

**Findings from Qualitative Research  
concerning Attitudes to Dementia for  
the Department of Health & the  
Alzheimer's Society**

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# ***I. Executive Summary***

## **1.1 Background**

The research was commissioned by the Department of Health and the Alzheimer's Society to inform the first action point of the National Dementia Strategy for England: a national awareness campaign to improve public understanding about dementia and reduce the stigma which leads to discrimination against people with dementia and their families.

The research was carried out in September and October 2009.

## **1.2 Findings**

A vague knowledge about dementia is widespread. It is understood to be the progressive condition of loss of short-term memory, loss of capacity for everyday functions, loss of social engagement and inhibition, increasing confusion and loss of control of bodily functions. The term "Alzheimer's" is commonly used for both the cause and the condition of dementia.

In principle, people are sympathetic to people with dementia, in practice they avoid people with dementia, and avoid thinking seriously about the topic. There was evidence of a reasonably powerful tendency for potential carers to be in denial at onset.

Given the tendency of avoidance, in general people have low exposure to people with dementia. As a result, any single contact with a person with dementia is highly impactful and understanding of dementia in general is heavily influenced by the particular symptoms and situation of the person with dementia whom they meet.

Whilst the disease itself is 'invisible' the off-putting consequences are visible, i.e. confused behaviour, poor personal hygiene, challenging emotions and the burden of care. Hence awareness of how the disease manifests is far more salient than any commentaries about the disease. This awareness generates fear of getting it and avoidance of those who have it.

Avoidance is the dominant attitude. Whilst people overall express sympathy, both towards people with dementia and towards carers, their behaviour is dominated by avoidance.

Stigmatization as such was not evident. Hence it is probable that the stigma noted by people with dementia and carers is not active stigmatization but rather the perceived outcome of avoidance.

### 1.3 Key Facts

A number of 'key facts' were tested in the research. When they were presented a good deal of confusion or rejection was generated because:

- some appear contradictory or incompatible
- some appeared to be ambiguous
- some were not believed
- some were damned as statistics.

The most common single response to the facts overall was an increased fear of Alzheimer's disease.

There was no single fact which had an impact congruent with the core strategic goal. Therefore, as they stand, we cannot recommend any of the Key Facts as a core message for a communications campaign. We recommend that if any of these messages are to be used in a communications programme, they should be re-crafted within the framework of a coherent messaging strategy.

### 1.4 Future messaging

Whilst, the strategic direction is still under review, a number of points can be considered when deciding messaging priorities.

(a) People do not know much about the medical facts and figures of dementia. They do however know a good deal about how dementia is manifest in everyday life.

(b) There are as yet no 'killer facts' about dementia which radically transform attitudes.

(c) Attitudes to dementia are created as much, if not more, by a society-wide reduction in social empowerment as by the specific details of dementia. In other words avoidance, ignorance and helplessness are all symptoms of the wider tendency towards social disengagement.

(d) Any messages about attitudes to dementia will be successful in the long-term only if they also offer an alternative to this tendency towards social disengagement.

### 1.5 Challenges

Given the high salience of personal lived experience it seems likely that evidence from everyday life will recreate avoidance as the dominant attitude unless an actionable alternative is offered. Therefore a campaign must do more than reduce fear or stigma. It must look to replace them with attitudes which are both congruent with the evidence of everyday life and offer better outcomes to members of the public, to people with dementia and to their carers.

### 1.6 Recommendations

A campaign which overtly acknowledges avoidance and offers a low-risk alternative would help move people away from behaviour perceived as stigmatizing and would be congruent with life experiences. The research indicates that people need encouragement, reassurance and permission to make small gestures of social inclusion.

We propose that a campaign route could be tested which overtly notes a few of the non-negotiable difficulties facing people with Alzheimer's disease (such as failing short-term memory, disorientation and difficulty performing familiar tasks) and highlights that additionally "people avoid you". The subsequent call to action could indicate that members of the public can make a difference with small gestures which break down avoidance.

There may be other routes which are consistent with the research findings. When a strategic direction has been decided it may be appropriate to review the research material for specific guidance to assist in crafting messaging.

## ***II. Research Objectives***

The overall research objective was to gather general public feedback to be used to inform and develop a strategy to address the issue of dementia and the stigma and discrimination which surround it.

More specifically, the research addressed the following requirements:

- Understand the knowledge, attitudes, reactions and feelings towards people with dementia and the disease itself
- Determine the reasons for negative attitudes and feelings towards dementia, and people with dementia

Further research objectives included:

- To inform the advertising and PR agency briefs and key messaging priorities
- To assist in the compilation of questions for possible quantitative research that will meaningfully ascertain the level and type of stigma.

These further objectives will be addressed in a follow-up meeting between Corr Willbourn, the Department of Health, the Alzheimer's Society and a creative agency in the light of a review of the strategic objectives.

## ***III. Method***

Two complementary research methods were employed: workshops and depth interviews.

### **Workshops**

The workshops were convened in large spaces - 120m<sup>2</sup> or larger - with two moderators and sixteen respondents. They were used to explore attitudes expressed in public and how they are expressed and evolve in the context of public discourse. The plenary discussions foster diversity and provide support for diverse opinions. Several spatial mapping exercises were used allowing respondents to express their feeling through movement and positioning.

### **Depth interviews**

The depth interviews were one-hour, face to face private meetings in the respondents' homes. The depth interviews provided a context within which

respondents would be free to express less socially acceptable opinions. They also allowed deeper exploration and ratification of views that had been expressed in the more public situation.

## **IV. Sample**

### **4.1 Workshops**

Three 3-hour workshops of 16 respondents were convened as follows:

	High ethnic diversity*	Low ethnic diversity
1 Central and East London	35 - 49 Low connection with dementia ABC1	
2 Durham		40 - 60 Low connection with dementia BC1C2
3 Coventry	50 - 65 Some connection with dementia C2DE	

\* See Recruitment Criteria below.

### **4.2 Depth Interviews**

Twelve 1-hour face-to face depth interviews were convened as follows:

1 Leicester	Asian F
2 Leicester	Asian M
3 North London	Mauritian M
4 West London	Asian F
5 North London	Afro-Caribbean, M
6 West London	African, F
7 Bristol	Afro-Caribbean, F

8 Bristol	White, M
9 Leeds	Afro-Caribbean M
10 Leeds	White F
11 Cheam, Surrey	White M
12 Cheam, Surrey	White F

### 4.3 Recruitment Criteria

#### Workshops

All the workshops were inclusively recruited, in other words there were no specifically "non-ethnic" workshops. In Durham there was a quota of no more than 25% to be from ethnic minorities. The 'High ethnic diversity' workshops were deliberately recruited in Central and East London and Coventry because they have a relatively high degree of ethnic diversity. Within that, there was a quota of 50% ethnic minorities.

All workshops were mixed gender and recruited from socio-economic groups BC1.

#### Depth interviews

The depth interviews were recruited across socio-economic groups A to E, and with a range of ages from 35 - 65. There was a quota of 66% ethnic minorities.



## **V. Analysis and Main Findings**

### **5.1 Knowledge**

There was universal awareness of Alzheimer's disease. Respondents had a good deal of knowledge based on encounters with people with dementia and discussions with both people with dementia and carers. However there was very little detailed medical or scientific understanding.

*"I don't think most people understand it fully."*

[White, Male, Surrey, low connection with dementia]

Coronation Street (Mike Baldwin) and Home and Away were both mentioned as portraying characters with dementia. Terry Prachett and a parent of Fiona Phillips were mentioned by a few as well-known people with dementia.

It was clear that understanding of dementia is very highly shaped by real life encounters with, or experience of, people with dementia. Experiential knowledge of this type far outweighs any knowledge gained through formal education, communications campaigns or media coverage.

The few respondents with more detailed and or accurate knowledge had gained it because of closer acquaintance with a person with dementia. The knowledge passed on from medical professionals by carers is disseminated to their acquaintances. However the knowledge does not take the form of an overview or insight into dementia as a whole, but is very much dominated by the particular symptoms and circumstances of the particular people with dementia with whom people have contact or whom they discuss with a carer.

#### **5.1.1 Associations**

Top of mind associations to the word "Dementia" included:

- Old age
- Memory loss
- Alzheimer's
- Loneliness
- Vulnerable

- Medication
- Dependent
- Neglect
- Lack of care
- Nursing home
- Social Services
- Support
- Carers
- Affects the family
- Finance
- Frustration
- Sad
- Confusion
- Going back into your childhood memories
- Temper
- Repetitive
- Erratic behaviour
- Mad
- Seen as mad
- Loss of dignity
- Loss of personality
- Lack of concentration
- Loss of confidence

Whilst there was considerable ignorance about accurate nomenclature and about the medical definition of dementia, this list accurately reflects the universal acquaintance with dementia and the widespread beliefs about how it manifests, and perceptions of the services or support available for people with dementia.

### 5.1.2 Nomenclature

"Alzheimer's" was the word most commonly used for both the cause and the condition of dementia. We hypothesize that "Alzheimer's" has become widely used for two reasons. Firstly, previous communications campaigns have raised public awareness and acceptance of Alzheimer's disease.

*"It's in the public domain more than it was 30 odd years ago [and] people have a better understanding."*

[Durham, low connection with dementia]

Secondly, dementia seems to many to be more serious both as a word and a condition.

*"Dementia is the unsaid word but Alzheimer's you can make a bit light of it."*

[Coventry, some connection with dementia]

A few, mostly in the "some connection" group, who had had contact with health professionals used the term 'dementia' to convey a meaning which was closer to the informed, medical usage of the term.

*"I think dementia is a symptom of Alzheimer's."*

[London, low connection with dementia]

We hypothesize therefore that people with some connection with a specific diagnosed person with dementia may well begin to use the term 'dementia' more frequently because they have a more accurate understanding of the term as referring to a condition resulting from an underlying disease.

There was considerable confusion as to the difference - if any - between Alzheimer's and dementia:

*"There is a difference but I don't know what that is."*

[London, low connection with dementia]

The term 'dementia' was universally understood, however as with 'Alzheimer's' cause and condition were conflated. As noted above, for some, 'dementia' was

the more negative word; it was phonetically closer to 'demented', thus having connotations of madness. For others it had associations of hospital.

*"Dementia ... used to be associated with geriatric wards and things in hospital."*

[London, low connection with dementia]

A few respondents referred to 'senile dementia', but many felt it was a term that less frequently used nowadays.

### 5.1.3 Aetiology and symptoms

No one knew the exact definition of 'dementia' nor the aetiology or the physiology Alzheimer's disease. It was seen understood variously as:

*"A disease or condition we associate with old people."*

[Durham, low connection with dementia]

*"Degeneration of brain cells."*

[Coventry, some connection with dementia]

*"A state of mind they don't know where they are."*

[White, Male, Bristol, low connection with dementia]

*"A form of mental illness"*

[Afro-Caribbean, Male, Leeds, low connection with dementia]

*"[Dementia is] losing their mind. Not going mad but losing their memory."*

[African, Female, low connection with dementia, London]

For most, the most salient symptom is loss of short-term memory.

*"I probably would just have said something about memory loss but nothing specific."*

[Mauritian, Male, London, some connection with dementia]

Other symptoms observed were:

- Losing the ability to do everyday tasks - including maintaining personal hygiene
- Becoming “stuck in the past”
- Being repetitive
- Being confused or bewildered
- Acting like a child
- Loss of understanding of other people’s feelings
- Mood swings
- Character change
- Paranoia
- Bad temper - leading to swearing or violence.

*"There's real nice old ladies there they lash out with their sticks and ... their language is terrible sometimes and these are people who have never sworn in their life."*

[Durham, low connection with dementia]

A good number of respondents used the phrase “*losing the plot*” to describe the impact of dementia. This meant, broadly, becoming unaware of environmental and/or social expectations, becoming easily confused, getting lost, losing competence at everyday tasks and having a tendency to act on random impulses. However the term was not necessarily pejorative. It was used in a friendly, non-judgemental fashion. It was often a normalizing description because the same phrase was used to describe ordinary episodes of confusion or disarray experienced by people in all walks of everyday life

*" I think we all lose the plot."*

[Durham, low connection with dementia]

Some people believed that lack of cognitive or social stimulation could potentiate dementia:

*"A lot of people when they're on their own they don't see people for days on*

*end and the brain closes down.”*

[Coventry, some connection with dementia]

There was no sure knowledge about the cause of Alzheimer's.

*“I don't think any of us really know what dementia is but ... [possible] causes are age, that it's inherited, it could be linked to genetics, and it could also be to do with lifestyle - drink and medication”*

[Coventry, some connection with dementia]

*“Environmental issues - all the additives and all the stuff in your basic foods that you eat now”*

[Durham, low connection with dementia]

*“We felt that part of the brain's not functioning properly but how that comes about we haven't got a clue.”*

[Durham, low connection with dementia]

*“Just living too long . . . I think it's maybe your body saying 'I've had enough”*

[White, Female, Surrey, some connection with dementia]

Other possible causes were thought to be poor diet in general or aluminium in the diet via use of aluminium cooking pots. Several respondents thought that there might be a genetic predisposition towards Alzheimer's disease, but there was no certainty nor specific references.

#### 5.1.4 Knowledge of Stage

There is a widespread understanding that the disease is not reversible and symptoms get worse. It is generally believed to start with memory-loss and confusion and to result finally in complete loss of cognitive functions.

*“We had an elderly aunt who was forgetful to start with and ... she could recognise you coming in but thought you were there for entirely different*

*reason. ... In the end she couldn't wash herself or feed herself and she had to have full time care. In the end she was looking like a vegetable."*

[Durham, low connection with dementia]

*"At first people are just asking are you ok, then you go to a day centre, then you go into a nursing home."*

[Afro-Caribbean, Female, Bristol, some connection with dementia]

However no one believed that dementia in itself was terminal. Respondents believed that people could live for quite a long time with dementia and that eventually another disease would kill them.

Some respondents had heard that there was medication that could help to arrest or delay the progress of the disease. Other respondents remained unsure as to whether there was medication available and if so what it did. Some believed that there was no treatment available at all and that all that could be offered was care.

## **5.2 Feelings, Reactions & Attitudes**

In the many and various relationships to Alzheimer's disease and people with dementia we can distinguish three types of response: Feelings, Reactions and Attitudes.

We call 'feelings' basic unthought emotions such as fear, anger, excitement, sadness and happiness. These feelings spring from the basic emotional engagement with the world (*vide* Ekman, Paul, "The Nature of Emotion", OUP USA, 1995).

We call 'reactions' the immediate and often transitory responses that arise on occasions when people encounter people with dementia.

We call 'attitudes' feeling-toned judgements towards people with dementia. A feeling-toned judgement is a consciously adopted belief combined with an emotional disposition. For example I can be 'ignorant' about something simply by virtue of not knowing about it. However an attitude of ignorance is lack of knowledge maintained by a disinterest in the topic, that disinterest having a

specific emotional charge. Whilst feelings and reactions arise unbidden, an attitude is, to some extent, chosen and thus can be changed. Attitudes have some consistency over time but are modulated by context, relationship, experience and elapsed time.

### 5.2.1 Feelings

#### Aversion

For most the primary feeling is aversion. People don't want to have to deal with the demands, embarrassment, disruptions or responsibility of dementia. They don't want to think about it and they don't want to suffer from it themselves. This aversion is an automatic response. Aversion is triggered without any thought or consideration. It is the emotional basis for the attitude of avoidance.

#### Fear

Many who do not immediately avert their attention are fearful around people with dementia and Alzheimer's. The greater fear is that a relative, or they themselves get Alzheimer's or suffer from dementia.

*I've got quite a lot of family members who have had it, so that's my fear is that it's hereditary.*

[Durham, low connection with dementia]

*"[I have a] fear that should a family member suffer from it. I don't know how I would be able to deal with it."*

[London, low connection with dementia]

A lesser but nevertheless widespread fear is the fear of having to deal with the dependency, demands or erratic behaviour a person with dementia.



## Sympathy

Sympathy is widespread. It seems that some people are simply naturally sympathetic. For others it appears to be a more deliberate response, a conscious modification of aversion, in other words an attitude (see below).

Although widespread, sympathy rarely provokes action because of equally widespread helplessness, ignorance and disempowerment.

### 5.2.2 Reactions

For most, the first reaction to meeting someone with dementia is avoidance. This is founded in fear or aversion (see above) or in a degree of distaste prompted by odd behaviour, odd appearance or poor hygiene, all reinforced by social disempowerment. When faced with unusual or challenging behaviour many people do not feel they know what to do, nor do they feel entitled to do anything even if they did know what to do. People with dementia are just one case of difficult behaviour which prompts avoidance.

*"You don't know what to say to them. You don't know whether to go out of the room or get involved. It's a big fear when you don't know what to do, when you're not trained."*

[Durham, low connection with dementia]

*"You feel like you don't want to say anything or get eye contact in case they get all crazy on you."*

[White, Male, Bristol, low connection with dementia]

Some respondents spoke of negative reactions when they first interacted with a relative with dementia.

*"[There's] revulsion ... at times when the person is maybe dribbling or perhaps having difficulty eating or not properly dressed and perhaps smelling a bit."*

[Afro-Caribbean, Male, London, some connection with dementia]

There were also reports, both direct and hearsay, of helpful actions.

*“I was travelling on the train there was a chap who went to the toilet and came back with everything flashing and people were just looking at him and ignoring him. And I just walked up to him and said, ‘your trousers are air conditioned’.”*

[Coventry, some connection with dementia]

*“He goes off walking you don’t know where he is and three times people have contacted somebody in the family, he carries a card, and say we’ve got John here he doesn’t know where he is.”*

[Coventry, some connection with dementia]

Notwithstanding these interactions, it seems the primary reaction to strangers with dementia is to steer clear.

*“I wouldn’t get involved, no. I would say nothing and do nothing.”*

[Coventry, some connection with dementia]

This default reaction, founded in the primary feeling of aversion, becomes the basis of the default attitude: avoidance.

### 5.2.3 Attitudes

Across the sample there was considerable consistency. The most prevalent attitudes are avoidance, sympathy, helplessness and ignorance.

#### AVOIDANCE

Avoidance seems to be the default response to people with dementia for the majority who are not naturally predisposed to be sympathetic. It is very important to note, however, that avoidance is currently the most common and dominant response to all threatening, embarrassing or in any way challenging public or social situations. It is now considered atypical, even dangerous, to

spontaneously offer assistance or to intervene in untoward situations, especially in large conurbations.

*“Everybody buries their head in the sand.”*

[Durham, low connection with dementia]

*“I take my step-dad shopping ... and he does act like a child. I can see people’s faces in the shop you know he will dribble and things like that. People ... walk away but he needs to be taken out into society and people avoid him.”*

[Coventry, some connection with dementia]

*“Young people usually avoid people with any sort of mental disease”*

[London, low connection with dementia]

*“My son said to me ‘If I didn’t know who he was and I’d seen him in the street I would walk over the road [to] avoid him.’”*

[Coventry, some connection with dementia]

Avoidance is also common amongst acquaintances and relatives.

*“The tendency is, and I think I’m guilty of that as well, is it becomes quite stressful and it’s easier to avoid the meeting with that particularly person purely and simply because it’s stressful for them and stressful for you”.*

[Afro-Caribbean, Male, London, some connection with dementia]

In conversations there is frequently an avoidance of taking the topic of Alzheimer's too seriously. If mention is made of Alzheimer's or a person with dementia the seriousness is often subverted with a humorous remark.

For many the most common uses of the terms 'Alzheimer's' and 'dementia' are in fact in jokes about their own everyday forgetfulness.

*“I work in a factory, and if anybody forgets anything he will say I reckon I’ve got Alzheimer’s.”*

[Coventry, some connection with dementia]

*"When you can't find something you say, 'senile dementia is setting in'."*

[Afro-Caribbean, Female, Bristol, some connection with dementia]

*"On Friday I left the hotel to go to the train station and I thought, 'Where's my handbag?' and I thought, 'My dementia is starting.'"*

[Durham, low connection with dementia]

Avoidance is supported by:

- Uncertainty: not knowing what a person with dementia might do or how much they might understand, and hence not knowing how to relate to them
- Fear of embarrassment
- Fear of unknown or unpredictable outcomes
- Disenfranchisement: not knowing whether any engagement would be welcomed or legitimate
- Insecurity: not knowing if any engagement would be containable
- Helplessness: not knowing what - if anything - is actually helpful
- The wider social tendency towards disengagement.

A significant consequence of avoidance is the maintenance of ignorance.

## SYMPATHY

Sympathy is widely avowed, but for the vast majority it is sympathy-at-a-distance. In other words most people feel sympathy for those they see in a difficult situation, but they do not intervene or engage. The feeling of sympathy is not strong enough on its own to overcome the multiple barriers to action. Hence, for most, sympathy is accompanied by helplessness.

*"It's a natural feeling when you feel that somebody is less fortunate than yourself. You don't know how to help them but you feel sympathy towards the situation that they're in."*

[Coventry, some connection with dementia]

*"I'd feel sympathy for the person suffering. I'd feel sympathy for their family"*

*as helpless and I'd feel sympathy for the person treating them."*

[Durham, low connection with dementia]

One respondent whose notion of sympathy entailed action was clear that she would not go out of her way to help a stranger with dementia.

*"I've got a big family I've got children and everybody to look after like. Why would I want to waste my energy being sympathetic about somebody I don't really know? I'm being honest."*

[Coventry, some connection with dementia]

However if a relationship with someone predates their dementia, sympathy and kindness may drive engagement:

*"I had a neighbour and he and his wife lived alone, they had one daughter who came regularly to see them, but she only came once a week. And so I used to look after them."*

[Coventry, some connection with dementia]

*"People who you don't know ... you can probably just be sympathetic. But people who are closer to you ... I think you're in a position where maybe you can ... do things to try and minimise the effect of the condition."*

[London, low connection with dementia]

Many respondents also expressed sympathy for carers of people with dementia whose symptoms were demanding or distressing.

*"[My friend's] auntie she works ... a carer and its difficult dealing with these people."*

[White, Male, Bristol, low connection with dementia]

*"[My cousin] found it a bit of a struggle because [my uncle] was quite cantankerous."*

[Afro-Caribbean, Male, London, some connection with dementia]

*"It's probably the carer or carers that end up with the biggest problem."*

[White, Male, Surrey, low connection with dementia]

## HELPLESSNESS

A good number of respondents felt helpless in that they felt there was nothing to be done to cure or alleviate the symptoms of Alzheimer's disease, and many also felt that there was a limit to what could be done to help people with dementia at a practical or emotional level.

*"[There is] helplessness ... in that you can do things for them but you can't really do anything about the condition that they have."*

[London, low connection with dementia]

*"[Helpless] would apply to everyone involved, the person who's suffering from dementia I imagine would feel helpless and the family members ... would feel helpless as well because they couldn't help that person."*

[Durham, low connection with dementia]

*"You would be more helpless as it increased. But it would depend on their level of dementia and you know how close you are."*

[Coventry, some connection with dementia]

Whilst people knew that they knew very little, they did not believe that there was a great deal of knowledge to which they did not have access. Rather they believed that not much was actually known about Alzheimer's, nor about how to cure or mitigate it. Hence it was felt that the only help to be given to people with dementia was increasing levels of care as the disease progressed. This job - caring - was Someone Else's job - that of a close relative, or if there was none, the state:

*"I would have thought that as it's a medical condition that the NHS would have a fair amount of input into their care ... through their GP who would source support [for] the family or whoever is the main carer."*

[London, low connection with dementia]

## IGNORANCE

Few people have detailed information about the diagnosis or treatment details of dementia. There are many erroneous, albeit often uncertain, beliefs about Alzheimer's and dementia.

*'I thought Alzheimer's is where they kept forgetting things ... whereas dementia was their brain fixating on they're in 1947 and they can't come out of it. That's the way I understood it I don't know if I'm right or wrong.'*

[White, Male, Bristol, low connection with dementia]

It was clear that outside of the research context, the only driver to find out more about Alzheimer's was if a close friend or relative was diagnosed with the disease. Almost all those who had more accurate information had gained it because they had an acquaintance or relative with dementia (*see earlier, Knowledge*).

It seems that some people did not want to know more about Alzheimer's - either because they feared getting it themselves, or because they feared having to care for a relative, so they preferred to put off knowing about Alzheimer's and hence potentially acknowledging their fears had some basis. Hence for these people we can call their ignorance not just a consequence of lack of knowledge but an attitude - in that it has an attached emotional disposition of fear or rejection and it is to a certain extent deliberately maintained.

A variation of ignorance was uncertainty about causes, prognosis and prophylaxis and about effects and symptoms. A good number were very unsure about the nature of the experience of people with dementia.

*"Do they know they've got it? Maybe if you don't know you've got it, you're ok."*

[Afro-Caribbean, Female, Bristol, some connection with dementia]

*"If someone suffers dementia or Alzheimer's are they aware of it?"*

[Durham, low connection with dementia]

For some the presentation of some people with dementia reinforces uncertainty in the observer.

*"I think that people might think you're mad, [a] mental health issue. I imagine that initially it could be mis-diagnosed as a mental health problem."*

[White, Male, Surrey, low connection with dementia]

Another respondent told of "Dora" who comes into the supermarket where she works everyday and always asks to be taken to every item on her shopping list, but drives herself, without accidents, to the shop and finds it every day. Whilst she joked about not wanting to be on the road when Dora was driving, she was puzzled by Dora's apparent competence and ability to find the supermarket, but her apparent lack of ability to find her way around inside the supermarket.

#### OTHER ATTITUDES

There were a great many more attitudes, most of them consequences of, or variations on, the core attitudes.

#### LEVITY

Many respondents remarked that they, or friends who were carers, made jokes as a means of coping with the situation.

*"My friend, sometimes instead of being serious she makes it as a joke"*

[Afro-Caribbean, Female, Bristol, some connection with dementia]

*"There is a time when a bit of levity has to come into it you know you have to look at the funny side and say, 'You know what I can't believe you just said that!' But it doesn't necessarily mean that you're being disrespectful."*

[Afro-Caribbean, Male, London, some connection with dementia]

*"She would ask the same question again and again. Sometimes we do have a bit of laugh because it is funny."*

[African, Female, low connection with dementia, London]



## MOCKERY

There were some hearsay reports of mockery. All the respondents in the research believed that mockery was almost exclusively likely to be expressed by youths.

*“There’s a lad at work and he went to see his mother in an old people’s home and I said how’s she doing and he said she’s not a dribbler yet she’ll be going that way and I thought that was pretty distasteful.”*

[Durham, low connection with dementia]

*“It would be terrible to think that people would mock people with dementia, but I don’t doubt that it would happen.”*

[London, low connection with dementia]

## EXPLOITATION

There were some reports of people exploiting people with dementia

*“Because my father-in-law is vulnerable his daughter will visit once in a blue moon and take cheques off him and he doesn’t realise what he is signing.”*

[Coventry, some connection with dementia]

## DENIAL

There were many stories of denial. A respondent told of an occasion when her denial was driven by her own fear of facing the burden of caring.

*“My husband made a comment recently about his mother, ‘I’m sure she’s got a problem she keeps forgetting things.’ I said to him, ‘No, no it’s her age.’ .... To be honest I didn’t want it to be more than that because I know my mother-in-law’s mother had dementia, ... and it’s almost, oh no, it’s hereditary - is she going the same way as her mother?”*

[Coventry, some connection with dementia]

Another respondent told of a friend who is unwilling to accept that her mother has dementia. Her denial drives her to avoid visiting her mother.

*“I’ve got a friend whose mum’s got dementia... Her mum’s been in a home for 3 years and she still can’t accept it, she’s terrified to go and see her.”*

[Durham, low connection with dementia]

Some respondents thought that people with dementia may also be in denial out of fear of the consequences of a diagnosis of dementia.

*“You might deny it as a patient yourself ... because there is a fear of losing independence. You might fear that you might have to move into a care home and not do things how you want. And so I think the patients themselves have that denial.”*

[London, low connection with dementia]

## SELFISHNESS

A good number felt that family mores have changed (although this was less true, as yet, of many ethnic minority communities respondents, see below) and hence traditions of caring for older family members have died. As a result some people with dementia are not given personal care by family members.

*“We are too selfish we’ve got our own homes set up nicely and we don’t want to give up the front lounge to have an old person.”*

[Coventry, some connection with dementia]

## SOCIAL AND ECONOMIC CIRCUMSTANCES

For others, it was not a matter of selfishness but simply the demands of modern lifestyles and economic necessity.

*“[In] days gone by ... the woman stayed at home and did the housework and ... if she had someone who needed looking after she would look after her. But [in] my age group with both of us working we couldn’t care for my mother or mother in law. We can do so much but after a short while we would be looking at putting her into a home. You can’t cope with it.”*

[Durham, low connection with dementia]

## **5.3 Modulation of Attitudes**

Although attitudes do have a certain stability they can be, and are, modulated by historical factors, relationship factors, context, the presentation of people with dementia and by ongoing experiences.

### **5.3.1 Historical factors**

The most significant factor in modulating attitudes is the history of encounter(s) with people with dementia. An elderly relative with dementia, even if rarely visited, easily becomes the key reference for thinking about the condition. However work with vulnerable people - young, old or disabled - also informs attitudes to people with dementia. Religious beliefs and cultural background can also inform attitudes (see ethnic minority communities section).

### **5.3.2 Relationships**

Attitudes are changed when a family member is diagnosed with dementia. Our sample specifically excluded those with direct caring roles, however a good number had relatives who were caring for older family members. With strangers and distant family members, attitudes of avoidance and ignorance could be maintained. In the case of slightly closer relatives, attitudes were changed by increased information and the family duties of meeting or supporting carers. However the ways in which attitudes and behaviours change are not straightforwardly predictable.

One exchange illustrates that the situation is easily understood from the point of view of the lived-world experience but does not lend itself to simple analysis:

*A: "When it comes to actually touching somebody that's probably where you would have the main difficulty" ...*

*B: "I think I would feel the other way around ... If it were my mother-in-law physically I could help her, but to actually talk to her about the illness I think I would find that very difficult."*

[Coventry, some connection with dementia]

Speaker A was talking about a public situation in which they would feel inhibited from lending physical assistance to a stranger by embarrassment and disenfranchisement. Speaker B was talking about her mother-in-law to whom she could imagine offering practical, physical help, but with whom discourse would be very difficult because of the traditions of privacy and distance in her family.

Our respondents, with two exceptions, had only limited contact with people with dementia and all believed that their views and understanding would change if they had closer contact. However they had no motivation at all to get closer to anyone with dementia before they had to:

*“It’s not something you focus in on until you meet somebody who’s had it.”*

[White, Male, Surrey, low connection with dementia]

### 5.3.3 Context

Respondents reported that their attitudes were different in private and in public and dependent on their roles in each context - for example in a retail environment, whether they were a worker or a customer. London respondents felt that Londoners on the whole avoided unplanned social intercourse and were perhaps less friendly than people in rural areas or other countries.

*“I agree with the thought that as a community ... London is more intolerant, just bordering on the intolerant. But I think individually people are tolerant.”*

[London, low connection with dementia]

Two hypothetical contexts - a dinner party and a railway carriage - were discussed in the research workshops. A few reported they would feel uncomfortable in close proximity to a person with dementia for a long time on public transport.

*“As for the dinner party scenario I would be fairly okay. Being in a [railway] carriage with somebody I didn’t know for a journey of an hour plus I would*

*be very uncomfortable.”*

[Coventry, some connection with dementia]

#### 5.3.4 Presenting symptoms

Respondents were aware that symptoms of dementia ranged from mild confusion and poor short-term memory to apparently total lack of awareness and loss of control of bodily functions.

Their attitudes to any given individual would thus vary according to the extent to which they could interact with them in an ordinary fashion.

#### 5.3.5 Reasons for Negative Attitudes

There is a relatively stable circularity which sustains ignorance and hence negative attitudes. Avoidance prevents acquaintance, and lack of acquaintance preserves ignorance. Continued ignorance offers no reasons to change the attitude of avoidance. Further the absence of a cure engenders helplessness and disempowerment which in turn sustain avoidance.

At a social and public level, the provision, or expectation, of state-provided care and assistance forestalls any requirement to get personally involved. Those with acquaintance with carers hear stories of trials and tribulations and the difficulties - rather than the successes and joys - of living with dementia and people with dementia and these stories, whilst engendering sympathy, also reinforce avoidance.

### **5.4 Ethnic minority communities Views**

#### 5.4.1 The older generation

Many respondents reported that 'back home' or amongst the older generation dementia was rarely named or diagnosed as such. Families were reported to use phrases such as “X forgets things, he can't remember much”.

*"In Jamaica I've never seen anyone with dementia. But there they'd just say, 'Her head's not right.' There's no more. No label.”*

[Afro-Caribbean, Female, Bristol, some connection with dementia]

*"My wife is Indian so I'm talking about her side of the family. They have a really different, old fashioned kind of attitude to [dementia] ...they'd say, 'oh no he's just getting old.'"*

[Mauritian, Male, London, some connection with dementia]

However if the symptoms of dementia were strange behaviour, some respondents felt it might be seen as madness.

*"[It would be seen as] a bad thing amongst Asians. ... dementia, they think it's to do with madness. ... I reckon yeah cos they don't understand it at all."*

[Mauritian, Male, London, some connection with dementia]

Others thought that less likely.

*"My perception is that people won't use words like 'he has gone mad' that is too harsh. But they will use words like senile."*

[Asian, Male, Leicester, low connection with dementia]

In some cultures dementia may be accepted as part of a normal course of events.

*"The Asian community always associates dementia with elderly people. ... It is accepted that gradually as you grow older you will become frail, quiet, and forgetful - so in that respect it is an accepted thing of ageing."*

[Asian, Male, Leicester, low connection with dementia]

#### 5.4.2 Shame

In many cultures, in particular South Asian, it is considered shameful to fail to live up to the expected ethos of caring for older relatives. Some Muslim respondents felt that they had a religious duty to care for their elderly parents. This duty was also integrated into their cultural values.

*"My parents instilled their cultural values like looking after the elders."*

[African, Female, low connection with dementia, London]

*"In our culture we don't send old people to homes. It is embarrassing for the family. But it is also our duty to look after our parents because they have done so much and have brought us up."*

[Asian, Female, Leicester, some connection with dementia]

There was one hearsay report of embarrassment or shame preventing a person seeking help for their mother.

*"I felt that my friend should have gone for some training to understand how to deal with dementia. She should have got outside help earlier on. She didn't want to tell anyone because she felt embarrassed."*

[Asian, Female, Leicester, some connection with dementia]

There were other reports of a lack of respect or understanding for socially-marginalised individuals, such as disabled people.

*"In Asians this happens a lot. I know another family who has a 9 year old son with mental problems. They hide their son in the room when anyone goes to visit them. Despite the awareness and education people are still behaving like they did 50 years ago."*

[Asian, Male, Leicester, low connection with dementia]

Hence it was felt that if a person with dementia were to be seen as disabled rather than merely elderly they might be harshly treated both within and outside the family. Thus shame could cut both ways: it could support the obligation to care for the elderly and infirm or it could support the victimisation of one seen as disabled.

Some respondents who had lived in India and Pakistan felt the situation was far better in the UK than in their countries of origin.

*"I come from Pakistan and my maternal aunt suffered from it ... and so my family had to accept it and it was part of the family. It is ... an affliction and she suffered for nearly 10 years. It was terrible because she had to be*

*caged in."*

[Coventry, some connection with dementia]

*"[India] is intolerant to people with any kind of disease. But here so far I've seen for the last 4 years I have seen people are very, very, very tolerant towards people with certain diseases. Not just Alzheimer's or dementia it can be any disease people are tolerant."*

[London, low connection with dementia]

### 5.4.3 Changing patterns

There was a widespread feeling that attitudes were changing quite fast in ethnic minority communities. The tradition of living closely with older relatives and the traditions of caring for older generations were felt to be waning fast.

*"Our religious books like Bhagwad Gita and Ramayana all say that parents have a high significance and we are brought up to respect them and look after them. But the trend might change with the younger generation of Asians."*

[Asian, Male, Leicester, low connection with dementia]

*"Although it is in our culture to look after our parents and live with them I don't think it's the reality of today's world ... 20 years ago there were no Asian people in old people's homes you look at it now and they're full of them."*

[Coventry, some connection with dementia]

*"Once our generation go ... our kids will not look after us in the same way that we look after our parents."*

[Coventry, some connection with dementia]



#### 5.4.4 Education

Some younger respondents believed that it would be a good thing if their elders knew more about dementia and knew that it was a disease so that they could take advantage of the help and treatment that is available.

*"That would help a lot if they know it's a disease like any other disease."*

[Mauritian, Male, London, some connection with dementia]

### 5.5 Stigma

There were very few spontaneous references to stigma. One use of the word was in direct relation to insanity and only by association to dementia.

*"I think it is associated with insanity [and] I think ... there has always been a stigma in relation to that."*

[London, low connection with dementia]

For some respondents there was no stigma because there is no volition, nor fault involved in getting Alzheimer's, hence the people with dementia could not be blamed.

*"Alzheimer's is not something that you bring onto yourself its something that happens to you."*

[London, low connection with dementia]

*"I don't think that there is necessarily the same stigma attached to Alzheimer's as with other mental health issues because people are sympathetic because they see it as a degenerative thing to do with somebody's age."*

[London, low connection with dementia]

Even those who acknowledged that there was still avoidance did not believe stigma was an appropriate word.

*"I don't think we are necessarily more accepting, but [there is] not a stigma"*

*about it."*

[Durham, low connection with dementia]

One respondent thought there could be denial (see above) driven by an underlying shame or embarrassment about a relative having dementia. However it is important to note that this thought was expressed hypothetically. In other words the respondent believed that someone - perhaps themselves, perhaps someone else - might behave in a stigmatizing way.

*"I think there can be a bit of shame attached to it though because of someone like losing their marbles type of thing. If it's their parents they might not want to admit to their neighbours. They just say 'oh she's getting forgetful' they don't want to say 'oh she's got Alzheimer's.' I think there is a bit of shame attached to it."*

[London, low connection with dementia]

One ethnic minority communities respondent felt that her friend had been ashamed of her mother's dementia (see 5.4.2). However, most discussion of stigma in relation to Alzheimer's was hypothetical.

*"You may hide it ... because you're ashamed of it or you don't want people to know."*

[London, low connection with dementia]

The most common hypothesis was that people would feel embarrassed or ashamed by dementia, or by association with someone with dementia

*"If you're talking about denial sometimes that indicates there is some stigma attached to the condition ... because obviously you're ashamed of it or you don't want people to know."*

[London, low connection with dementia]

*"It might not be stigma it might be fear. It might just be there is a refusal to admit that ... it's downhill from here ... Your close loved one ... is never going to be the person that you've known for X number of years and it's*

*going to be painful ... so it could be fear that drives that denial."*

[London, low connection with dementia]

## **5.6 Key Facts**

Towards the end of the research sessions, thirteen statements about dementia or Alzheimer's disease known as 'key facts' were shown to respondents. These are listed in Appendix III.

Responses to each of the key facts are presented below. Overall, a good number of respondents found the key facts frightening.

*"I feel more scared now after finding out the facts."*

[Asian, Male, Leicester, low connection with dementia]

It became clear that as a group of messages the statements generated confusion and misunderstanding. Some appeared to contradict each other, others when taken together were misleading.

This indicates that if these messages are to be used in a communications campaign a careful selection should be made and the messages phrased in such away as to avoid misunderstanding.

### **100,000 people in the UK develop dementia every year**

### **One million people will develop dementia in the UK during the next ten years**

Most respondents saw these statements as equivalent. Some thought the numbers were very large.

*"I'm shocked that it's that many people that have dementia."*

[Coventry, some connection with dementia]

*"This is a very high number of sufferers."*

[Asian, Male, Leicester, low connection with dementia]

Some thought the numbers were not large enough.

*"One million in 10 years, I think potentially that's on the low side."*

[Durham, low connection with dementia]

**There are 700,000 people in the UK living with dementia, this is set to rise to 1 million by 2025**

For some this was the most plausible of the figures, and some believed that the increase was a consequence of lengthening lifespans.

*"Out of the facts and figures I thought that was the most believable one."*

[Durham, low connection with dementia]

*"Your population is living longer. 100 years there might not have been dementia cases because they were dying before dementia had set in."*

[Durham, low connection with dementia]

However, few were able to posit death rates, population increase or demographic variables to reconcile the apparently contradictory numbers in the statements that 100,000 will develop dementia every year and the number of people with dementia will rise from 700,000 to 1,000,000 by 2025.

A significant number of respondents dismissed all the key facts which included numbers because they were 'just numbers' or they felt statistics could be twisted to show almost anything.

*"The figures don't really appeal to me; they don't really stand out to me."*

[Coventry, some connection with dementia]

*"The statistic ones. They can be true or not true."*

[Mauritian, Male, London, some connection with dementia]

**If you have a stroke, you have a one in three chance of developing a disease which will cause dementia in three months**

Many found this striking, although the majority did so because they believed it to mean (for a few a bit implausibly) that one in three people who have a stroke will have dementia within three months of the stroke.

*"I didn't know that. If you have a stroke you have one in three chance of developing dementia in three months. That's really quick. That's pretty alarming."*

[Mauritian, Male, London, some connection with dementia]

A very few understood the statement to mean that after a stroke one in three people will, within three months, develop a disease which will, in due course, lead to dementia.

**Dementia is not a natural part of ageing**

Some understood the statement to mean that dementia is not an inevitable nor inherent part of the ageing process. On that basis, they agreed with the statement.

*"As you get older not everybody is going to develop dementia so it's not a natural part of ageing it won't happen to everybody."*

[Durham, low connection with dementia]

However, many disagreed because they believe it was quite within the bounds of the normal, and hence natural, course of things for a good number of older people to develop dementia.

*"It says 'Dementia is not a natural part of ageing' but we all think it is."*

[London, low connection with dementia]

For many the statement effectively amounted to an overstatement - because the quasi-equivalent statement "Dementia is an un-natural part of ageing" was considered definitely untrue.

*“Everyone put age as a contributing factor.”*

[London, low connection with dementia]

*“I think it's something that happens to older people more than younger people.”*

[London, low connection with dementia]

Some therefore gave only qualified and reluctant agreement.

*“I kind of agree with it but on the basis that I don't really know what causes dementia.”*

[London, low connection with dementia]

### **One in three people over 65 will die with dementia**

For many, this was a shocking fact. A good number felt more scared as a result and hence moved emotionally further towards denial and avoidance.

Of those who found it shocking, a good number initially read it as ‘die of dementia’ - especially those who conflated it with...

### **There is no cure for dementia. The condition is terminal.**

The few who believed this statement felt more frightened as a result. Most however did not believe it, as they felt dementia was cognitive disorder or a disease of the brain but that it was not, in itself, fatal. Those who believed it felt more scared as a result and hence, as above, moved further towards denial and avoidance.

*“You don't really want to frighten people . . . if someone saw that they'd think their life was over.”*

[Afro-Caribbean, Male, Leeds, low connection with dementia]

*“I know that there is no cure for dementia but I thought that you just remained demented until your natural death I didn't realise it actually shortened your lifespan.”*

[Coventry, some connection with dementia]

**There are at least 15,000 people under 65 living with dementia in the UK**

As with other numbers some saw this number as large, others as small.

*"It stands out to me cos of the number, 15,000. That's a lot."*

[Mauritian, Male, London, some connection with dementia]

A few felt it was an important point about the prevalence of the possibility of early onset of dementia. A good number paid it little attention.

**Each person with dementia is unique and will experience dementia in their own way**

Some respondents - particularly those with experience of voluntary work with disadvantaged persons - warmed to this statement as a recognition of the value of the individual. A few others felt it reinforced the unwelcome unpredictability of people with dementia. A good number did not seem to find any significant meaning in it.

**Two thirds of people with dementia live in their own homes. Half of them live alone**

Many respondents ignored this statement. Some read it as a message of hope, seeing that some people with dementia were managing to live by themselves.

*"I mean I'm pleased for that. ... I didn't realise it two thirds of people with dementia live in their own homes and half of them live on their own. ... Because it means that you're not stuck to a chair with tubes and pills all day long and that you can lead a normal life to some extent."*

[White, Male, Bristol, low connection with dementia]

**Dementia is caused by diseases of the brain.**

This had very little impact overall.

*"I just thought that was commonsense."*

[Afro-Caribbean, Male, Leeds, low connection with dementia]

*"I assume that's true . . . it's the cells in the brain that die isn't it?"*

[White, Male, Surrey, low connection with dementia]

However, as noted in the section on ethnic minority communities views, one respondent believed that it would be useful if older South Asian people were informed that dementia was in fact a specific disease for which some treatment is available.

**The earlier the diagnosis, the longer the time the person with dementia can live well with the condition**

For some this was a message of hope

*"From thinking that there's no answer to it ... to see that with some sort of treatment you can live well with the condition."*

[Durham, low connection with dementia]

Some thought perhaps treatment would help one live longer. A good number didn't believe it, including some who felt it was contradicted by...

**The average time from diagnosis to death is 5-7 years.**

This statement was frightening to most respondents, but not believed. For some it was a signal to despair.

*"I don't believe it but if it's true then I'm even more shocked."*

[Coventry, some connection with dementia]

*"Shock therapy"*

[London, low connection with dementia]

*"To think according to that if it's correct once you've been diagnosed you've got an average of 6 years left I found very shocking."*

[Coventry, some connection with dementia]

*"It's frightening and could make you think if it is only 5 – 7 years then why bother? Why not just put them in a home?"*



## **5.7 Conclusions**

The research revealed that members of the public do not generally stigmatize people with dementia. However they do, for several reasons, avoid them. This avoidance could easily appear to be stigmatization from the point of view of people with dementia or their carers.

It follows that "a strategy to address the issue of dementia and the stigma and discrimination which surround it" must address the phenomenon of avoidance without appearing to misrepresent it, either to people with dementia or other members of the public.

### **5.7.1 Key Facts**

Different people found different 'key facts' striking but there was not one single fact that was striking to a majority of respondents. Nor was there a clear group of facts which hung together to form a messaging direction. When they were taken as a group, there was considerable confusion and misunderstanding. Overall the single most common take out from the facts as a whole was that people became more frightened of they themselves, or a relative, getting Alzheimer's disease. As they stand, we cannot recommend any of the Key Facts as a core message for a communications campaign.

### **5.7.2 Challenges**

People are frightened of the condition and believe that interacting with a person with dementia is demanding and potentially embarrassing. To gain buy-in, messaging about dementia will need to acknowledge these fears, either implicitly or overtly.

Given the high salience of personal lived experience it seems likely that evidence from everyday life will recreate avoidance as the dominant attitude unless an actionable alternative is offered. Therefore a campaign must do more than reduce fear or stigma. It must look to replace them with attitudes which are both

congruent with the evidence of everyday life and offer different possible outcomes to members of the public, to people with dementia and to their carers. If communications include messaging which helps to empower people and engender confidence in their ability to interact successfully with people with dementia it will open alternatives to avoidant behaviour and thus begin to break down the primary cause of perceived stigma.

All respondents were aware that they tend to avoid people with Alzheimer's. Recognition of this fact would be a very powerful starting point for a campaign.

A campaign which overtly acknowledges avoidance and offers a low-risk alternative would both help move people away from behaviour perceived as stigmatizing and would also be congruent with life experiences. The research indicates that people need encouragement and permission to make small gestures of social inclusion and they need reassurance that it is safe to do so and that they will not be forced to take on more involvement than they wish.

We propose that a campaign could be tested which overtly notes a few of the non-negotiable difficulties facing people with Alzheimer's disease (such as failing short-term memory, disorientation and difficulty performing familiar tasks) and highlights that additionally "people avoid you". The subsequent call to action could be framed, "We can't do much about first three yet - although we are working on it. But you can do something about the fourth - a little gesture can make a big difference."

### 5.7.3 Next Steps

We understand that our client will be considering their forthcoming campaign in the near future. The proposals in section 5.7.2 are indicative of one route which may usefully inform this consideration. There may be other routes which are consistent with the research findings. When a strategic direction has been decided it may be appropriate to review the research material for specific guidance to assist in crafting messaging.

# **APPENDIX I**

## **Recruitment Questionnaire**

# **CORR WILLBOURN**

R E S E A R C H & D E V E L O P M E N T

150 Waterloo Road LONDON SE1 8SB

Tel: 020 7633 9957 Fax: 020 7633 9816

**Job No:** 928

**Job name:** Triton

## RECRUITMENT QUESTIONNAIRE

### PARTICIPANT DETAILS

Name of Participant \_\_\_\_\_

Address \_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

Tel No: \_\_\_\_\_ Mobile No: \_\_\_\_\_

E-Mail \_\_\_\_\_

Date, time and location of Workshop / Depth Interview

\_\_\_\_\_

\_\_\_\_\_

Workshop / Interview No: \_\_\_\_\_

### **RECRUITER: PLEASE SIGN AND DATE EACH QUESTIONNAIRE**

I certify that I have carried out this interview according to your instructions and that the interview was conducted face to face with the respondent who is not a relative or friend of mine:

**SIGNED:** \_\_\_\_\_ **DATE:** \_\_\_\_\_

**QUESTIONNAIRE SCRIPT**

Good morning/afternoon. I am acting on behalf of Corr Willbourn Research, an independent market research company who have been commissioned to carry out research for the Department of Health. We aim to involve a cross-section of people in the research and therefore need to ask you some questions.

Q1. Have you ever taken part in or market research depth interview or group discussion?

Yes    V        **ASK Q2**                      No    X        **ASK Q4**

Q2. Have you taken part in a market research depth interview or group discussion in the last 12 months? - **CLOSE IF YES. IF NO, ASK Q3**

Q3. What subjects have you been interviewed on before? **(LIST ALL)**

---

*IF ON A SIMILAR SUBJECT AS THIS PROJECT, CLOSE INTERVIEW.*

Q4. **ASK ALL: READ OUT**

Could you please tell me if you or any of your immediate family work now, or have worked in the past two years, in any of the following forms of employment:

Advertising	V
Market Research	X
Journalism	0
Public Relations	1
Social Care	2
Medicine	3
None of these	4

All must code at 4 only - otherwise close.

**Q5. ASK ALL: PLEASE RECORD GENDER OF RESPONDENT**

Male V

Female X

Workshops 1, 2 and 3 should have equal numbers of men and women.

Depth Interviews 2, 3, 5, 8, 9 and 11 must code at V.

Depth Interviews 1, 4, 6, 7, 10 and 12 must code at X.

Q6. Please could you tell me your age.

Write in and code below \_\_\_\_\_

34 or younger V Close

35 - 39 X

40 - 49 0

50 - 60 1

61 - 65 2

66 or older 3 Close

Workshop 1 must code X or 0. Please recruit a good spread.

Workshop 2 must code 0 or 1. Please recruit a good spread.

Workshop 3 must code 1 or 2. Please recruit a good spread.

Depth interviews can code from X to 2. However please check with office to ensure a good spread across the sample as a whole.

Q7. (a) May I ask what is the occupation of the chief income earner in your household?

*Write in occupation and all relevant qualifying criteria* \_\_\_\_\_

\_\_\_\_\_

(contd.)

Q7 (b) Code Social Class:

A	V
B	X
C1	0
C2	1
D	2
E	3

Workshop 1 must code V, X or 0. Please recruit a good spread.

Workshop 2 must code X, 0 or 1. Please recruit a good spread.

Workshop 3 must code 1, 2 or 3. Please recruit a good spread.

Depth interviews can code from V to 3. Check each recruit with office to ensure a good spread across the sample.

Q8. ASK ALL - Could you please tell me which of these best describes your ethnic origin. READ OUT

White British origin	V	Pakistani	3
White Other	X	Bangladeshi	4
Black-Caribbean	0	Chinese	5
Black-African	1	Mixed race	6
Indian	2	Other	7

At least 8 respondents in Workshops 1 and 3 must code from 0 to 7.

No more than 4 respondents in Workshop 2 to code from 0 to 7.

Depth Interviews 1 & 2 must code 2, 3 or 4.

Depth Interviews 3 & 4 must code 2, 3, 4 or 6

Depth Interviews 6 and 9 must code 0, 1, or 6

Depth interviews 5 & 7 must code 0.

Depth interviews 8, 10, 11 & 12 must code V or X.

(contd.)

Q9. Please tell me which of these sentences best describes you.

READ OUT ALL.

I do not have now, nor have I had in the past, a close connection with a person with dementia*	V	
I know, or knew, someone with dementia but I see, or saw, them only a few times a year	X	
I know, or knew, someone with dementia and see, or saw, them from time to time, but typically no more than once a month.	0	
I know, or knew, someone with dementia and see, or saw, them regularly, generally more than once a month	1	Close
I care, or have cared, for someone with dementia	2	Close

\* Note to recruiter: If respondent needs an explanation of the term dementia, please read this, **"Dementia is a condition which is the result of various different brain diseases (like Alzheimer's) which have in common a loss of brain function that is usually progressive and eventually severe."**

Workshops 1 and 2 must code at V or X only.

Workshop 3 must code at 0.

Depth Interviews 1, 3, 5, 7, 9 & 12 must code at 0 only.

Depth Interviews 2, 4, 6, 8, 10 & 11 must code at V or X only.

CHECK AVAILABILITY AND RECRUIT.



# **APPENDIX II**

## **Discussion Guides**

# Workshop Discussion Guide

## Project Triton, Job No. 928

### **Research Objectives**

*The overall research objective is to gather consumer feedback to be used to inform and develop a strategy to address the issue of dementia and the stigma and discrimination which surround it. More specific objectives include:*

- *Understand the knowledge, attitudes, reactions and feelings towards people with dementia and the disease itself*
- *Determine the reasons for negative attitudes and feelings towards dementia, and people with dementia*
- *To inform the advertising and PR agency briefs and key messaging priorities*
- *To assist in the compilation of questions for possible quantitative research that will meaningfully ascertain the level and type of stigma.*

### **1 Introduction**

Moderators to introduce process and timing.

Respondents introduce themselves - first name and something about themselves  
- job, family, hobbies etc.

### **2 Open frame**

[Provide each participant with pen and paper]

- Thinking about the future, what do you imagine life will be like in say 20 years time
  - (a) In general, and
  - (b) For you specifically?

Collect up broad themes to flipchart and explore (where appropriate) the drivers behind these possible futures (such as 'what leads you to think that X might happen? etc)

[If Dementia is mentioned in this section acknowledge but do not probe].

### **3 Orienting to the substantive topic**

- Thinking more specifically about health and wellbeing what hopes and/or concerns do you have concerning the next 20 years or so
  - (a) In general, and
  - (b) For you and your family / children / parents specifically?

Collect up broad themes to flipchart and explore (where appropriate) the drivers behind these possible futures (such as 'what leads you to think that X might happen? etc)

### **4 Acquaintance with Dementia**

Write up "Dementia" in centre of flipchart

Respondents are invited to call out any words or phrases that are prompted by this word.

Words and phrases are noted on flipchart

After initial round, respondents are invited to call out any words or phrases that they have heard used, in any context, that are associated with dementia.

[Key words/ phrases noted on A4 cards for use at 5 below]

- What experiences do you have of encountering people with dementia  
*From stories of encounters with relatives / friends / strangers who are believed to have dementia note perceptions of the other and elicit also attitudes and narrative of teller's behaviour*

### **5 Exploring attitudes**

Thinking about society as a whole, what sort of attitudes do you think people have about dementia?

*Note onto Cards*

These cards - and others from 4 - above are laid out around the room on A4 cards. Participants are invited to walk around and look at and consider each card.

They are then invited to choose the one that most closely reflects their own attitude - and if, on reflection they believe that their own attitude is not included they can take another card and write on it the word or phrase that describes their own attitude more accurately.

- Explore with each person why they have chosen/written their card
- What other one/s were they drawn to
- Elicit where appropriate discussion between the various positions.

(Cards collected for re-use at 11 later)

## ***6 Range of Engagement***

Responses to the most salient beliefs, fears or characteristics are explored with line-ups.

Participants are asked to line-up to demonstrate their own position with regard to specific ideas or attitudes. For example, if the word 'Frightening' has come up participants will be asked to line up on a continuum from 'Very frightening' to 'not at all frightening'.

People's positions on the continuum are then explored – what brings them to this position? Why not higher or lower on the continuum etc.

## ***7 Core beliefs about effect, aetiology and treatment dementia***

In groups of 3 (for ca. 5-8 minutes each round)– discuss and make key notes about:

- (a) How you think dementia affects people. When each group is finished move on to next topic:-
- (b) What causes dementia? When each group is finished move on to next topic:-
- (c) What treatment/s you think of believe are available for dementia?

To Flipchart:

Taking each topic in turn explore key themes and any idiosyncratic responses.

Pay particular attention to:

- Participants' information sources (formal e.g. leaflets at GP surgery, magazine articles etc., and informal such as 'urban myths')
- Areas of (assumed) certainty and uncertainty
- Emotional reactions to each topic discussed (esp. where are the emotional blocks etc)
- Attitudes expressed - to those with dementia, to carers and to significant others

In discussion explore degree of consensus about the causes and progress of dementia.

- Explore consensus (or lack) within the group

Explore with the group the degree to which they believe their views are or may be shared by:

- their family
- their wider circle of acquaintance
- society in general
- On which notions, if any, is there agreement?

Considering the "stages" of dementia - (if possible pick up on earlier remarks to) explore beliefs about different types / stages / progressions

- Is it seem as a progressive disease
  - If, so what are the perceived stages
  - Do they always occur in the same way / order
- Are people 'different' in different stages of dementia

*Probe to explore attitudes to different stages.*

## **8 Focus on Stigma**

Respondents are asked to review their thoughts and discussions to date and to imagine that someone they know is diagnosed with dementia.

- What do you imagine will be the difficulties they face? (*Leave ambiguous initially in order to let respondents locate 'difficulties' in most salient spheres - e.g. physical, cognitive or social etc.*)

Respondents to call out difficulties and each are written on a card.

- After initial call out, moderator to probe and explore to ensure that all the potential range of difficulties (from those pertaining to the condition itself to those pertaining to attitudes of others and to social constructs) are explored.

Further 'difficulties' written on cards.

Respondents are asked to create a 'map' on the floor of all the difficulties oriented by whatever axes are most important to them - e.g. severity, physicality, cognitive, etc.

As map evolves, moderators can introduce further known issues - such as key issues from depth interviews - to ensure significant issues are all included included, e.g. Poor personal hygiene, Memory Loss, Mood swings, Loss of personality, Loss of appropriate social boundaries, Social difficulties and Stigma.

## **9 Care**

- What is known about the care available for people with dementia
  - Collect personal anecdotes, hearsay and opinions
  - Is there consensus or variety of opinion
- How does care for people with dementia compare with that available for people with other conditions

## **10 Dementia - Key Facts**

Key facts about dementia (supplied by our client) are placed around the room on A3 boards as a gallery. Respondents are asked to walk round and look at and consider them all, and then stand by the one that is most striking to them, for whatever reason.

- What brought you here

- Was it an easy choice?

Respondents are asked to listen to each others' reasons and to respond to them, creating dialogue about the different Key Facts.

## ***11 Dementia - Review and key questions***

Cards from Section 5 are laid out again around the room. Respondents are asked to review them and choose the card that now best represents their own attitude.

- If anyone has now chosen a different card, what prompted the change?

Explore as necessary.

- Thinking now of all these attitudes, if one attitude that is prevalent in society could be changed, which one should be changed to bring about the best outcome for people with dementia?
  - To what should it change?
  - Why?
  - How will that help?
  - Why is this the most important change?

Final Plenary discussion

- If we had an expert here who knew all about dementia, are there any questions which respondents would like answered?
  - If so what are the questions
  - Probe motivation for question
- Is there anything else people wish to say about dementia?

*Thank respondents and close.*

# Depth Interview Discussion Guide

## Project Triton, Job No. 928

Revised 29/09/09

### **Research Objectives**

*The overall research objective is to gather consumer feedback to be used to inform and develop a strategy to address the issue of dementia and the stigma and discrimination which surround it. More specific objectives include:*

- *Understand the knowledge, attitudes, reactions and feelings towards people with dementia and the disease itself*
- *Determine the reasons for negative attitudes and feelings towards dementia, and people with dementia*
- *To inform the advertising and PR agency briefs and key messaging priorities*
- *To assist in the compilation of questions for possible quantitative research that will meaningfully ascertain the level and type of stigma.*

*NOTE: The researcher will utilise the flow of the respondent's conversation and hence the topics may be explored in an order different from that laid out below. However the research will ensure that all the topics are addressed within the interview.*

### **1 Introduction**

- Researcher to introduce him / her self, MRS code of conduct and project
- Respondent introduces him / her self - first name and something about themselves - job, family, hobbies etc.
- Ice-breaker: what events or issues are on your mind at the moment

### **2 Acquaintance with Dementia**

Researcher introduces word "Dementia"

- Which words or phrases that are prompted by this word?



- Which words or phrases have you heard used, in any context, that are associated with dementia?

[If key attitude words or phrases come up, note them on cards for use at 5 below]

[If descriptions of condition or symptoms are offered, note but do not correct misapprehension or misunderstanding at this stage]

- What experiences do you have of encountering people with dementia  
*Elicit stories of encounters with relatives / friends / strangers who are believed to have dementia.*  
*Note perceptions of the other and elicit also attitudes and narrative of teller's behaviour.*

### **3 Exploring attitudes**

Thinking about society as a whole, what sort of attitudes to you think people have about dementia?

*Write key words or phrases, if offered, onto cards.*

*Create a pack of cards from (i) words or phrases offered here, (ii) words or phrases from 2 above and (iii) words from previous interviews. Include the following pre-written on cards by moderator: "Ignorance", "Sympathy", "Fear", "Avoidance", "Mockery", "Bewilderment". Add further cards in later interview as more different attitudes are offered.*

*Ask the respondent to sort through them and*

- chose the one that most closely reflects their own attitude*
- lay out the cards in a hierarchy from the attitudes they believe to be most prevalent to the least prevalent.*

*If, on reflection they believe that their own attitude is not included ask respondent write a word or phrase on a fresh card that describes their own attitude more accurately.*

- Explore why they have chosen/written their card
- What other one/s did they consider / were they drawn to, and why

## ***4 Range of Engagement***

Explore attitudes - in particular strong emotions and invite respondent to talk discursively about times they felt strongly and less strongly.

Explore different times and ways in which respondent has engaged with dementia.

- What conversations have you had about dementia?
- In which circumstances have you had a strong reaction to someone with dementia - or the idea of dementia?

Explore degree of strength of feeling across range of engagements.

If appropriate / relevant explore their own hopes and fears for themselves and / or their parents in terms of:

- the future
- their health
- their care needs

## ***5 Core beliefs about effect, aetiology and treatment dementia***

Explore beliefs around the 'facts' of dementia

- (a) How you think dementia affects people.
- (b) What causes dementia?
- (c) What treatment/s you think of believe are available for dementia?

Pay particular attention to:

- Respondent's information sources (formal e.g. leaflets at GP surgery, magazine articles etc., and informal such as 'urban myths')
- Areas of (assumed) certainty and uncertainty
- Emotional reactions to each topic discussed (esp. where are the emotional blocks etc)

- Attitudes expressed - to those with dementia, to carers and to significant others

Considering the "stages" of dementia - (if possible pick up on earlier remarks to) explore beliefs about different types / stages / progressions

- Is it seem as a progressive disease
  - If, so what are the perceived stages
  - Do they always occur in the same way / order
- Are people 'different' in different stages of dementia

*Probe to explore attitudes to different stages.*

## **6 Exploring Cultural Issues**

*[Probe sensitively as required].*

Explore the degree to which they believe their views are or may be shared by:

- their family
- their wider circle of acquaintance
- society in general
- On which notions, if any, is there agreement?

Thinking about the culture or cultures of your own background:

- Do you feel that any of your thoughts, feelings or learning about dementia are informed by your culture(s)?
- Do you think that other people in your culture(s) have similar views to yourself or different views
  - If they differ, in what way do they differ?

*[Explore sensitively as required].*

## **7 Focus on Stigma**

Respondents are asked to review their thoughts and discussions to date and to imagine that someone they know is diagnosed with dementia.

- What do you imagine will be the difficulties they face? (*Leave ambiguous initially in order to let respondents locate 'difficulties' in most salient spheres - e.g. physical, cognitive or social etc.*)

Researcher to probe and explore to ensure that all the potential range of difficulties (from those pertaining to the condition itself to those pertaining to attitudes of others and to social constructs) are explored.

- Which do you think are the biggest difficulties - and why?

As discussion evolves, researcher can introduce further known issues - such as key issues from other interviews - to ensure significant issues are all included included, e.g. Poor personal hygiene, Memory Loss, Mood swings, Loss of personality, Loss of appropriate social boundaries, Social difficulties and Stigma.

## **8 Care**

- What do you know about the care available for people with dementia
  - Collect personal anecdotes, hearsay and opinions
- How do you think care for people with dementia compares with that available for people with other conditions?

## **9 Dementia - Key Facts**

Lay out key facts about dementia on cards.

- Please consider them all, and choose the one that is most striking to you, for whatever reason.
  - What prompted this choice
  - Was it an easy choice
  - Which other Facts are striking?

## **10 Dementia - Review and key questions**

Show pack of cards from section 3 again.

- Please choose the card that now best represents your own attitude

- If it is different from earlier, why - if not has anything confirmed your position

Explore as necessary.

- Thinking now of all these attitudes, if one attitude that is prevalent in society could be changed, which one should be changed to bring about the best outcome for people with dementia?
  - To what should it change? Why?
  - How will that help?

#### Final Questions

- If we had an expert here who knew all about dementia, are there any questions which you would like answered? If so, what are they?
  - Probe motivation for question
- Is there anything else you wish to say about dementia?

*Thank respondent and close.*

# **APPENDIX III**

## **Stimulus Material**

## Key Messages

- Dementia is caused by diseases of the brain
- Dementia is not a natural part of ageing
- One in three people over 65 will die with dementia
- If you have a stroke, you have a one in three chance of developing a disease which will cause dementia in three months
- There are 700,000 people in the UK living with dementia, this is set to rise to 1 million by 2025
- One million people will develop dementia in the UK during the next ten years
- 100,000 people in the UK develop dementia every year
- There are at least 15,000 people under 65 living with dementia in the UK
- There is no cure for dementia. The condition is terminal.
- Each person with dementia is unique and will experience dementia in their own way
- The earlier the diagnosis, the longer the time the person with dementia can live well with the condition
- Two thirds of people with dementia live in their own homes. Half of them live alone
- The average time from diagnosis to death is 5-7 years.