 They were asked if they or their family member had dementia would they pay for the treatment:**

16 (22%) said they would pay for Chinese herbal medicine;  
21 (29%) said would pay to seek treatment for Chinese medicine doctor;  
21 (29%) said they would take and pay for western medicine;  
28 (39%) would seek help from their family doctor.  
(see Chart 3.9)



**Illustration of quotes from the respondents as below:**

*If I go to Hong Kong, I'll go to see a Chinese herbal doctor. Chinese herbal doctor in England is too expensive.*

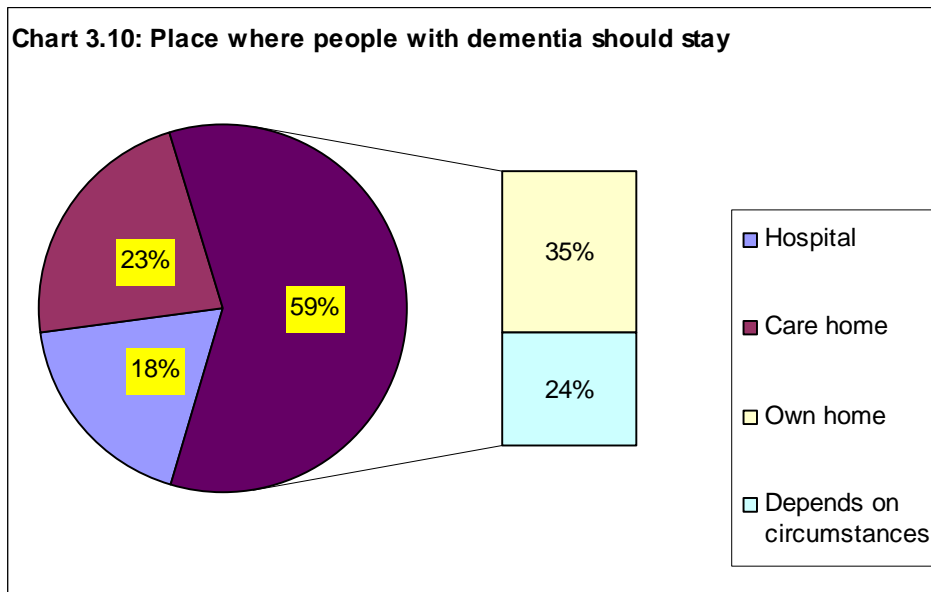
*As long as it can be treated, I'll try anything.*

*I don't know anything, if anyone takes me there, I'll go.*

*People getting old, no cure, no need to take medicine.*

**3.10 Respondents were asked about their views if they or a family member had dementia, where the person should stay**

A total of 71 respondents responded to this question)  
13 (18%) said that they should be placed and be cared for in a hospital;  
16 (23%) said that they should be placed and be cared for in a care home  
25 (35%) said that they should be looked after in their own home  
17 (24%) said that in circumstances it depends on the level of severity. If it is not serious they should stay at home, otherwise they should stay in a hospital or a care home. However, the government should help to handle this problem (see Chart 3.10).



### 3.11 They were asked their opinions about the attitude of the Chinese community toward people with dementia

24 (1/3) of the respondents did not respond to this question.

Among the 48 respondents who responded to this question;

20 respondents think that the person with dementia needs help. They should talk to someone and seek help from the Chinese organisations within the community.

13 respondents said people should show sympathy to the person with dementia

7 respondents said Chinese people will discriminate against them

4 respondents said people's response to dementia will depend on the level of severity accordingly

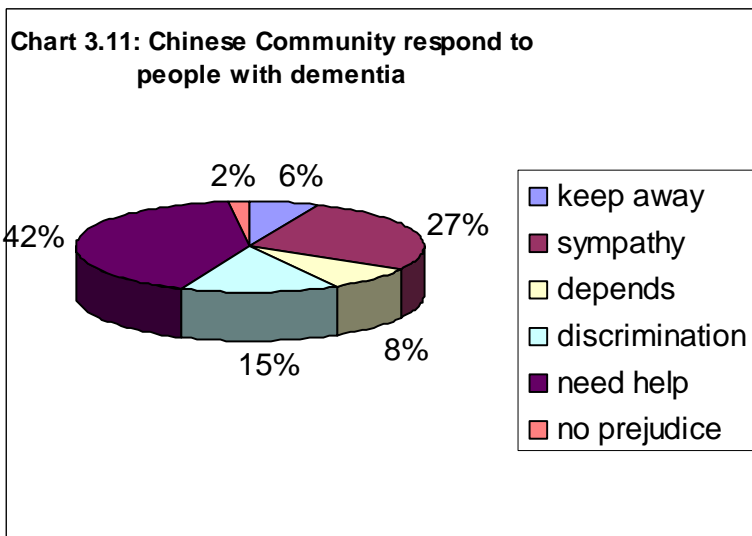
3 respondents said Chinese people will keep away from the person with dementia

1 respondent said Chinese people will not discriminate against the person with dementia

(see Table 3.6 and Chart 3.11)

**Table 3.6 Chinese community response to people with dementia**

		Frequency	Percent
Valid	Need help	20	28
	Sympathy	13	18
	Discrimination	7	10
	Depends	4	6
	Keep away	3	4
	No prejudice	1	1
	No response	24	33
	Total	72	100.0



The following verbatim illustrations are the views from the respondents about Chinese community respond to people with dementia:

*‘(The person needs help) for interpreting, apply for suitable housing, needs volunteers to help, (such as) meals’ 58 years old male respondent*

*‘It’s difficult to say, depends on individuals, some are very kind’ (69 years old male)*

*‘People’s response to the illness depends on how serious the illness condition is, they’ll less contact, less visit. But if it is not serious, they will visit each others, life will be more lively visiting each other.’ (75 years old male)*

*‘(the person) won’t say anything, but if (the person) has difficulty and asks for help, they will help, but (the person) will be discriminated’ (74 years old female)*

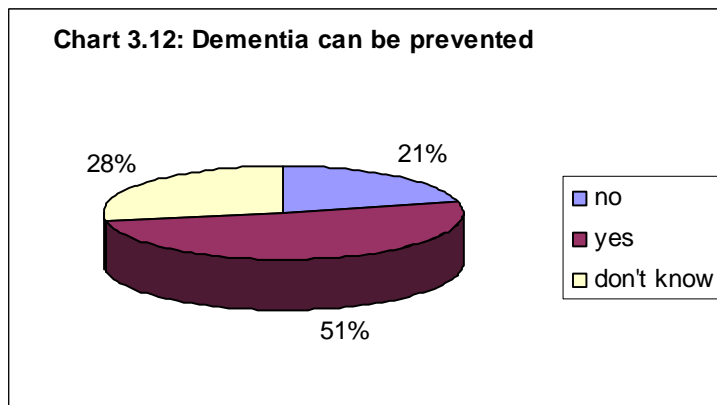
*‘(they) show sympathy, but are scared of (the person), worry danger will occur, especially the older people, they scare of you and keep away from you’(51 years old female)*

*‘(the person) has no chance to talk to someone willing to listen. If (the person) not hitting anyone, they won’t scare of (the person)’ (87 years old female)*

**3.12 Respondents were asked their views whether or not dementia can be prevented**

37 (51%) of the respondents said dementia can be prevented;  
 15 (21%) of them said it is unpreventable;  
 20 (28%) of them said they do not know whether or not dementia can be prevented.  
 (See Chart 3.12)

Respondents also suggested that ‘being happy’, ‘don’t think too much’; do more exercise and playing Ma Jaing are the methods of preventing people having dementia.



**3.13 Respondents were then given a list of activities and asked their opinion of which one might help in reducing the chance of having dementia**

58 (80%) of them said making friends  
 55 (77%) said outdoor activities  
 39 (54%) said doing Tai Chi  
 52 (72%) said playing Ma Jiang  
 41 (57%) said singing such as Chinese opera  
 42 (58%) said card games  
 34 (47%) said dancing  
 4 (6%) said no need to do anything.  
 (See Table 3.7)

Table 3.7 Activities that could reduce the chance of having dementia

Activity	No of respondents	
Making friends	58	80%
Outdoor activities	55	77%
Tai Chi	39	54%
Ma Jiang	52	72%
Singing	41	57%
Card games	42	58%
Dancing	34	47%
Nothing	4	6%

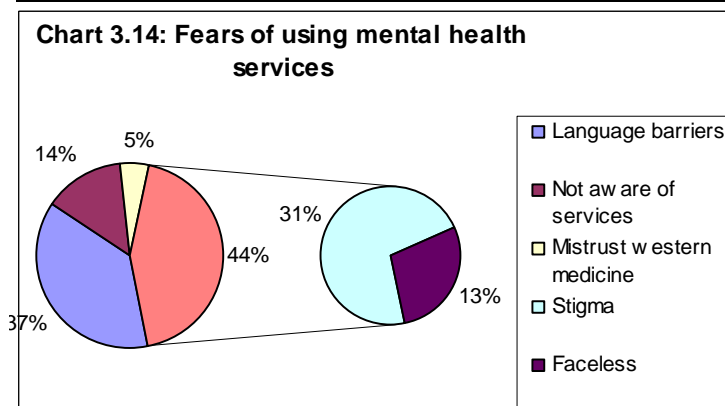
**3.14 An open question was asked about their opinions of any fears stopping older Chinese people accessing mainstream or mental health services.**

Respondents may give more than one answer.  
8 of them refused to answer this question.

30 (42%) of the respondents said language barriers are their main fear of using the services  
25 (35%) of the respondents said stigma attached to the person using mental health services  
10 (14%) said feeling 'faceless' is their fear to gain access the services  
11 (15%) said they are not aware of the available services and the support network  
4 (6%) said they do not trust the western medicine or the health profession unable to understand them  
(see Table 3.8 and Chart 3.14)

Table 3.8 The fears that stopping older Chinese people accessing the mainstream or mental health services

Reasons for not accessing services	No. of respondents	
Language barriers	30	42%
Fear of stigma /discrimination / traditional concept of mental illness	Stigma	25 35%
	Faceless	10 14%
Not aware of service and support network	11	15%
Mistrust western medicine and health profession	4	6%
Don't know or refuse to answer the question		



*'They don't speak English, it is to lose face if you cannot communicate with the English, also to get into the mainstream the procedure is too complicate.'*  
(Male aged 58)

*'Language problem, also fear of people laugh at them. They do not know the support network and where to seek help' ( 71 years old male)*

*'...first is the language barrier; second is fear of knowing oneself has the illness and third is the fear of other people knowing about the person has got this illness. They are worried that people will not be their friend and won't contact them anymore. ( a 55 years old male)*

*'It is because of the language barrier, it is very hard to find an interpreter. Also I won't know which government department that I should go to and seek help from ( 81 years old female , living on her own)*

*'It is hard to face reality, worry about other people gossip behind them, the only thing to do is to hide it inside themselves ' ( 52 years old male)*

## Section 4 Family doctor (General Practitioner GP)

### 4.1 Respondents were asked whether or not they have registered with a GP.

71 (98.6%) of the respondents registered with a GP.

Only one respondent said he/she could not recall whether or not that he/she has registered with a GP.

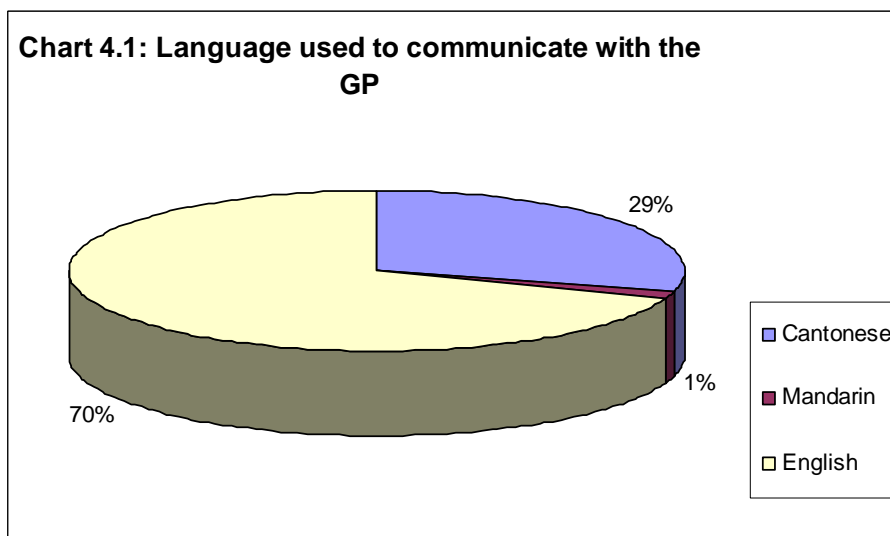
### 4.2 They were asked what language that the GP uses to speak to them.

21 (29%) said the GP speaks to them in Cantonese

1 (1%) speaks to them in Mandarin

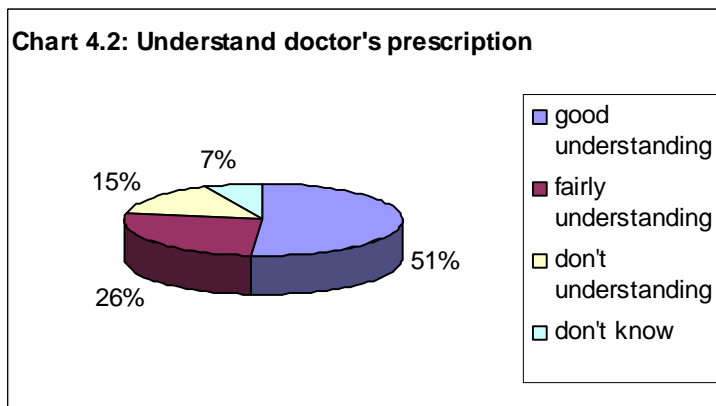
50 (70%) said the GP speaks to them in English

(see Chart 4.1)



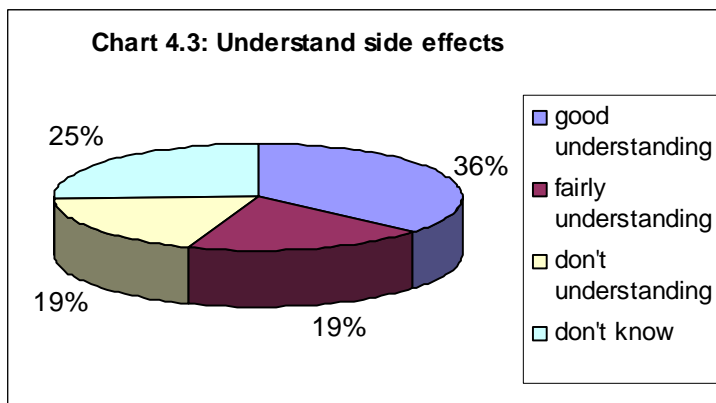
#### 4.3 Respondents were asked whether or not they were able to understand the prescribed medication given to them by their doctors

37 (51%) of the respondents said that they had a good understanding of their doctor's prescription;  
19 (26%) said they that they understand a little bit about the prescription;  
11 (15%) and 4 (7%) don't understand or don't know respectively  
(see Chart 4.2)



#### 4.4 Respondents were then asked whether or not they were aware of the side effects of the medicine

26 (36%) respondents said that they have a good understanding the side effects of the prescribed medication;  
14 (19%) said they fairly understand a little bit;  
the same number said they do not understand the side effects  
18 (25%) said they that they are not sure.  
(see Chart 4.3)

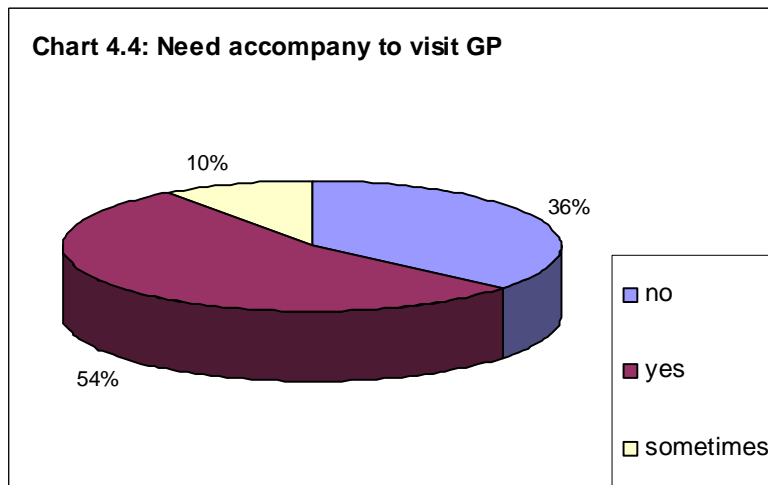


#### 4.5 Respondents were asked whether or not they need someone to go with them to visit her GP

39 (54%) of the respondents said they need someone to go with them to visit their GP;

26 (36%) of them said no.

7 (10%) of them said sometimes they need to be accompanied and this depended on the severity of the illness (see Chart 4.4)

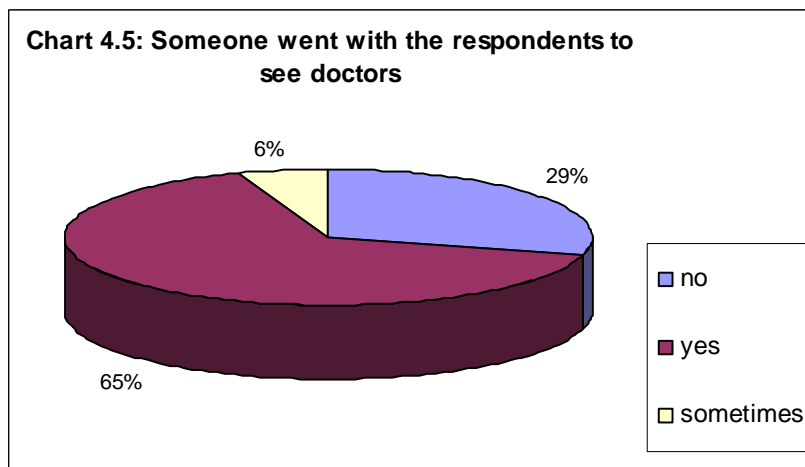


#### 4.6 Respondents were asked if anyone actually accompanied them to see their doctor.

47 (65%) said that they were actually accompanied with someone to see their doctor

4 (6%) said sometimes they were able to get someone to go with them.

21 (29%) of them said they were not accompanied with anyone to see their doctor (see Chart 4.5)

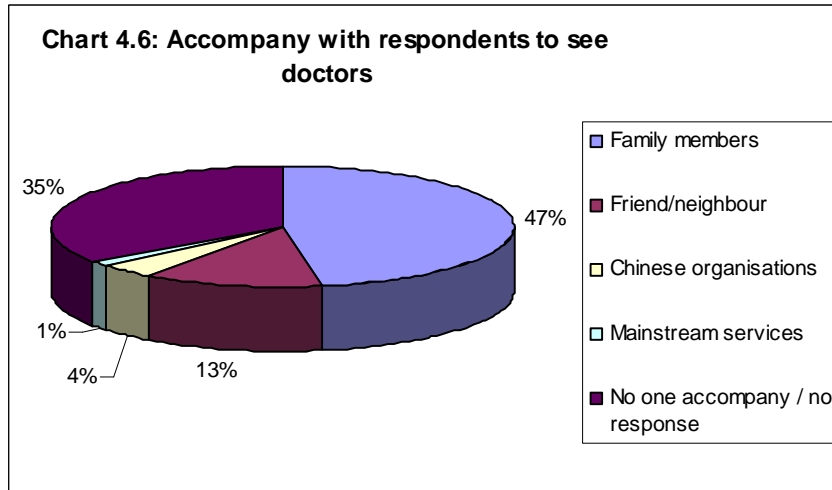


Among 47 respondents who stated that they went with someone.

22 of them said they went with their children or their spouses,  
 3 went with their grandchildren,  
 4 went with their spouse or partner and  
 5 went with any family member who was available (see Table 4.1 and Chart 4.6)

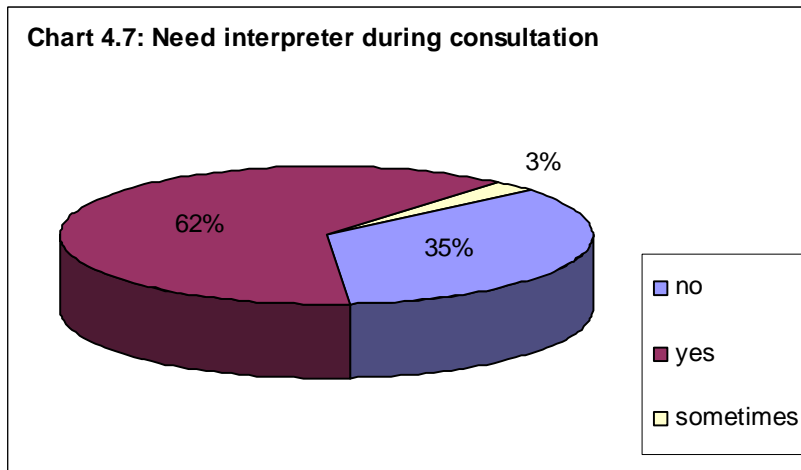
Table 4.1 Members accompany with respondents to see doctor

Family members	Children/ their spouses	22	34
	Spouse / partner	4	
	Grandchildren	3	
	Any member of the family	5	
Friends / neighbours			9
Chinese organisations			3
Mainstream service			1



**4.7 Respondents were asked whether or not they needed an interpreter during the consultation.**

45 said they need someone to interpret for them;  
2 said sometime they needed an interpreter;  
25 said they did not need an interpreter  
(see Chart 4.7)

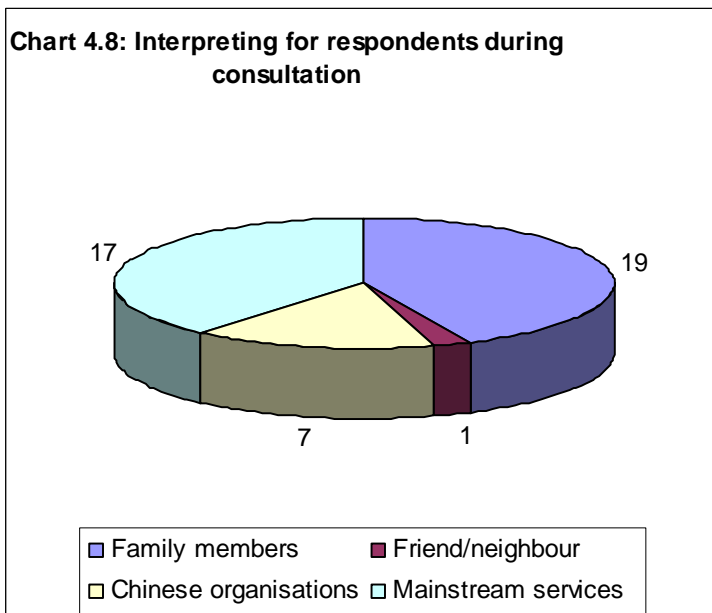


**4.7.1 Respondents were also asked who was interpreting for them during consultations.**

19 of the respondents relied on their family members;  
 17 obtained interpreting service from the mainstream service,  
 7 supported by Chinese organisations and  
 1 sought help from their friends or neighbours  
 (see Table 4.2 and Chart 4.8)

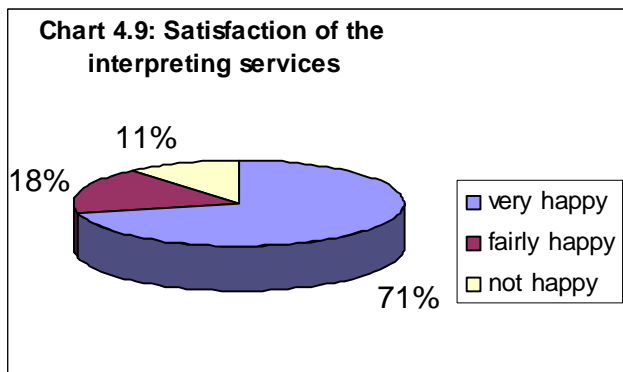
Table 4.2 Members interpreting for the respondents during consultation

Interpreters during consultation			
Family members	Children/ their spouses	11	19
	Spouse / partner	2	
	Grandchildren	2	
	Any member of the family	4	
Friends / neighbours			1
Chinese organisations			7
Mainstream service			17
Interpreter not required / no response			28



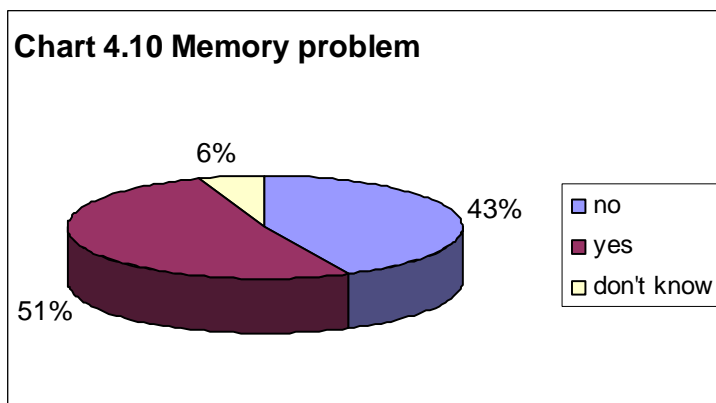
#### 4.8 Respondents were asked whether or not they were satisfied with the interpreting services

A total of 45 respondents responded to this question  
32 of them said they were very happy with the interpreting services.  
8 of them said they were fairly happy while 5 of them said they were not happy with the service (see Chart 4.9)  
For those who were not happy with the service explained that it was because the interpreter was not available or being late. Also they are not happy with their family members involved with the consultation.



#### 4.9 Respondents were asked whether or not they have a memory problem.

37 (51%) of them said they have a memory problem while  
31 (43%) said no;  
4 (6%) of them said they are not sure whether or not they have a memory problem  
(see Chart 4.10).



**4.10 Respondents were then asked did they consult their GP about the memory problem.**

Only 3 went to see their GP to consult about their memory problem (see Chart 4.11) .

Among those 3 respondents,

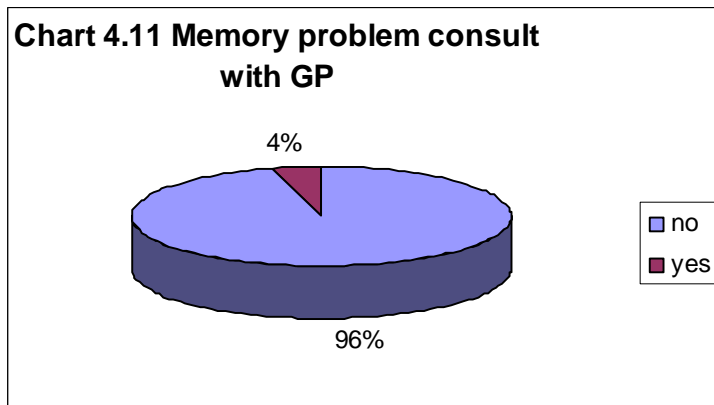
**4.11 For those who went to the GP about memory problem they were asked whether or not they were given an assessment**

Among those 3 respondents

2 said they did not have an assessment and

1 did not know what assessment was

none of them were referred for further investigation.



**4.12 A list of referral services were shown to respondents, and they were asked whether or not they had been referred to those services.**

23 (32%) of the respondents said they had been referred to other health services as shown in Table 4.3

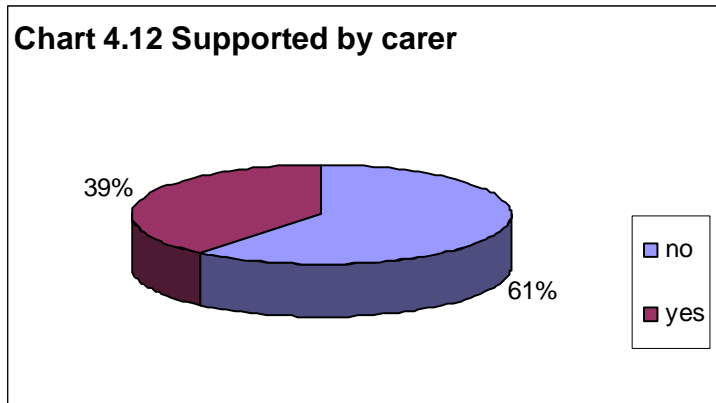
Table 4.3 Problems consult to doctor and referral was made to health services

Problems consult doctor and referred to Health Services	No. of respondents	
Heart problem	3	4%
Gynaecology	2	3%
Hospital treatment	4	6%
Hospital check up	5	7%
Joints problems	2	3%
Total	16	23%

**No respondents answered 4.13 – 4.18 questions.**

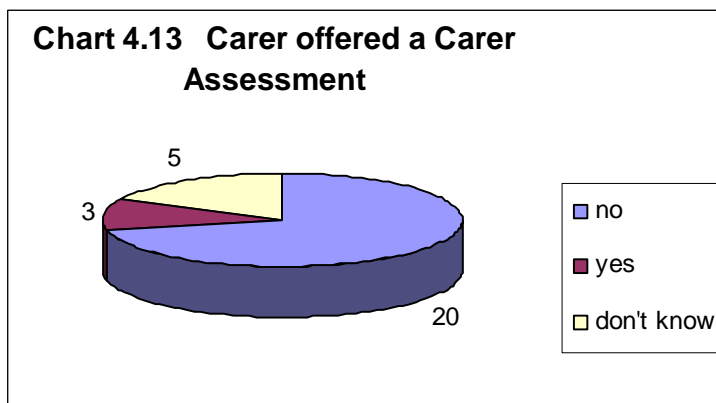
#### 4.19 Respondents were asked whether or not they were supported by a carer

28 (39%) of the respondents said they are supported by a carer  
44 (61%) said they were not (see Chart 4.12).



#### 4.20 Then they were asked whether or not the carer had been offered a carers assessment.

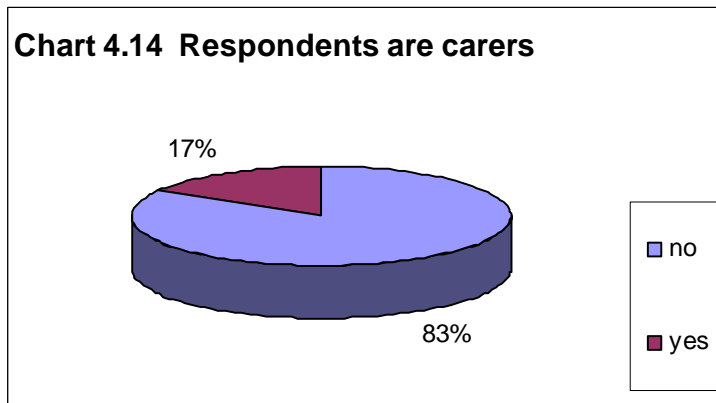
Among 28 carers,  
3 respondents said that the carer had been offered a carer assessment;  
20 respondents said they do not know what a carer's assessment was (see Chart 4.13).



#### 4.21 Respondents were asked whether or not they are a carer

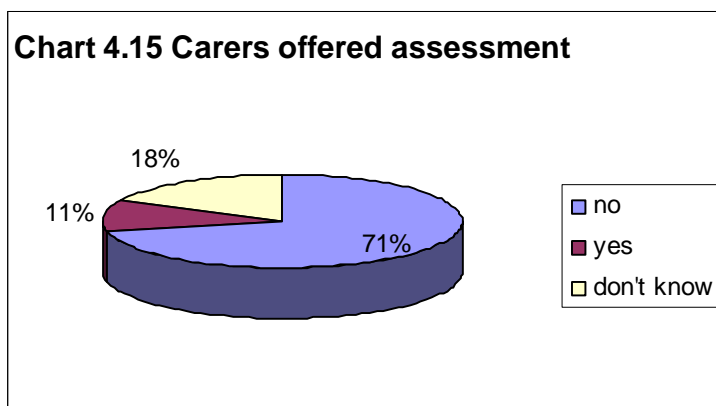
12 (17%) said they are a carer and

59 (82%) said they were not a carer (see Chart 4.14) .



**4.22 For those who are carers then they were asked whether or not they were offered an assessment**

Among 12 carers,  
3 of them had been offered an assessment,  
8 said they did not have an assessment and  
1 was not sure what an assessment was (see Chart 4.15)



**4.23 The carers were asked if the support the person was receiving was from the Mental Health Services.**

Among the 12 carers none of them responded to this question

**4.24 Then they were asked to list services and rate the satisfaction level of the services**

1 referred to memory clinic and said the service was good

5 referred to community nurse, 2 said it was excellent, and the same number said it was good and one said it was fairly good

1 referred to Community Psychiatric Nurse and the service was good

2 referred to social services, 1 said it was good and 1 said it was fairly good

No referral was made to a counselling service

No referral was made to psychology services

1 referred to psychiatrist and the service was good

No referral was made to self help group

(see Table 4.4)

Table 4.4 Carer referral services and rating of satisfaction of the services

	Rating of satisfaction of the services				Total No. of referral
	Excellent	Good	Fair	Poor	
Memory Clinic	1				1
Community Nurse	2	2	1		5
Community Psychiatric Nurse		1			1
Social Services		1	1		2
Counselling					0
Psychology					0
Psychiatrist		1			1
Support Group					0

## Section 5: Health and Social Care need

### 5.1 Respondents were asked if their children could not help them, whether or not they would think their children not show filial piety (a son's responsibility to care for his parents).

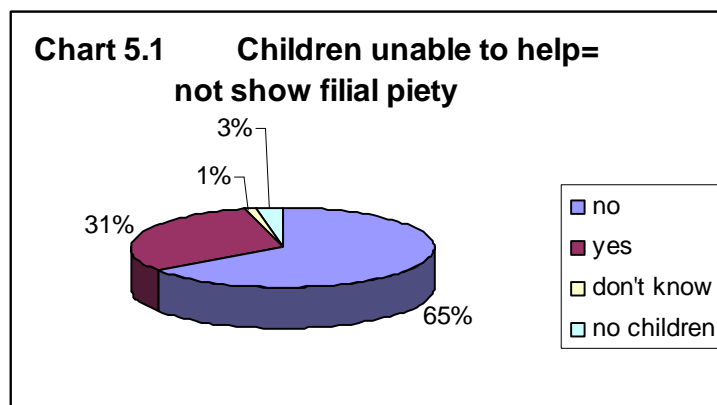
22(31%) of the respondents think that if children were unable to offer help that meant they are not showing "filial piety"

47(65%) of the respondents said they would not think they are not showing "filial piety" even though they could not help them;

1 said he/she is not sure and 2 said they had no children, therefore could not make any comment on this aspect. (See Table 5.1 and Chart 5.1)

**Table 5.1: Children unable to offer help means not show filial piety**

		Frequency	Percent
Valid	Yes	22	31
	No	47	65
	Don't know	1	1
	No children	2	3
	Total	72	100.0



Among those 22 respondents who expressed that children are not able to offer help is not showing filial piety,

14 respondents explained their views in this aspect as shown in Table 5.2  
7 said it is the responsibility of the children. They should offer help when their parents are in need.

3 said it is a moral standard

1 said that children should offer help because they are family.

3 respondents stated although they understand the difficulties their children encounter, they still think that the children are not showing filial piety if they are not able to offer help. (see table: 5.2)

**Table 5.2: Reasons of children should filial piety to parents**

		Frequency	
Traditional concept			
	Children's responsibility	7	11
	A standard	3	
	We are family	1	
Unconditional regard			
	Should help even busy at work	2	3
	Should help even not incapable to do it	1	
	Total	14	14

*'because, they have grown up, they should show filial piety and looking after their parents' (Age 50 female)*

*'yes, I will say they are not showing filial piety, because we are getting old. However, society has changed and we all think differently, we have to accept this change' (age 55 female)*

Among those 47 respondents who do think their children are not showing filial piety even if could offer help when they are in need.

23 explained that their children are too busy at work and / or living far away from home  
 2 said they have grown up and have their own lives  
 5 respondents said they understand and are concerned about the problems that their children encounter  
 1 said once being a parent is always being a parent  
 3 respondents think their children are always good to them, and never think of this issue (see table 5.3)

**Table 5.3 Reasons for children unable to offer help**

		Frequency	
Valid	busy at work / away from home	23	30
	have their own life	2	
	understanding their problems	5	
	being a parent	1	1
	all good to them	3	3
	Total response	34	34

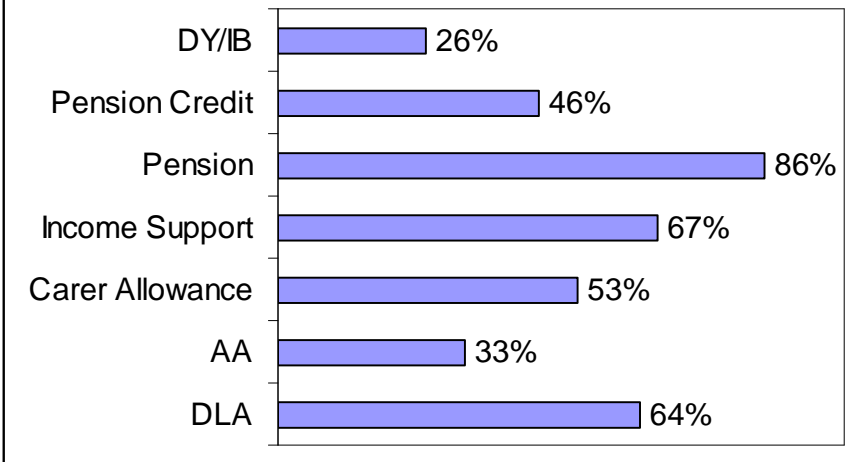
**5.2 Respondents were given a list of names of different benefits and asked if they were aware of them.**

46 said they have heard of Disability Living Allowance (DLA);  
 24 heard of Attendance Allowance (AA)  
 38 heard of Carer Allowance  
 48 heard of Income Support  
 62 heard of Pension  
 33 heard of Pension Credit  
 19 heard of direct payment / individual budgets  
 (see Table 5.4 and Chart 5.2)

**Table 5.4: Respondents had heard of the benefits:**

Disability Living Allowance (DLA)	46	64%
Attendance Allowance ( AA)	24	33%
Carer Allowance	38	53%
Income Support	48	67%
Pension	62	86%
Pension Credit	33	46%
Direct Payments (DP) / Individual Budes (IB)	19	26%

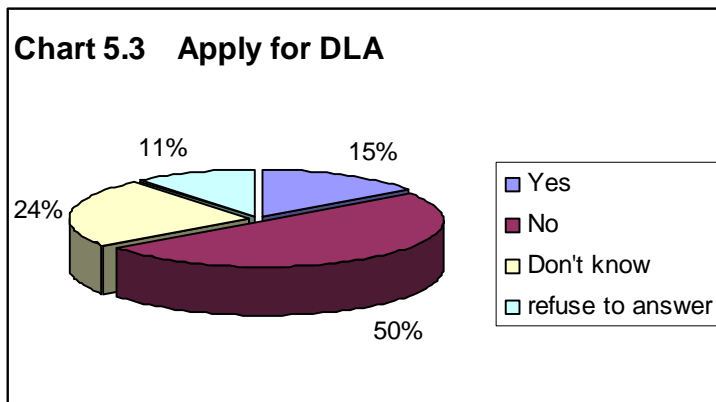
**Chart 5.2 Heard of the benefits**



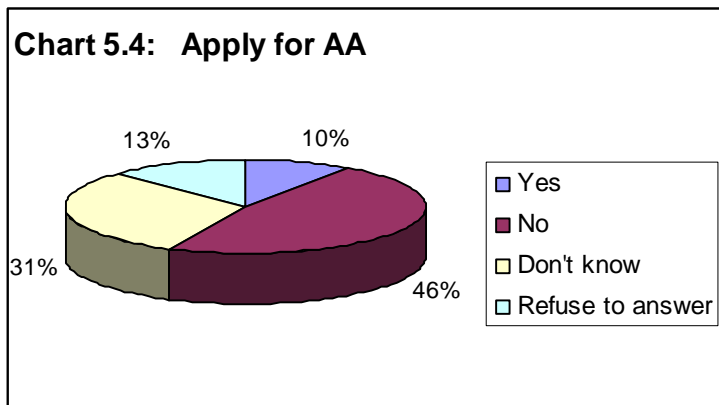
**5.3 They were then asked whether or not they would apply for those benefits:**

11 (15%) said they will apply for Disability Living Allowance (DLA)  
36 (51%) said they will not apply for DLA  
17 (19%) said they are not sure  
8 (11%) refuse did not wish to answer  
(see Chart 5.3)

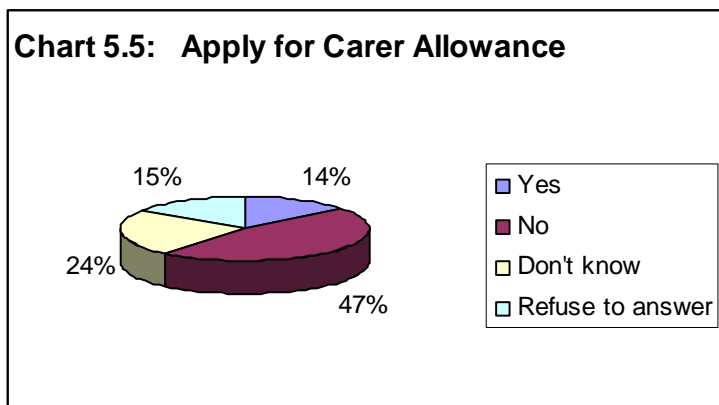
**Chart 5.3 Apply for DLA**



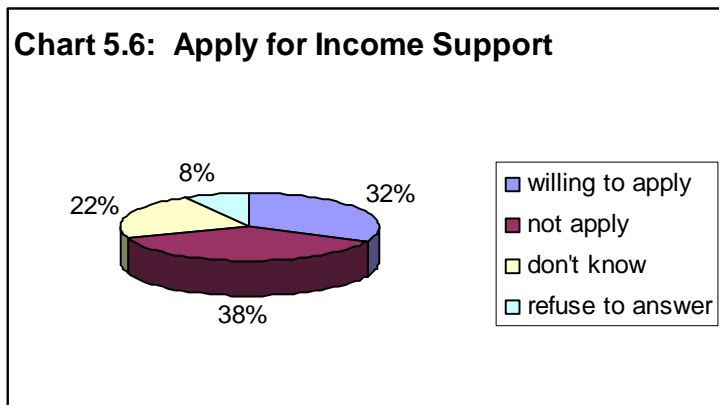
7 (10%) of the respondents said they will apply for Attendance Allowance (AA); while 34 (46%) of them said no 22 (31%) said not sure and 9 (13%) did not wish to answer the question (see Chart 5.4)



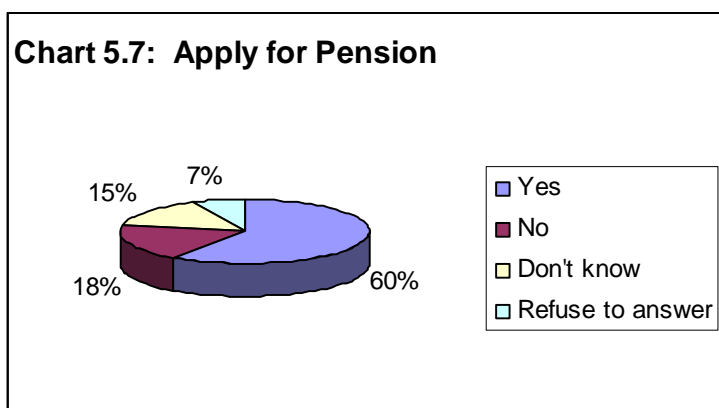
10 (14%) said they will apply for Carer Allowance; while 34 (47%) said they no (24% ) not sure and 15% of the respondents did not wish to answer this question. (see Chart 5.5)



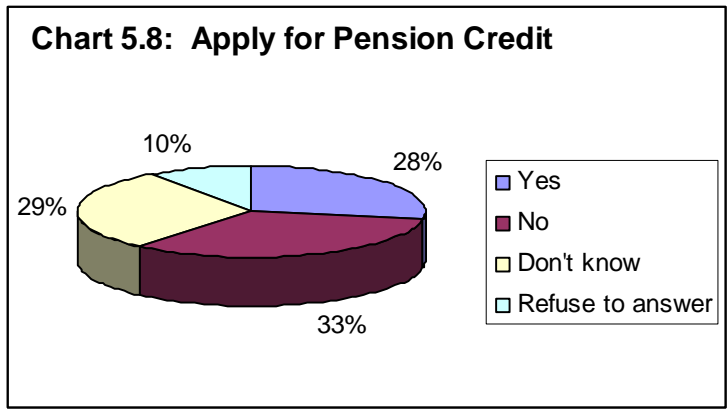
23 respondents said they will apply for Income Support while 27 (38%) said no 16 (22%) of them are not sure and 6 (8%) of them did not wish to answer the question (see Chart 5.6)



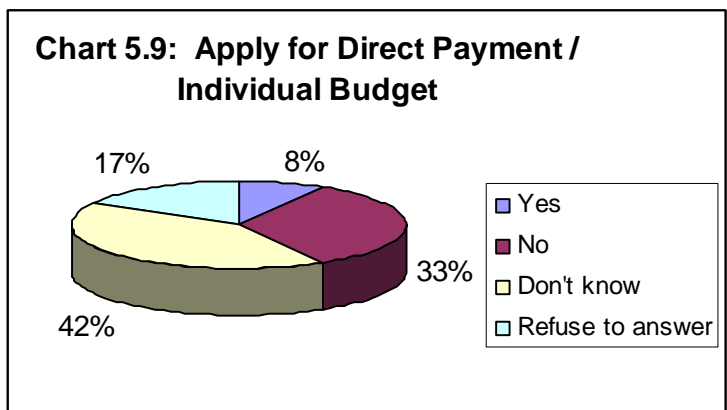
43 (60%) of the respondents said they will apply for Pension while 13 (18%) said no 11 (15%) said they are not sure and 5 (7%) of them did not wish to answer this question (see Chart 5.7).



20 (28%) said they will apply for Pension Credit; while  
 24(33%) said no  
 21 (29%) of them not sure and  
 7 (10%) of them did not wish to answer the question (see 5.8)



6 (8%) of the respondents said they will apply for Direct Payment or Individual Budget; while 24 (33%) of them say no.  
 39 (42%) of them not sure and 17 (17%) of them did not wish to answer the question (see Chart 5.9)



**5.4 Respondents were asked if they require a carer, what kind of help that they would look for from the carer.**

52 (72%) of the respondents said it would be better to have a carer of the same gender

62 ( 86%) of them said the carer should speak the same language

51 (71%) of them said the carer should aware of their health problems and the symptoms of their illness

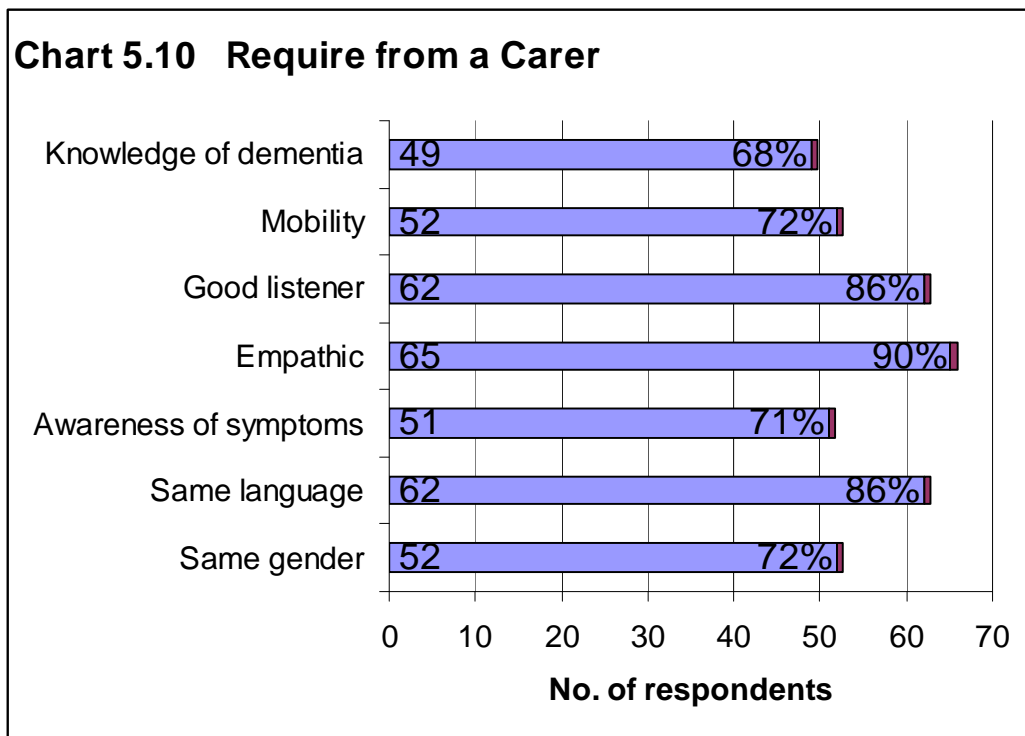
65 (90%) of them said the carer should have empathy

62 (86%) of them said the carer needs to be a good listener

52(72%) of them said the carer would have to be able to help them move around

49 (68%) of them said the carer should have a lot of knowledge about dementia.

(see Chart 5.10)



## 5.5 Respondents were asked what type of services they would like to see to support older Chinese with dementia.

20 respondents expressed that people with dementia should have someone to look after them

5 respondents suggested that they should have Chinese speaking carer worker;

5 said that the person should have someone to visit them and talk to them, and suggested set up a group for older people volunteers to pay home visits to the person with dementia

5 said the person should be able to go to a day centre for people with dementia, so that people with the same illness can meet and share experience. Also, the workers who work in the day centre should be Chinese speaking, have knowledge of dementia, and then they (service user) will be able to communicate with the worker and obtain information from them.

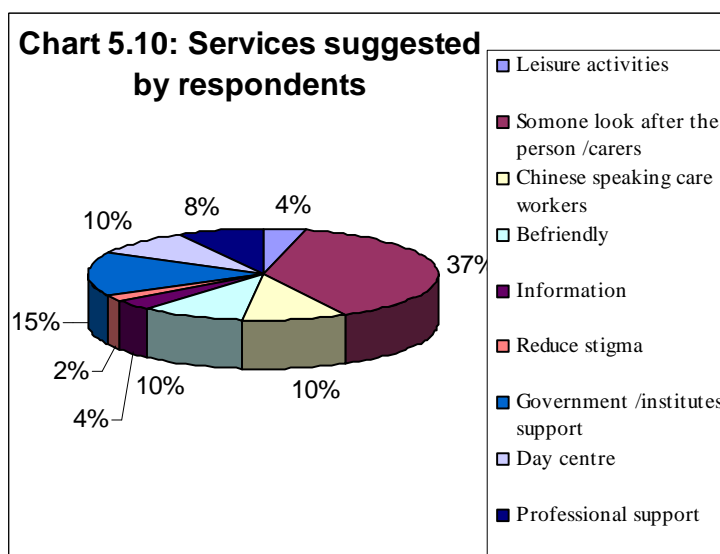
8 respondents said that the government and other institutions should provide support and resources to help the person with dementia

3 said that they need help from professionals or people with adequate knowledge of dementia, so that they will be able to received medical care and counselling services or to arrange care provided by a care home.

2 respondents suggested more healthy leisure activities should be provided for people with dementia and their carers.

1 respondent said need to have more information about dementia

1 respondent said need to take more action to reduce stigma attached to people with dementia. (see Chart 5.10)



## 5.6 Respondents were asked their view of the mental health services and Staff working in these services

Verbatim illustrations from the respondents are as follow:

*' not enough, (Chinese) do not know how to say "dementia" (in English), Western people know little about Chinese older people, they won't understanding what we say in Chinese' (58 years old male)*

*'... they understand the need of Chinese people, it's good to have a dementia care centre for Chinese. ' (63 years old female)*

*'They understand and are aware (of our problems), but is there enough money (funding) to help? There is useless just talk' (71 years old male)*

*'(they) should know ... so many people have dementia, but no services... ' (74 years old female)*

*'don't know, I don't know any professional, Chinese don't understand the disease, don't know the help available, especially support group and care centre, health visitors, who can speak the same language is essential' (51 years old, female)*

*'they don't understand what Chinese needs, we are old and that is it.' (81 years old female)*

*' communication and cultural difference, they won't understand Chinese community's problems. They (Chinese) do not understand dementia, so they can't get the services that they should get' ( 62 years old female)*

*'(they) know ...(we) need interpreter' (86 years old female)*

*'they don't understand, the best is get help from Chinese. I think Chinese in the Chinese community can't get the need for dementia' (76 years old female)*

*' The health professional are very helpful to try their best to help, but unfortunately there is no services for us. They (Chinese) have no information about dementia service , not enough information or right service for dementia.' (82 years old male)*

*'(they) won't care. Language is the big barrier, we have communication problems, our customs and culture they won't understand' (87 years old female)*

## Section 6 Discussion

### 6.1 Profile of the respondents

#### 6.1.1 Age and residential area of the respondents

This research defined older people as anybody over 50. However, our target group was Chinese people aged over 65. However, we found that respondents from the younger age group were more willing to participate in this research and were able to provide more information about their views than the older respondents.

The project also planned to target Manchester residents, due to the interviews taking place in community centres it was impossible to predict and we had little control over the attendance of the participants. 53 respondents lived in Manchester, among these 53 Manchester respondents 75% are aged over 64. (See Table 6.1)

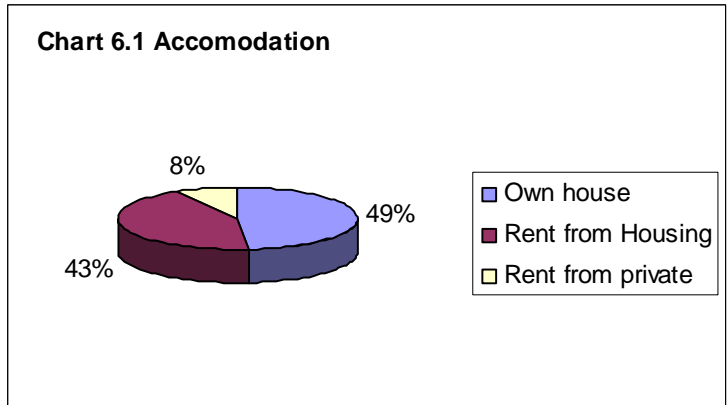
**Table 6.1: Live in Manchester and age group**

		Frequency	Percent
Valid	50-64	16	30
	65-74	15	28
	75 -84	17	32
	85-94	5	10
	Total	53	100.0

#### 6.1.2 Living circumstances

69 out of the 72 respondents are British citizens and 75% of them came from Hong Kong. Only just over 10% of the respondents have lived in the UK under 10 years and over 50% of the respondents have lived in the U.K over 30 years.

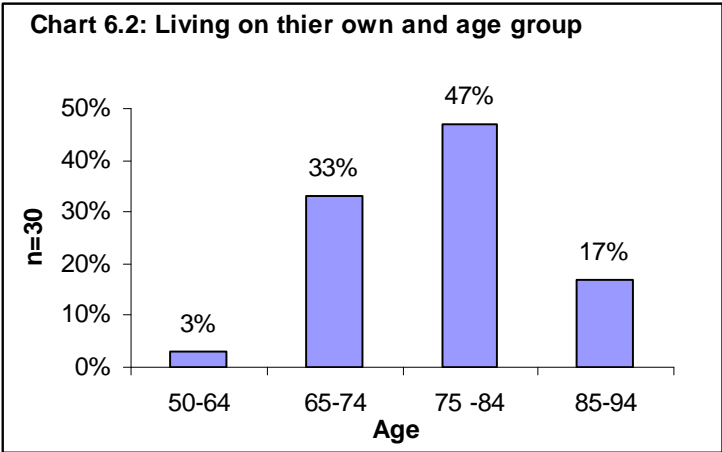
Furthermore, just under half of the total respondents lived in their own property (either own or mortgaged), a high proportion of the respondents rent from either housing association or council; also less than 10% of the respondents rent from private landlords or others (see Chart 6.1)



As mentioned in Section 1.8 , 30 (41%) of the respondents lived on their own, among these 30 respondents 73% of them rent from a housing association (see Table 6.2 ) and their age falls between age 75 and 84 years old (Chart 6.2)

**Table 6.2: Respondents living on their own and housing**

		Respondents living on their own	Percent
Valid	Own property	3	10
	Council	3	10
	<b>Housing Association</b>	<b>22</b>	<b>74</b>
	Private	1	3
	Other	1	3
	Total	30	100



There were 15 respondents aged between 50-64 who had not retired from their work and their occupation. As table 6.3 shows that age between 50-64 year olds have a higher portion of respondents engaging in catering industry.

### 6.1.3 Occupation

It should be noted that most of the older Chinese immigrants in the UK were engaged in the catering industry (see Table 6.3), however, a list of occupations as shows in Appendix 4 which was addressed by the respondents. This may suggest professions of the respondents and the skills that they had before they came over to the UK. Furthermore, many older Chinese women did not regard being a housewife as a job, therefore 17 (24%) of the respondents said that they never work may due to this reason.

**Table 6.3: Age 50-64 age group and occupation**

Catering Industry	take-away	4	10
	Housewife	1	
	business/self-employ	1	
	Chief	4	
Skill worker	child minder	1	2
	Driver	1	
Manual worker	Cleaner	1	2
	warehouse worker	1	
	Missing	1	1
	Total	15	15

The majority 59 (82%) respondents said that they were not a disabled person. However, they did express that they had different levels of health problems. Observation from the researchers, respondents were reluctant to disclose or discuss about their disability.

*'He was sitting on the wheel chair and told me he had no disability.'*  
*Researcher K*

### 6.1.4 Language profile

Most respondents their first language either Cantonese or Hakka (see Table 1. 4). Only 17 (24%) of them do not understand the written Chinese. All respondents have a level of understanding Cantonese, and 93% of them speak fluent Cantonese (see Table 6.4)

**Table 6.4 : Languages Profile of the Respondents**

	Not at all	A little	Fluent
English	23 (32%)	39 (54%)	10 (14%)
Mandarin	27 (38%)	34 (47%)	11 (15%)
<b>Cantonese</b>	<b>0</b>	<b>5 ( 7%)</b>	<b>67 (93%)</b>
Hakka	29 (40%)	11 (15%)	32 (45%)

### 6.1.5 Religion

It should be noted that for most of the Chinese there is no clear cut practice Buddhist and Ancestor Worship. Over half of the respondents either practice Buddhist or Ancestor Worship or both.

## 6.2 Daily Life needs

### 6.2.1 Mental well-being

Respondents were asked what makes them happy, their responses were focused around family, friends and social life with them. The common theme emerging from the responses was to be able to be with family and friends. Seeing the children settled down without problems would make them happy. This consists of 45% nearly half of the total responses, and this represents their wishes and worries which reflects their current situation of without family support and feeling of loneliness. This finding replicates a similar result with the previous research (Jones and Lam, 2004).

It should be noted that to be able to join activities also had a high score from the responses. It shows the importance of being able to move around and to participate in activities, it is not only to reduce the feeling of loneliness and being healthy but it was important to be able to have control over their life and have a level of independence.

The second highest response from the respondents was to be content, not to worry too much and have a religious faith. This is also culturally significant. 'To be content that makes people happy' is a Chinese proverb and a cultural belief. To be content is important in maintaining mental health in a Chinese context. This has a significant implication on the concept of Chinese mental health. Thus respondents also gave similar answers when they expressed their views about mental health in Section 2.2. Furthermore, the Chinese concept of mental health is a holistic approach that health is physical, mental and social well-being as it is shown in Chart 2.2. In addition, 26% of the respondents said they did not know what mental health is, as mental health is a western concept (Wong and Richman, 2003). Therefore, mental health promotion must consider the cultural context of mental health.

### 6.2.2 Seeking help

Respondents were asked their views about the difficulties that Chinese older people encounter in seeking help. The overwhelming response was that language problems undermine their real problems which are directly or indirectly derived from language barriers. In Section 2.3 shows has provided further evidence of the difficulties of the respondents encounter to in their daily life as mentioned before - inadequate family support and isolation, although a lot of them live very close in housing association flats.

Further evidence also shows that Chinese older people are heavily reliant on support from family members. About 75% of them said that they would seek help from their children, and therefore, the responsibility of taking care of the older Chinese is more likely to fall on their children and their partners.

More respondents would seek support from Chinese communities rather than Government service, this was due to the language barrier; also respondents expressed that at their age, friends and neighbours are getting old as well, and they are not capable to help even if they wanted to offer help to them.

### **6.3 Dementia Awareness**

#### **6.3.1 Concept of dementia among the Chinese older people**

83% of the respondents said that they had heard of dementia, only 18% of the total respondents had attended dementia talks. Therefore, the knowledge of dementia has little influenced the responses from the respondents.

When respondents were asked for a description of dementia; the behaviour change and the cause of dementia. 10% of them were unable to provide a description; 23% didn't know the behaviour change and 43% were unable to provide answers for the cause. The increase figure of unsure can be explained that was due to a lack of information or knowledge about the 'term' dementia in western medicine (Wong and Richman, 2000).

Furthermore, the description can be seen as an indication and a reflection within their network circle. The description of people with dementia from the respondents creates the image: dementia is the person who has a memory lost, mobility problems, is unable to communicate because they have speech problem and unable to think 'properly'. Also dementia is due to ageing or stimulation (means an unexpected shock, for example a death of the family) or unhappy.

About half of the respondents think that dementia is a mental illness and can be cured. However, when they were asked how to respond to dementia when they or their family member has dementia, the top three highest score of the responses are: 37% said the person will not be able to look after him/herself, he/she need someone to look after, 29% would not know what to do and 24% would seek help from doctors.

#### **6.3.2 Treatment of dementia**

A higher percentage of the respondents would seek advice from GP and prefer to pay for western medicine than to consult a Chinese medicine doctor and receive Chinese herbal medicine. One of the reasons the respondents point out was the availability of Chinese medicine professionals and affordable Chinese medicine. Also evidence shows that GP service play an important role for the Chinese older people to gain access to services and this will be discussed later.

*'If I go to Hong Kong, I'll go to see a Chinese herbal doctor. Chinese herbal doctor in England is too expensive.'* (Respondent 3 - 65 years of age female)

It should be noted that whether or not they seek treatment also depends on how respondents view dementia as it is illustrated below. If they think dementia is due to aging, and there is no cure for dementia then it is not necessary to receive any treatment while others are very positive in seeking treatment as long as it can be treated. Therefore, positive adequate information about dementia is crucial for dementia awareness.

*'As long as it can be treated, I'll try anything' (respondent 15, 85 years old female)*

*'People getting old, no cure, no need to take medicine' (respondent 25, 66 years old female)*

When they are asked their opinions about where the respondents should be placed, mixed feelings were expressed on whether or not they can handle the person with dementia. However, over half of the total respondents would like to stay at home and think the options for being admitted to hospital or care provided by a care home is the only alternative if they are not able to handle the situation. They think that at that stage, the government should help to handle this problem.

### 6.3.3 Support network and mental health promotion

When they were asked about how the Chinese community would respond to people with dementia, the majority of them think that they need help and this echoes the previous seeking help pattern within the Chinese community which rely on family members especially children. There were mixed feelings about whether or not the Chinese community would discriminate against people with dementia.

It should be noted that almost the same portion of the respondents think that Chinese people would show sympathy or discriminate against them (see table 6.5). Therefore, it is important to raise awareness and provide adequate information about dementia to the Chinese older people since Chinese people are aware that the person with dementia needs help rather than to be discriminated against.

Table 6.5 Attitudes towards people with dementia

		Frequency	Total
Valid	Need help		20
	Sympathy	13	14
	No prejudice	1	
	Depends		4
	Discrimination	7	10
	Keep away	3	
	no response		24
	Total		72

With regard to the prevention of dementia, respondents suggested several methods of preventing dementia which were being happy, don't think too much and do more exercise and playing Ma Jaing,

A list of activities asking respondents their views about how to reduce the chance of having dementia shows the majority of respondents think that meeting people and making friends, being involved with outdoor activities and playing Ma Jiang all help. This is a similar view of their suggested methods of prevention and the previous view of things that can make them happy.

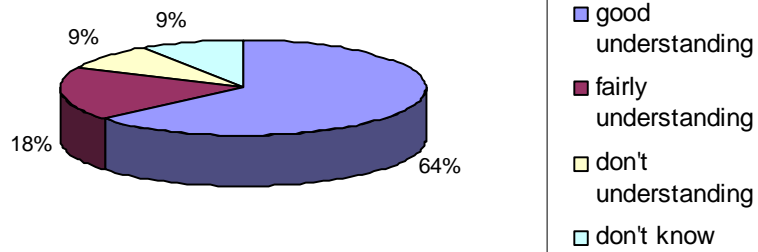
Respondents were asked about the fears that stop older Chinese people accessing mainstream mental health services. The verbatim illustrations in section 3 shows a strong feeling about stigma relating to language barriers across the age groups (over 50 years old in this research) When people with little English communicate with health professions, they feel they "lose face" because the situation makes them feel embarrassed that they have to explain their problems to the interpreter who is a stranger to them. They feel vulnerable and powerless, especially with such strong stigma attached to people with mental health problems, interpreting would become too difficult.

Moreover, respondents expressed that they had little information about the mainstream services and did not know how to gain access to the services. In addition, they expressed worry about 'injection' and 'taking medication' ( an expression of receiving treatment in Chinese language). Therefore, it is crucial that a worker understands Chinese language, is aware of Chinese culture, as well as an ability to form a trustworthy relationship with the older people. It is particularly important when people who are both physically and mentally unfit and socially restrained.

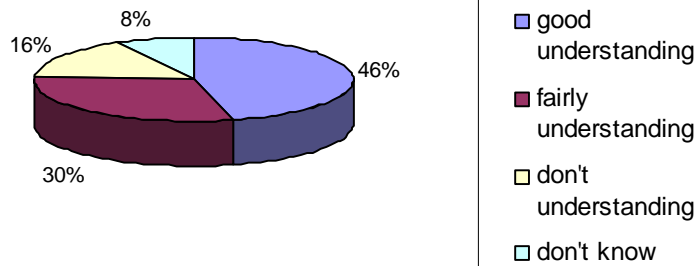
#### **6.4 Family doctor (General Practitioner GP )**

As mentioned in Section 4, nearly 33% of the respondents registered with a Chinese speaking GP. It didn't matter if the GP spoke Chinese or not as long as the respondents understood what the prescriptions were for and their side effects. However, it seems that, if the GP speaks Chinese, respondents have a better understanding their GP's prescriptions. However, respondents have more understanding about the side-effects of their prescriptions if their GP speaks English. However, very good understanding is dependent on good quality interpreting (see Table 6.4a &b, Chart 6.4a,b,c, &d)

**Chart 6.4a GP speaks Chinese - Understanding prescription**



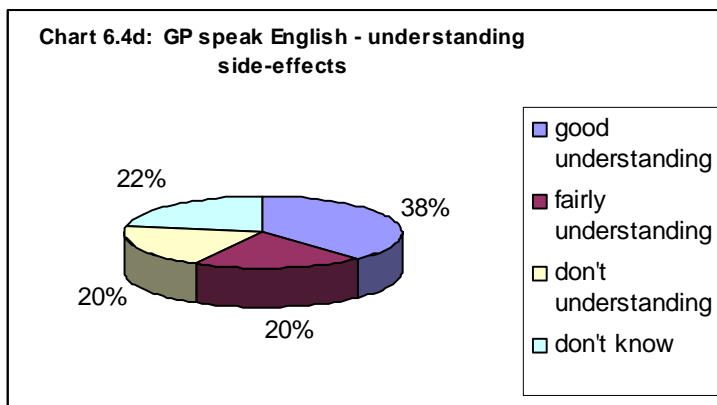
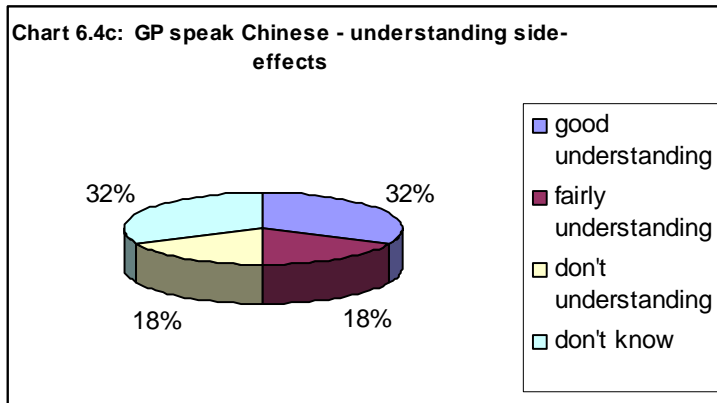
**Chart 6.4b GP speaks English - Understanding prescription**



**Table 6.4a Understanding GP Prescriptions**

GP speak Chinese		Frequency
Valid	good understanding	14
	fairly understanding	4
	don't understanding	2
	don't know	2
	Total	22
GP speak English		Frequency
Valid	good understanding	23

	fairly understanding	15
	don't understanding	8
	don't know	4
	Total	50



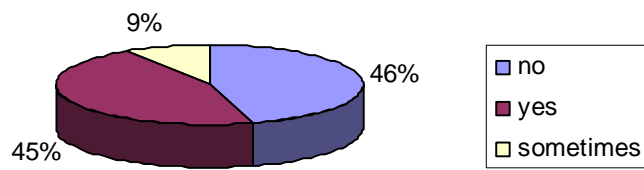
**Table 6.4b Understanding side-effects of the prescriptions**

GP speak Chinese		Frequency
Valid	good understanding	7
	fairly understanding	4
	don't understanding	4
	don't know	7
	Total	22
GP speaks English		Frequency
Valid	good understanding	19

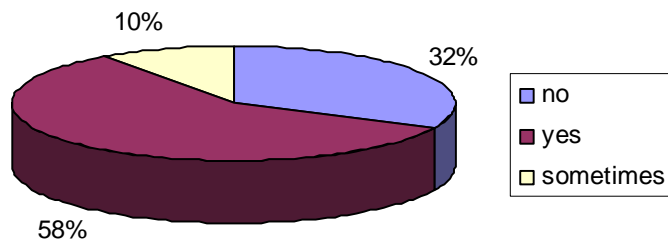
	fairly understanding	10
	don't understanding	10
	don't know	11
	Total	50

Section 4 reveals that respondents who need someone to go with them to see doctors, or if they require interpreting during consultation or rely on family members. Attention should be paid to the respondents who live on their own.

**Chart 6.4e: GP speaks Chinese - need accompany**



**Chart 6.4f: GP speaks English - need accompany**



**Table 6.4c Respondents need accompany to go to see doctors**

GP speaks Chinese		Frequency	Percent
Valid	no	10	47.6
	yes	10	42.9
	sometimes	2	9.5
	Total	22	100.0
GP speak English		Frequency	Percent
Valid	no	16	32.0
	yes	29	58.0
	sometimes	5	10.0
	Total	50	100.0

A total of 30 respondents live on their own as mentioned in 6.1.2. Among these 30 respondents, half of them need someone to go with them to see a doctor at some point due to their health circumstances. As Table 6.4f shows that respondents living on their own, on one hand, when they go to see a doctor, interpreters are more likely provided by Chinese organisations or the Trust hospitals. On the other hand, they rely on their family members, or seek help from friends or neighbours accompany with them to the doctors. As some of the respondents expressed that their friends and neighbours are getting old, and also need someone to look after them. Therefore, evidence shows that older people not only require interpreting services, it is the fact

that they encounter many difficulties in their daily lives and they need someone to look after them as mentioned in Section 2 . It would relieve stress from family and friends and not duplicate resources by providing them with support.

**Table 6.4d: Respondents living on their own need accompany to see doctors**

Living on their own		Frequency	Percent
Valid	No	15	50
	Yes	13	43
	sometimes	2	7
	Total	30	100.0

**Table 6.4e: Respondents living on their own – accompany to see doctors**

Accompany with respondents to see doctors	Frequency
Family member	8
Friends/neighbours	7
Chinese organisations	1
government	1
Do not require accompany	13
Total	30

**Table 6.4f Interpreting for respondents living on their own**

Living on their own		Frequency	Percent
Valid	missing / no	16	53.3
	children / spouses	2	6.7
	Chinese organisations	5	16.7
	government	7	23.3
	Total	30	100.0

In Section 4. we asked the respondents about whether or not they have a memory problem. Over half of them said they had a memory problem, only 3 went to see their GP to with regard to their problem. Respondents expressed that due to aging, memory loss should not be a problem to be concerned about.

Regarding referral to health services, no respondent was referred to mental health services, little comment and response about the health services indicates there is a gap of accessibility and culturally appropriate services for the Chinese older people.

## 6.5 Health and Social Care

Amongst the 22 respondents who expressed those children were not able to offer help is not showing filial piety, respondents explained that it is a responsibility of the children. They should offer help when their parents are in need. Moreover, it can be seen as a moral standard, and this moral standard also extended to offering help to close relatives. Therefore, 3 respondents stated that although they understand the difficulties their children encountered, they still think that children are not showing filial piety to their parents. (see table: 5.2)

In addition, attention should be paid to Section 1 when they were asked about their disability. Most of them did not regard themselves as a disabled person, as they view their disability is due to their age and it is a normal process of aging. A strong stigma is attached to people with disability and therefore as Table 6.5a shows there is a high proportion of the respondents who do not want to apply for DLA , AA or Carer Allowance.

Table 6.5a Responding to benefits

	Yes	No	Don't know	Refuse to answer
Disability Living Allowance (DLA)	11	36	17	8
Attendance Allowance (AA)	7	34	17	9
Carer Allowance	10	34	22	6
Income Support	23	27	16	6
Pension	43	13	11	5
Pension Credit	20	24	21	7
Direct payment/ individual budget	6	24	30	12

Regarding their choice of a care worker who is not necessarily a highly qualified professional, but a person who is able to show empathy, listening to them and being able to speak the same language (see Table 6.5b)

Table 6.5b Quality of the care workers

Same gender	52	72%
Same language	62	86%
Awareness of symptoms	51	71%
Empathic	65	90%
Good listener	62	86%
Mobility	52	72%
Someone with a lot of knowledge of dementia	49	68%

Finally the service that they would like to see is simply one which is accessible, culturally sensitive that would maintain their dignity, allow them to make choices and control over their life.

## Section 7 Recommendations

### **R1 Partnership to develop with Alzheimer's Society to promote a positive image of mental health and to reduce stigma attached to people with dementia – less fear of Mental Health care and services amongst Chinese communities and Chinese service users**

- R1.1 Provide adequate information of dementia
  - Produce Chinese information leaflets about dementia
  - Deliver dementia awareness talks to the Chinese communities:
    - Religious organisations
    - Community organisations
- R1.2 Promote mental health and independence
  - Through partnership working with Alzheimer's Society organise activities for service users and carers
  - Training volunteers to promote mental health activities.
- R1.3 Establish a long term partnership strategy by developing a National Chinese branch of the Alzheimer's Society

### **R2 Increase satisfaction with mental health services by providing accessible and culturally appropriate services through Dementia Outreach Link-worker**

- R2.1 Drop in assessment session
  - Collaborate with Admiral Nurses and MRI outreach service to set up a drop in session monthly
  - Carry out assessments by Admiral Nurse
  - Establish a referral system with Primary Care Trust
- R2.2 Professional training
  - Deliver cultural awareness talks to health professionals
  - Training and support volunteers
- R2.3 Provide individual and family support
- R2.4 To provide use of the Sheung Lok Centre (Wai Yin Day Centre for older people) to run activities for service users and carers

### **R3 Establish a more balanced range of effective therapies**

- R3.1 To set up support group for carers
- R3.2 To set up be-friending scheme run by volunteers
- R3.3 To develop a Chinese speaking counselling service for service users and carers.
- R3.4 To collaborate with Universities both in the UK and Hong Kong/ China to establish research based effective therapies for Chinese people with dementia

- R4** Develop the existing volunteer researchers and recruit more volunteers from the Kwan Wai (Mental Health) Project service users and carers to take an active role in the training of professionals, in the development of mental health policy and in the planning and provision of services
- R4.1 To establish collaboration with City College of Manchester to deliver NVQ 2 in Health and Social Care for volunteers
  - R4.2 To establish collaboration with Salford University to involve volunteers in the training of professionals
  - R4.3 Identify funding to support volunteers who participate in training programmes
- R5** To establish a workforce and organisation capable of delivering appropriate and responsive mental health services to the Chinese communities
- R5.1 Continuous volunteer development as mentioned (in R1.2; R3.2; R4.1; R4.2)
  - R5.2 To establish a social firm to provide home support services to dementia sufferers and their families

## Appendix 1

### Focus Group interview questions

1. What are the problems that you encounter in your daily life?
2. How will you seek help?
3. What is dementia? (How do you know it is dementia?)  
Do you know anyone who suffers from dementia? How did you find out?
4. Should the people with dementia go to see doctors? What doctors that they should go to?
5. Do you know what kind of benefit that you are entitled if you have dementia?
6. Do you know any of statutory or voluntarily organisations that can help / support you if you or your family members suffer from dementia? And how?
7. If a care worker is arranged to provide you with support, what is the specification of the person required?

## Appendix 2

### 慧妍社華人婦女中心 關懷心理健康計劃 社區配合計劃 曼徹斯特華人長者失智症服務需要問卷調查

問卷人姓名:	訪問日期:
問卷使用語言:	開始時間:
問卷使用地點:	結束時間:

#### 第一部份: 個人資料

- 1.1 性別:            男  
                           女  
                           變性

- 1.2 年齡: (實足年齡)              
      如果年齡在 50 歲下, 終止訪問

- 1.3 你的母語是

		講	寫
1	客家話		
2	廣東話		
3	普通話/國語		
4	其它 (請說明)		

1.4 你還會說那一種語言？

		完全不懂	少少 (一點點)	非常流利
1	英語			
2	普通話/國語			
3	廣東話			
4	客家話			
5	其它 (請說明)			

1.5 你的宗教是

1	拜祖先	
2	佛教 (拜觀音)	
3	基督教	
4	印度教	
5	猶太教	
6	伊斯蘭教	
7	錫克教	
8	無宗教	
9	其它 (請說明)	

1.6 住的區域:

1.7 你的住屋是.....

1	自置	
2	按揭	
3	租用市政府	
4	租用房屋協會	
5	租用私人房屋	
6	公司宿舍	
7	其它	

1.8 你現在是

1	單獨居住	
2	與配偶同住	
3	與子女同住	
4	其它(請說明)	

1.9 你是否在英國出生?

- 是
- 否

如果‘否’，你在英國居住了多久?

1	少於一年	
2	一年至五年	
3	六年至十年	
4	十一年至二十年	
5	二十一年至三十年	
6	三十一年至四十年	
7	四十一年至五十年	
8	超過五十年	

1.10 你是從那裏來?

1	中國大陸	
2	台灣	
3	香港	
4	其它(請說明)	

1.11 你是不是

1	英國公民	
2	難民	
3	尋求庇護	
4	其它 (請說明)	

1.12 種族

1	中國人	
2	白人	
3	混血	
4	亞洲人或亞洲英國人	
5	黑人或英國黑人	
6	其它 (請說明)	

1.13 你為什麼來這個國家?

1	工作	
2	伴隨家人	
3	讀書	
4	其它 (請說明)	

1.14 教育程度:

1	無受過教育	
2	小學	
3	中學	
4	學院 (高中)	
5	大學或以上	

1.15 職業 / 工作 \*現在 / 以前:

\*刪除不適當的

1.16 你是不是傷殘人士

是 (請說明)

不是

## 第二部份：日常生活的需要

2.1 有什麼事會令你快樂 (開心) ?

2.2 你覺得什麼是心理健康?

2.3 以你的意見, 華人長者日常生活中會遇到什麼困難?

2.4 你有否感到有同樣問題?

有 如果有, 是什麼

無

2.5 如果你有任何困難, 你會向誰尋求幫助?

1	家人 / 親屬		1	子女 / 其配偶	
			2	兄弟姐妹或其配偶	
			3	叔伯 / (姑) 孀母	
			4	孫子女	
			5	父母	
2	鄰居				
3	住宅管理員				
4	朋友				
5	華人社區支持				
6	政府服務				
7	其它 (請說明)				

### **第三部份：癡呆症的認識**

3.1 你有沒有聽過癡呆症?

- 有
- 無

3.2 你有沒有參加過癡呆症討論會?

- 有
- 無

3.3 你覺得什麼是“癡呆症”?

3.4 你覺得癡呆症的人在行為上會有什麼改變?

3.5 你覺得癡呆症怎樣得來?

3.6 你覺得癡呆症是不是精神病

- 是
- 不是
- 不知道

3.7 你覺得癡呆症可以醫治嗎?

- 能
- 不能
- 不知道

3.8 如果你或者你的家人患有癡呆症, 你會怎樣做?

3.9 如果你或者你的家人患有癡呆症, 你會不會?

如果會在下 ✓

如果不會在下 ✗

		需要付錢	不需要付錢
1	找中藥治療		
2	找西藥治療		
3	看中醫		
4	看家庭醫生		
5	其它 (請說明)		

3.10 如果你或者你的家人患有癡呆症, 你認為他應否?

1	留在醫院	
2	留在護理院	
3	留在家中	
4	其它 (請說明)	

3.11 如果你或是你家人患有癡呆症, 你認為華人社區的人會對你或者你的家人有什麼反應?

3.12 你認為癡呆症可以預防嗎？

- 可以 如果可以, 怎樣去預防?
- 不可以
- 不知道

3.13 你認為有什麼活動可以減少患有癡呆症的機會？

1	交朋友	
2	戶外的活動	
3	太極	
4	麻將	
5	唱曲	
6	紙牌	
7	社交舞	
8	沒有任何活動	
9	其它 (請說明)	

3.14 你覺得華人長者會有什麼恐懼令到他們不去使用 (政府) / 心理健康服務？

#### **第四部份：家庭醫生服務的需要**

4.1 你有沒有注冊家庭醫生？

- 有
- 無 為什麼？

4.2 你的家庭醫生跟你說什麼語言？

1	廣東話	
2	普通話 / 國語	
3	英語	
4	客家話	
5	其它	

4.3 你明不明白醫生開給你藥物的作用？

1	非常明白	
2	明少少 (一點點)	
3	不明白	
4	不知道	

4.4 你知不知道處方藥物的副作用？

1	非常清楚	
2	知少少 (知一點點)	
3	不清楚	
4	不知道	

4.5 你需不需要其他人陪同你去看醫生？

- 需要
- 不需要

4.6 有沒有人陪同你去看醫生?

- 有 是誰?
- 沒有

4.7 你需要翻譯人員嗎?

- 需要 如果需要, 請註明是誰\_\_\_\_\_
- 不需要

4.8 你對翻譯員滿意嗎?

- 滿意
- 還可以
- 不滿意  為什麼?

4.9 你記憶力有沒有問題?

- 有
- 沒有 去 4.13
- 不知道

4.10 你有沒有因為記憶力問題去見家庭醫生?

- 有 請說明你獲得什麼支持
- 沒有 去 4.13

4.11 你有沒有接受評估?

- 有
- 沒有
- 不知道

4.12 有沒有通知你評估確定的主要問題?

- 有
- 沒有
- 不知道

4.13 你有沒有接受過經家庭醫生轉介的服務?

- 有 請√
- 沒有

轉介服務	有	等多久
1 記憶力診所		
2 社區護士		
3 社會福利部		
4 心理輔導 / 治療		
5 精神科醫生		
6 心理醫生		
7 其它 (請說明)		

如果有, 你對服務有何意見

4.14 這些服務你喜歡那一方面?

4.15 你對這些服務有沒有不滿意的地方?

4.16 這些服務有沒有迎合你的文化需要?

4.17 這些服務上有沒有合適的員工去支援你?

4.18 如果有,你喜歡見到那一方面可以改善?

4.19 你有沒有人照顧你?(家人, 伴侶, 朋友)

- 有
- 沒有 去 4.21

4.20 如果有, 照顧者有沒有接受評估?

- 有
- 沒有 去第五部份
- 不知道

4.21 你是不是是一位照顧者?

- 是
- 不是 去第五部份

4.22 如果你是一位照顧者, 你有沒有接受過評估?

- 有
- 沒有 為什麼?
- 不知道

4.23 你照顧的人在心理健康服務上得到什麼援助?

4.24 你有沒有得到以下的援助

		非常好	好	普通	差
1	記憶診所				
2	社區護士				
3	社區精神科護士				
4	社會福利部				
5	心理輔導				
6	精神科醫生				
7	心理醫生				
8	自助小組				
9	其它 (請說明)				

4.25 如果你覺得服務只是普通或差, 這些服務可怎樣改進?

4.26 你從什麼地方取得更多有關失智症的資料?

4.27 你覺得有什麼方法可以做得到去增加你對這個病的認識?

有 是什麼?

沒有

4.28 你是一名照顧者, 心理健康服務有沒有給你額外的支援?

- 有
- 沒有

4.29 你覺得你和被你照顧的人, 在文化需要上有没有迎合你们的需要?

- 有
- 沒有

如果沒有 - 為什麼沒有, 又如何達到需求?

## 第五部份：社區護理服務的需要

5.1 如果你的子女不能夠幫助你, 你會不會覺得他們不孝順?

- 會 為什麼?  
 不會 為什麼?

5.2 你聽過以下的福利嗎?

1	傷殘補助金	
2	注意補助金	
3	照顧者補助金	
4	生活補助金	
5	退休金	
6	退休補助金	
7	直接付款 / 個別經費	

5.3 你會不會申請下列的福利?

		會	不會	不知道	扔絕回答
1	傷殘補助金				
2	注意補助金				
3	照顧者補助金				
4	生活補助金				
5	退休金				
6	退休補助金				
7	直接付款 / 個別經費				

5.4 如果你需要一位照顧者給你, 你希望在哪一方面給你幫助?

1	相同性別	
2	會說中文 / 相同語言	
3	理解症狀	
4	有同情心	
5	細心傾聽	
6	行動上	
7	他們對失智症有認識和與有失智症工作經驗的人	
8	其它	

5.5 你希望有什麼服務可以幫助有失智症的華人長者？

5.6 你认(不认)为心理健康服务和从事这个服务的员工，他们明不明白华人社区面对处理有关癡呆症问题 / 或者承认华人在华人社区不能获得长者癡呆症的需要服務

5.7 你還有什麼想補充？

**以下两个问题是兰開夏大学所要求的问题，你可以拒绝回答**

5.8 你是否一位變性者？

- 是
- 不是
- 不願回答

5.9 你是否一位

1	女同性戀者	
2	男同性戀者	
3	異性戀者	
4	雙性戀者	
5	不願回答	

## **Appendix 3**

### **Information for One-to-one interview**

**The aim of this interview is to express your views of the mental health needs of Chinese older people with dementia and their carers in Manchester. I'll ask you a few questions regarding this topic and perhaps if needed ask you to elaborate and explain certain answers. Your participation is voluntary and you do not have to answer any questions that you feel uncomfortable with; you also have the right to withdraw from the interview at any point during the interview.**

**You can be assured that your name, address and personal information will not be given to outside agencies and that all information and views and have expressed will be kept anonymous and confidential, unless you disclose anything that indicates that there is an immediate and serious risk to yourself, a child or a vulnerable adult.**

**When we have completed the report all recordings / transcripts will be erased or destroyed. The findings from the data will be written in a report in which we will make recommendations for improvements in Mental Health Services and presented to the Centre for Ethnicity and Health (University of Central Lancashire) and the National Institute of Mental Health in England.**

**If you wish to receive information about dementia and the report, please leave your contact details with us and we will forward the information to you.**

**Any questions before we start?**

**Are you happy to proceed?**

# Wai Yin Chinese Women Society

## Kwan Wai Mental Health Project - Community Engagement Project

### The needs of Chinese older people with dementia and their carers Research Questionnaire

Name of Interviewer	Date:
Language used:	Time Starting:
Venue:	Ending:

#### **Section 1: Personal details**

1.1 Gender:

Male

Female

Transgender

1.2 Age (last birthday):        **If under 50 years old, terminate interview.**

1.3 Your first language is:

		Written	Spoken
1	Hakka		
2	Cantonese		
3	Mandarin		
4	Other (please specify)		

1.4 What other languages can you speak?

		Not at all	A little	Fluent
1	English			
2	Mandarin			
3	Cantonese			
4	Hakka			
5	Others (please specify)			

1.5 Religion:

1	Worship Ancestors	
2	Buddhist	
3	Christianity	
4	Hindu	
5	Jewish	
6	Muslim	
7	Sikh	
8	None	
9	Others (please specify)	

1.6 District of residency: \_\_\_\_\_

1.7 Type of accommodation:

1	Own property	
2	Mortgaged property	
3	Rented from Council	
4	Rented from Housing Association	
5	Rented from private landlord	
6	Company accommodation	
7	Other (please specify)	

1.8 You are now living:

1	On your own	
2	With spouse/partner	
3	With children	
4	Other (please specify)	

**1.9 Were you born in the UK?**

Yes

No

If no, how long have you lived here:

1	Less than 1 year	
2	1-5 years	
3	6-10 years	
4	11-20 years	
5	21-30 years	
6	31-40 years	
7	41-50 years	
8	Over 50 years	

**1.10 Where did you come from?**

1	Mainland China	
2	Taiwan	
3	Hong Kong	
4	Other (please specify)	

**1.11 Are you a:**

1	British citizen	
2	Refugee	
3	Asylum seeker	
4	Other (please specify)	

**1.12 Ethnicity:**

1	Chinese	
2	White	
3	Mixed	
4	Asian or Asian British	
5	Black or black British	

6	Other (please specify)	
---	------------------------	--

1.13 Why did you come to this country?

1	To work	
2	Accompanying family	
3	Studying	
4	Other (please specify)	

1.14 Education attendance:

1	None	
2	Primary	
3	Secondary	
4	College/high school	
5	University or higher	

1.15 Profession/work ( now / previous\*) \_\_\_\_\_  
 \*delete the inappropriate answer

1.16 Do you have a disability?

Yes (Please specify \_\_\_\_\_)

No

**Section 2: Daily life needs**

2.1 What makes you happy?

2.2 What do you think mental health is?

---



---

2.3 What difficulties do you think older Chinese people face in their everyday life?

---



---

2.4 Do you face similar difficulties?

Yes If yes, what are they? \_\_\_\_\_

No

2.5 When you face these difficulties, to whom would you turn to for help? (you may tick more than one answer)

1	Family/relative		1	Children and/or their spouses	
			2	Siblings and/or their spouses	
			3	Uncles/aunts	
			4	Grandchildren	
			5	Parents	
2	Neighbours				
3	Warden				
4	Friends				
5	Chinese community Centres				
6	Government services				
7	Other (please specify)				

### **Section 3: Dementia awareness**

3.1 Have you heard about dementia?

Yes

No

3.2 Have you ever attended any talks about dementia?

Yes

No

3.3 What do you think dementia is?

---

3.4 What changes might happen to a person with dementia?

---

3.5 How do you think people get dementia?

---

3.6 Do you think dementia is a mental illness?

Yes

No

Don't know

3.7 Do you think dementia can be cured?

Yes

No

Don't know

3.8 What would you do if you or a family member has dementia?

---

3.9 If you or a family member has dementia, would you?

(√ for "would" and X for "would not")

	Would you?	If it is free	If you need to pay
1	Take Chinese medicine		
2	Take Western medicine		
3	See a practitioner of Chinese medicine		
4	See your family doctor		
5	Others (Please specify)		

--	--	--	--

3.10 If you or a family member has dementia, where do you think the person should stay?

1	In hospital	
2	In a care home	
3	At home	
4	Other (please specify)	

3.11 If you or a family member has dementia, what do you think the attitude of the Chinese community will be?

---

3.12 Do you think dementia can be prevented?

Yes If yes, how? \_\_\_\_\_

No

Don't know

3.13 Which activities do you think might help in reducing the chance of having dementia?

1	Making friends	
2	Outdoor activities	
3	Tai Chi	
4	Ma Jiang	
5	Singing	
6	Card games	
7	Ballroom dancing	
8	Nothing	
9	Others (please specify)	

3.14 What do you think are the fears that stop Older Chinese people accessing mainstream/mental health services?

## **Section 4: Family doctor (GP)**

4.1 Are you registered with a GP?

Yes

No (If No Why not?)

---

4.2 Which language does your GP speak?

1	Cantonese	
2	Mandarin	
3	English	
4	Hakka	
5	Other (please specify)	

4.3 If prescribed medication by your doctor are you able to understand why it is prescribed for you?

1	Yes, very much	
2	A little bit	
3	No, I don't understand	
4	Don't know	

4.4 Are you aware of the side effects of the medicine?

1	Yes, very much	
2	A little bit	
3	No, I don't understand	
4	Don't know	

4.5 Do you need someone to go with you when you visit your GP?

Yes

No

4.6 Does someone actually go with you?

Yes Who? \_\_\_\_\_

No

- 4.7 Do you need someone to translate for you when you see your GP?
- Yes  
If Yes who, please state
- No
- 4.8 If you have used the services of an interpreter, were you happy with the service?
- Yes, very much
- So, so
- No Why? \_\_\_\_\_
- 4.9 Do you have a memory problem?
- Yes
- No **Go to 4.13**
- Don't know
- 4.10 Have you gone to your GP about the memory problem?
- Yes Please state what support you received \_\_\_\_\_
- No **Go to 4.13**
- 4.11 Were you given an assessment?
- Yes
- No
- Don't know
- 4.12 Were you informed of the key issues identified in your assessment addressed?
- Yes
- No
- Don't know

4.13 Were you ever referred by your GP to the following healthservices?

	Service referred	Yes	How long does it take to get an appointment?
1	Memory Clinic		
2	Community Nurse		
3	Social Services		
4	Counselling/ Psychotherapy		
5	Psychologist		
6	Psychiatrist		
7	Others		

If yes, how did you find the service? \_\_\_\_\_

4.14 What did you like about this service?

4.15 Was there anything you disliked about the service?

4.16 Does the service meet your cultural needs?

4.17 Does the service have appropriate staff to support you?

4.18 What improvements would you like to see, if any?

4.19 Are you supported by a carer (family, partner, friend)?

Yes

No **Go Section 5**

4.20 If yes, has he/she been offered a Carer assessment?

Yes

No

Don't know

4.21 Are you a carer?

Yes

No **Go to Section 5**

4.22 If yes, have you been offered a carer assessment?

Yes

No Why? \_\_\_\_\_

Don't know

4.23 What support does the person that you are caring for receive from the Mental Health Services?

4.24 What support have you receive from the following

		Excellent	Good	Fair	Poor
1	Memory Clinic				
2	Community Nurse				
3	Community Psychiatric Nurse				
4	Social Services				
5	Counselling				
6	Psychology				
7	Psychiatrist				
8	Self help groups				
9	Other (please state)				

4.25 If you were dissatisfied with the service (Fair / Poor), how could the service have been improve?

4.26 Where did you get most of your information about dementia from?

4.27 Do you feel that more could be done to improve your knowledge of the illness?

Yes if yes – what?

No

4.28 As a carer were you offered any additional support for yourself by Mental Health Services?

Yes

No

4.29 Did you feel that your cultural needs and those of the person you care for were met?

Yes

No

If No – why not and how could they have been met

---

## **Section 5: Community health care needs**

5.1 If your children could not help you, would you think they do not show filial piety?  
Don't understand this question

Yes Why? \_\_\_\_\_

No Why? \_\_\_\_\_

5.2 Have you heard about the following benefits?

1	Disability Living Allowance (DLA)	
2	Attendance Allowance (AA)	
3	Carer Allowance	
4	Income Support	
5	Pension	
6	Pension Credit	
7	Direct payments/individual budgets	

5.3 Would you apply for any of these benefits?

		Yes	No	Don't know	Refuse to answer
1	Disability Living Allowance (DLA)				
2	Attendance Allowance (AA)				
3	Carer Allowance				
4	Income Support				
5	Pension				
6	Pension Credit				
7	Direct payments/individual budgets				

5.4 If you require a carer, what kind of help are you looking for?

1	Same gender	
2	Same language	
3	Awareness of symptoms	
4	Empathic	
5	Good listener	
6	Mobility	
7	Someone with a lot of knowledge of dementia and experience of working with others who have dementia	
8	Other(please specify)	

5.5 What type of services would you like to see to support Older Chinese with dementia?

---

5.6 Do you think mental health services and staff working in these services understand the issues that the Chinese community face in dealing with dementia/or acknowledge that there are members of the Chinese community not accessing older peoples services for dememntia who need to.

5.7 If there anything else you would like to add please state.

**The following two questions are required by UCLAN, it is OK if you do not want to answer.**

5.8 Are you a transgender or transsexual?

Yes

No

Do not wish to answer

5.9 Are you a:

1	Lesbian or gay woman	
2	Homosexual or gay man	
3	Heterosexual or straight	
4	Bisexual	
5	Do you wish to answer	

Contact details for respondents to take away:

**Thank you for your time spent in taking part in this interview.**

**Wai Yin Kwan Wai (Mental Health) Project is aiming to provide a high quality mental health service to the Chinese community. Your views are valuable to improve our services.**

**If you have any queries or require further information about this research project, please do not hesitate to contact Louise Wong at Wai Yin.**

Address: 1<sup>st</sup> Floor, 61 Mosley Street, Manchester M2 3HZ

Telephone No: 0161-2375908

e-mail : [louise\\_wong@waiyin.org.uk](mailto:louise_wong@waiyin.org.uk)

## Appendix 4

### Occupation of the respondents

		Frequency	Percent
Valid	None	17	23.7%
	Take-away	11	15.3
	Waiter / waitress	2	2.8
	Kitchen staff	6	8.3
	Housewife	8	11.1
	Textile worker	2	2.8
	Teacher	1	1.4
	Business/self-employ	2	2.8
	Chief	9	12.5
	Manager	1	1.4
	Child minder	3	4.2
	Sale assistant	1	1.4
	Banking	1	1.4
	Driver	1	1.4
	HKG	1	1.4
	Farming	1	1.4
	Laundry	1	1.4
	Factory worker	1	1.4
	Travel agency	1	1.4
	Cleaner	1	1.4
	Warehouse worker	1	1.4
Total		72	100.0

## References:

DoH (2005) Delivering race equality in mental health care. An action plan for reform inside and outside services and the Government's response to the independent inquiry into the death of David Bennett.

Jones, A. and Lam, B. (2004) Breaking down the barriers: Service usage by Chinese older people – obstacles and remedial actions. Wai Yin Chinese Women Society.

Wong, L. and Richman, J. (2000) Chinese mental health. *Mental Health Nursing* Vol. 20, 6, 14-18 and Vol. 20, 7 16-19.

Wong, L. and Richman, J. (2003) Chinese Understanding of Diankuang in a Metropolitan City in the United Kingdom. *International Journal of Mental Health*, Vol 32, No. 3, Fall 2003, pp.5-30.