Dementia Care
Qualitative Analysis Report

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EXECUTIVE SUMMARY

Objective of report

The objective of this report is to analyse and interpret the opinions of various clinicians on the key factors that influence dementia care in the three boroughs; in order to inform future service development. This report presents the results of a thematic analysis conducted with 11 different clinicians involved in dementia care in Westminster (W), Royal Borough of Kensington and Chelsea (KC) and Hammersmith and Fulham (HF) areas in November to December 2014. Conclusions made are from the findings of this report only and are intended to form one source of evidence in the context of service review and decision-making in dementia care.

How diagnoses are made

Psychiatry and specialist neurology/geriatric services both add value to the diagnostic process for different groups. Post diagnosis support tends to be stronger via mental health led services. GPs are variable in their engagement with assessment and dementia care, and are short on time and resources.

Clinicians were sceptical about screening and diagnostic incentives for dementia in primary care without emphasis and linkage to better post diagnostic support. They would need extra training and/or support from secondary services to do increase diagnosis. Ideally, there is one point of referral and an experienced member of staff would triage to appropriate service. Acute hospital admissions represent an opportunity for detection and could be better linked into the diagnostic process.

Factors affecting diagnosis rates

Physical comorbidities can distract from a patient obtaining a dementia diagnosis. Those picked up in hospital do not get referred directly to the memory service and there is the possibility of losing referrals in this step. Cultural beliefs and stigma can affect patients' willingness to present.

Service cohesion

The remit and referral criteria for different services are not clear to all clinicians using them, and memory services may exclude patients with non-Alzheimer's or vascular dementia. The two memory services in Hammersmith and Fulham do not currently cross-refer appropriate patients. There is little oversight of the range of different services available to dementia patients and how to access them – admiral nurses when available are very useful in this context.

Specific strengths in service cohesion are highlighted as: the good links between memory service and community mental health/ social care in Westminster and Royal Borough of Kensington and Chelsea; the links between Charing Cross services and specialist dementia nurses; increasing role of psychiatry liaison and dementia nurses in Chelsea and Westminster/St Mary's hospitals.

Specific areas for improvement in service cohesion are highlighted as: lack of joint decision-making across health and social care in resource allocation in Kensington, Chelsea and Westminster; links between geriatric and memory/community services in Kensington Chelsea and Westminster; links between the two memory services in Hammersmith and Fulham, links between memory services and community/social care in Hammersmith and Fulham; links between memory services, dementia care team and psychiatry liaison in Hammersmith and

Top down support can be important for enabling collaborative working and historically this may have been lacking in HF. This may go some way to explain the difference between HF and KCW. 'Borough boundaried' and 'specialty boundaried' funding and commissioning has been highlighted as leading to difficulties in resource distribution and access to services for patients.

Communication

Communication between memory services and GPs is not standardised or always timely. Communication to patients and carers regarding access to support and changes they could make does not seem to always happen from memory service or GP. Communication between specialties is hindered by different IT and governance systems.

Service capacity

Key areas where service capacity is currently strained were identified as: the supply of residential and nursing homes in borough, availability of admiral nurses, liaison psychiatry in HF; time and resource for GP-led dementia assessments.

Escalation of care

Difficulties have been noted in escalating people from home to residential care in a timely fashion, avoiding a crisis admission. Focussed care from the start of admission may help shorten admissions and reduce need for escalation to interim or residential care.

Interface between medical and psychiatric care

It is recognised that many patients will present with dementia and physical comorbidities which complicate treatment. The role of liaison psychiatry in dementia care varies, a specialist old age liaison service has been set up in St Mary's and Chelsea and Westminster but still tends to be used only for complex cases. In Hammersmith hospital liaison psychiatry has minimal involvement with patients who have dementia due to lack of capacity. A dementia care team in Imperial and a dementia nurse in Chelsea and Westminster are present but collaboration between these and psychiatric / medical services has only recently started to happen.

There is some confusion regarding responsibilities of care in patients with dementia related to other physical diagnoses.

Greater collaborative working between services is generally supported, but concerns are raised that entire new models of integrated care would not create as much output as strengthening existing services, especially the community support element, and collaboration between them would. Ideas proposed by clinicians include dual frailty and virtual wards to optimise in hospital care and early discharge, care coordination by a lay worker; extra telecare support for care homes; better designed memory services in HF with a single point of referral and triage.

Clinicians expressed interest in working more closely with voluntary and charity sectors to inform better care with holistic decision-making, fill gaps in dementia care provided by traditional services; and ensure equitable access to support. The services already provided by Alzheimer's society and Age Uk, as well as various day centres and activity groups are highly valued, but the perception is that there is little strategic oversight of provision.

Quality of care

Quality of hospital care has improved with introduction of dementia CQUINS. There are no concerns raised regarding antipsychotic usage, and skin and nutritional care was reported to be good in Chelsea and Westminster. Continuing need for improving environments and increasing range of activities available in hospital were identified.

The relatively new memory service in KCW has been recognised as providing excellent care. Difficulties have been noted with HF services, largely relating to poor links with social and community services, communication and delays in assessment.

Clinicians rarely had direct experience of care homes, the interviewees felt that quality of care varied, some were very good, but others could improve in terms of training to pick up dementia, deal with distressing behaviours and needs, and keeping residents hydrated.

Generally it was felt social care staff had a good understanding of dementia, but finding and retaining good staff was a challenge in London. They could be supported with extra training and encouraged to think of ways to preserve dignity and independence for patients. This knowledge, alongside how to create a dementia friendly environment, should be passed on to carers but it is not clear that this is consistently happening. Few clinicians were aware of availability of independent advocates between clinicians.

Attitudes and environment

As an inner city area, patients are less likely to have social support from families leading to increased dependence on services and later presentation. Some ethnic minority groups offer much support but may access services later. A lack of public awareness of the significance and ability to treat dementia prevails which limits peoples' willingness to access treatment.

The majority of clinicians endorsed individualised care due to the large variation in presentation and need seen. There were examples cited of GPs who did not feel that effective care was available, care staff that found it difficult to deal with behavioural issues, and hospital clinicians being unwilling to initiate the diagnostic process.

The current elderly demographic is stoical and less likely to seek help than younger patients; thus may be better reached by outreach and informal services. Patients were likely to want to stay in borough once diagnosed. There are mixed reports as to the impact of BME beliefs on diagnosis.

Clinicians were very keen to support dementia friendly communities and some involved in initiatives with local providers. There were challenges identified locally with a less community orientated population and difficulties in urban planning and design in a London borough.

Support for carers

Caring for someone with dementia can cause considerable stress – support mechanisms in place should be reinforced and will need increase in the future.

Quality of life

Factors associated with better quality of life were identified as: good support from carers and family; fewer comorbidities and ability to retain independence and hobbies.

Demographics

Clinicians perceived that there were a large proportion of patients diagnosed at late stages in Hammersmith and Fulham, but that patients were usually picked up in early stages in Westminster and Kensington and Chelsea. Clinicians felt that their patient base was likely to increase due to ageing population, but that preventive work, better fitness levels and those of working age moving away from London may affect the impact of this.

CONTENTS

1 INTRODUCTION AND METHODOLOGY

The objective of this report is to analyse and interpret the opinions of various clinicians on the key factors that influence dementia care in the three boroughs; in order to inform future strategy development. This report presents the results of a thematic analysis conducted with 10 different clinicians involved in dementia care in Westminster (W), Royal Borough of Kensington and Chelsea (KC) and Hammersmith and Fulham (HF) in November to December 2014.

Methodology:

Semi-structured interviews were conducted with 10 different clinicians:

2 psychiatrists: **P1** (KCW) and **P2** (HF)

2 geriatricians: **G1** (KCW) and **G2** (Westminster and HF)

1 neurologist: **G3** (HF)

4 GPs: **GP1** (HF) **GP2** (W) **GP3** (KC) **GP4** (HF)

1 nurse: **N1** (KCW)

Notes from the interviews or transcripts, carried out by three different interviewers, were then analysed using an inductive process. Due to capacity constraints this was carried out by the author only. Results for each theme have been collated and conclusions summarised at the end.

2 DIAGNOSIS THEMES

2.1 HOW AND WHERE DIAGNOSIS IS MADE

Diagnosis happens generally through memory service, some through other hospital specialties, such as geriatricians or through GPs.

There are site specific differences, as illustrated in the Dementia JSNA service mapping. The Imperial younger onset service takes patients from all North West London so has a larger catchment area. Both the KCW and HF models have a core mental health run memory service and an alternative hospital route more focussed on diagnostics run by clinicians with special interests in the field.

Concerns were raised over GPs diagnosing and proposed 'dementia screening' policy. It was raised that there is little guidance on how GPs should be diagnose dementia. **GP1** raised the point that the MoCA tool (advised for the referral process) took longer to administer and thus used up more resource than other assessments; however national guidance was not clear as to whether this was more clinically effective. **GP3** indicated that only specially trained GPs should be diagnosing dementia and that they would like to see some guidance in regards to training standards. **G3** indicated that whilst it was appropriate for GPs to initially diagnose they should be well trained and be supported by or work with secondary care dementia specialists for subtype diagnosis. **G3** felt that dementia diagnostics should be primary care led.

Concerns over geriatricians diagnosing were raised in terms of thoroughness of investigation and links to community support (**P1**, **G1**.) The process in HF is thought to be intensive as it is all in one day which will only be suitable for more robust and independent individuals, and the mandatory neuropsychology assessment was critiqued as sometimes being inappropriately taxing and unnecessary, although very helpful for the right candidates (**GP1**). The access to high quality imaging was felt to be superior in the Imperial service compared to the outsourced imaging from memory service, which may lead to over-diagnosis of vascular dementia: adequate triaging would ensure that those who needed higher quality imaging would get it. **G3** also felt there was a need for newer PET imaging techniques for a select group, with selection of appropriate patients through a multidisciplinary team. The general consensus from all clinicians was that it is useful to have neurology input for more complex diagnostics but that the memory service should allow diagnosis to be linked better to on-going community support. Several clinicians felt that referrals should be streamlined to having one point of referral and a subsequent triage service to the right specialty for on-going diagnosis and treatment (**GP1**, **GP3**, **P1**, **G1**).

In hospital diagnosis is limited by the fact that the patient is out of their normal context, and may well be delirious at the time so symptoms are exaggerated. Additionally clinicians cannot see them at home or may not have the longitudinal history (**G1**, **P1**, **P2**). However one interviewee raised the idea that in some contexts, especially delayed stays, the diagnostic process should be opportunistically started in hospital and completed at home (**N1**).

The point was also raised that many people may not self-present to GP and so the hospital is a key place that they may be picked up, and to miss this may be a lost opportunity (**P2**, **G1**, **N1**).

G3 discussed nursing and other allied professionals making diagnoses. They felt that some experienced nurses would be appropriate but to his knowledge that use of nurses in this context has caused problems where the need for extra support or a missed diagnosis is not recognised; and thus is risky.

Conclusions:

Psychiatry and specialist neurology/geriatric services add value to the diagnostic process in different ways. There is the capacity for GPs to diagnose dementia but the majority of clinicians felt that they would need extra training and/or support from secondary services to do this. Post diagnostic support tends to be stronger via mental health led services. Ideally, there is one point of referral and an experienced member of staff would triage to appropriate service. This model is better represented in KCW than in HF.

Acute hospital admissions represent an opportunity for diagnosis and could be better linked into the diagnostic process.

2.2 FACTORS AFFECTING DIAGNOSTIC RATES

Some GPs are more geared than others to diagnosing – this was described as a 'bimodal distribution' in KCW and a small minority in HF (**P1**, **GP1**, **G3**). Challenges facing GPs include pressure on services: ten minute slot is not enough (**GP3**, **GP1**), with an anecdote given by **GP1** of how they had seen an elderly female patient several times in a 10 minute consultation and thought she was cognitively intact until a family member reported that she was getting lost on the way home on a regular basis.

An audit in KCW a few years ago showed a high proportion of those with dementia diagnosed in early stages (**P1**). Anecdotally there are a larger proportion of cases of late diagnosis in HF, especially in those from extended care who have perhaps not had surrounding family and friends or regular enough contact from carers to allow memory impairment to be picked up (**GP4**).

Those with comorbid physical disease were felt to present later:

> *In the acute hospital we tend to see patients with a high burden of co-morbid disease, especially vascular risk factors such as diabetes, hypertension etc. These patients are very likely to have significant cognitive impairment but because memory loss is often not the most prominent feature, they often do not receive a diagnosis until very late in the disease, such as when they present with frequent falls and self-neglect* (**G2**).

It was also raised that groups that were socially excluded, homeless and with substance dependency were less likely to present or attend for diagnosis and/or follow up (**P2**).

For those that were identified as potentially having dementia in hospital, communication has traditionally been sent to the GP to ask for memory clinic referral. Concern has been raised that there is no feedback loop to ensure that this actually happens (**G1**, **N1**)

Cultural beliefs regarding diagnosis were also cited, for further discussion in the beliefs and attitudes section below.

Conclusions:

Some GPs are better engaged with diagnosing dementia than others in all boroughs, in HF this cohort is perceived as smaller than the majority. All GPs are pushed to deliver adequate assessment without extra dedicated time and resource. Physical comorbidities can distract from a patient obtaining a dementia diagnosis. Those picked up in hospital do not get referred directly and there is the possibility of losing referrals in this step. Cultural beliefs and stigma can affect patients' willingness to present.

2.3 IDEAS ON HOW TO INCREASE DIAGNOSTIC RATES

There was some interest in encouraging social care staff to increase vigilance for cognitive impairment and encourage referral for dementia diagnosis. (**GP1**)

Many expressed concerns that the proposed £55 enhanced payment would not enhance quality of diagnosis (**P1**, **N1**, **G1**, **GP1**, **GP3**). There was some concern that only worried well would be targeted. Also, that for the amount of time and resource required to carry out the screening it would not be cost efficient even with an enhanced payment (**GP1**). Many felt that screening for dementia was not appropriate without linkage to better post diagnostic support (**GP4**, **GP1**, **P1**, **G3**). **GP4** raised the issue that opportunistic screening did not allow time for a meaningful consent process and conversation around dementia and actually a dedicated GP dementia clinic would be more useful. Indeed, some felt education for GPs as well as increased faith in the usefulness and quality of care received post diagnosis would increase diagnostic rates better than screening (**GP1**, **G2**).

One interviewee raised the point that for those identified with cognitive impairment in hospital, in some contexts, especially delayed stays, the diagnostic process should be started in hospital and completed at home (**N1**)

Conclusions:

Clinicians were sceptical about screening and diagnostic incentives for dementia in primary care without emphasis and linkage to better post diagnostic support. There is potential to encourage vigilance and referral from care staff and acute hospital admissions.

3 SERVICE DESIGN THEMES

3.1 CURRENT SERVICE COHESION

Some GPs have expressed lack of clarity and understanding of memory services' referral and discharge criteria, and that there is a lack of clear remit as to what each service can offer (**GP1**, **GP2** **GP4**, **G1**). Memory services were also reported to not stick to 6 month post diagnosis limit of care (**P1**, **GP1**) and clinicians outside felt that the reasons for doing this were unclear and confusing to deal with (**GP1**, **GP4**). Dementia linked to other diagnoses such as alcohol related or HIV related was highlighted as a grey area where some other specialties were expected to manage dementia when they lacked the specialist resource (**GP1**).

In HF it was highlighted the one stop shop and the memory service worked separately and did not cross- refer between each other to share strengths (**GP1**, **GP4**).

In KCW GPs were happy with the referral process and felt the memory service was well linked with the community and social care. This was not felt to work as well in HF, where it was felt that patients were sometimes left without support after discharge from the memory service due to poor links with on-going social care and community services.

Another key point is lack of understanding or overview of the 'myriad' of different services available in the community and the complexity of their different referral criteria (**G1**, **GP1**, **GP2**, **GP3**, **N1**). Many clinicians felt the presence of admiral nurses was useful in this context however posts were few and not always filled (**GP3**).

Interviewees working in liaison psychiatry and hospital dementia nursing felt that more inter-hospital collaboration and streamlining of services would be beneficial (**P2**, **N1**). Those working in hospital also felt that their links with the community were not as good as they could be (**G1**, **P2**, **N1**). There was some interest in a joint referral strategy across the 3 boroughs (**P2**).

Links between liaison psychiatry and community teams are not ideal in HF: there has been some historic frustrations with long stays in psychiatric inpatient wards so the liaison team tend to prefer admitting those with dementia to general hospital (**P2**). Increasing collaboration is happening between liaison psychiatry and the hospital dementia nursing team (**N1**).

For those working in hospital, referral to memory service must be done through the GP however there is little way of following up whether this actually happens. Dementia CQUINs mean there is increased emphasis on recognising potential dementia and communicating this in discharge summaries but after that clinicians have expressed concern that it is not known whether onward referral actually happens, nor are there easy mechanisms for finding out (**G1**; **N1**; **G2**). Frustration was expressed at models of care where there was a large separation between hospital and community care, and some felt that patients with complex needs would benefit from joint input by teams across community and secondary services (**P2**; **G1**, **P1**). Although the KCW memory service was highlighted as being well linked with community, the geriatric/acute medical specialties were not reported to have and substantive links with the memory and community services.

In historical transactions some 'guarding' of patches and organisational attitudes, more pronounced at senior level, have been cited as impeding attempts at care collaboration (**GP1**). **G3** mentioned different cultural attitudes between psychiatric and medical specialties. There was awareness around the role that joint funding/incentivisation and statutory roles have to play in encouraging collaboration. The introduction of the better care fund was highlighted as helping 'improve the gap between social care and healthcare,' (**GP4**) however some clinicians reported difficulty in aligning goals with social care. For example, **G3** spoke of social workers sitting in on clinic who were in a position to assess a patients' needs and offer care there and then via joint consultation but were only able to offer that patient a phone number as they were bound by a rigid social care protocol. Also **GP4** and **G1** reported difficulties in escalating people from home to residential care without a crisis related hospital admission to galvanise processes, which is not the best use of resources. An example of a lack of 'joined up thinking' was given where a service was co-funded by CCG and local authority; one party cut its funding without consulting the other with significant implications for the service. (**N1**) **G3** was frustrated that borough based funding restricted equity of access for patients to services.

Conclusions:

The remit and referral criteria for different services are not clear to all clinicians using them, and memory services may exclude patients with non-Alzheimer's or vascular dementia.

The 2 services in HF do not currently cross-refer appropriate patients.

There is little oversight of the range of different services available to dementia patients and how to access them – admiral nurses when available are very useful in this context.

Specific strengths in service cohesion are highlighted as: the good links between memory service and community mental health/ social care in KCW; the links between Imperial services and specialist dementia nurses; increasing role of psychiatry liaison and dementia nurses in Chelsea and Westminster/St Mary's hospitals.

Specific areas for improvement in service cohesion are highlighted as: links between the two memory services in HF, links between memory services and community/social care in HF; links between memory services, dementia care team and psychiatry liaison in HF; lack of joint decision-making in resource allocation in KCW, links between geriatric and memory/community services in KCW .

Top down support can be important for enabling collaborative working and historically this may have been lacking in HF. This may go some way to explain the difference between HF and KCW. 'Borough boundaried' and 'specialty boundaried' funding and commissioning has been highlighted as leading to difficulties in resource distribution and access to services for patients.

3.2 COMMUNICATION BETWEEN PROVIDERS AND TO PATIENTS

The differing electronic systems used by memory service, GP and acute services have been highlighted as obstacles to collaborative working (**N1**, **GP1**).

The referral process to memory clinic would be better if automatized straight from hospital and not having to come from GP (**G1**) External feedback is that a process which allows this has been put in place in Hammersmith but not in KCW.

'*Long time delays between referring a patient and subsequently hearing back with an action plan or clinic letter'* from memory clinic were noted throughout the three boroughs (**GP1**, **GP3**, **GP4**). Written letters were thorough but may be severely delayed in reaching the GP (2-3 months) or may not reach the GP at all (**GP1**, **GP3**). GPs cited that they lacked the capacity to chase each and every referral. If detailed letters took time some feedback to say how long they planned to do the assessment over and when to next expect news would be useful (**GP1**, **GP2**, **GP3**). Some key factors that aid management were identified: '*what the plan is and how has the family received the diagnosis, medication and follow up have been discussed or not and have they decided on a lasting power of attorney*.' (**GP1**, **GP4**)

The issue of computer literacy for patients was addressed – many of the community and voluntary services were easily accessed on line but for patients who could not do this it was seen as very difficult to find support needed. Some GPs were seen as better than others in making this information readily available (**N1**, **GP2**). It was also raised that many times patients seemed to have not been given information regarding creating a dementia friendly environment at home from the memory services, if this did happen then GPs should be made aware so that they can reinforce it (**GP1**).

Conclusions:

Communication between memory services and GPs is not standardised or always timely.

Communication to patients and carers regarding access to support and changes they could make does not seem to always happen from memory service or GP.

Communication between specialties is hindered by different IT and governance systems.

3.3 SERVICE CAPACITY

Supply of care homes and nursing homes was noted to be tight, with many people being placed out of borough (**P1**, **GP3**), although clinicians felt that many people rarely had to move far away (**G1**, **GP3**, **GP2**). It was noted that some homes lacked the specialist skills and confidence to deal with more distressing behaviour and those with younger onset dementia who tend to have neurological problems and chronic disability (**G3**, **GP2**, **GP3**).

Many felt that admiral nurses were very useful but that 1 per borough was not enough (**GP1**, **GP2**). Services such as dementia café's, community outreach and carer's support were valued but not very widely available (**GP1**, **GP2**).

GPs were seen as having little extra time and resources to push into extra diagnostics. '*The national screening have offered a screening tool, in my practice the tool identifies 400/11000 patients to screen, in reality we don't have the capacity to spend half an hour doing and adequate assessment on each of these*' (**GP1**, **GP2**, **GP3**).

Memory services in KCW were noted to see people on time (**GP2**) Liaison psychiatry in HF is underfunded with 1.5 instead of 2 consultants and none which are psycho-geriatrically trained (**P2**.)

Conclusions:

Key areas where service capacity is currently strained were identified as: the supply of residential and nursing homes in borough, availability of admiral nurses, liaison psychiatry in HF; time and resource for GP-led dementia assessments.

3.4 ESCALATION AND DE-ESCALATION OF CARE

Two clinicians mentioned that often people who were being cared for at home would 'struggle on until crisis point' before getting escalated to residential placement post admission (**G1**, **GP4**). **GP4** mentioned difficulty in arranging placements for those noted to be struggling and that many had to reach a crisis admission before this happened.

A couple of interviewees highlighted the admission process as a pivotal point where long waits could escalate behavioural disturbance and instigate delays and complications in care (**N1**, **P2**, **GP1**). In KCW an A+E based liaison service is being commissioned to target this area (**P1**). **G1** mentioned that currently a larger focus lay in preventing admission than to shortening admission and suggested thatshortening admission would be the route to efficient and effective patient care.

Conclusions:

Difficulties have been noted in escalating people from home to residential care in a timely fashion, avoiding a crisis admission. Focussed care from the start of admission may help shorten admissions and reduce need for escalation to interim or residential care.

3.5 INTERFACE BETWEEN MEDICAL AND PSYCHIATRIC CARE

Clinicians recognised that there is a large burden of co-morbid disease in patients with dementia. These patients pose challenges to care and tend to have longer stays: '*most patients have other co-morbidities that will affect the rate of progression of dementia – if patients need frequent operations, this will affect their future cognitive ability as any use of anaesthetic affects brain cells.*' (**P1**; **G1**; **G2**; **P2**; **GP1**).

The role of liaison psychiatry seems to be stronger in KCW, with a specialist old age liaison service with good collaboration with the memory service (**P1**) however geriatricians reported only calling on liaison psychiatry for complex cases:

> *We frankly deal with dementia, delirium and behavioural disturbance, and depression quite a lot so I'm comfortable enough in dealing with most of those problems in inpatients. In terms of referrals to liaison psychiatry I'd be surprised if we generate more than 1 or 2 a week - for background info and diagnostic support for people already known or for on-going management for people who have got problems requiring on-going psychiatric support*.

There were concerns raised that perhaps some delirium and/or dementia is missed or not managed optimally on general wards. The introduction of CQUINs and dementia nurses has improved support available for this, and it was acknowledged that services are developing and improving (**N1**, **P2**, **G2**). In HF capacity and expertise limitations were identified as limiting the input of liaison psychiatry, although clinicians were keen for more collaborative working.

A tension was identified with crossover into different specialties:

> *The other thing about dementia is that it touches on so many other hospital specialities, for example with Parkinson's disease and alcohol-related dementia or schizophrenia-related. The current service bats them all back to their original speciality thinking they can deal with the dementia but that is not the case. I think the dementia service itself needs to understand what pathways there are into other specialities and accept what their role is in that* (**GP1**).

Conclusions:

It is recognised that many patients will present with dementia and physical comorbidities which complicate treatment. The role of liaison psychiatry in dementia care varies, a specialist old age liaison service has been set up in KCW but still tends to be used only for complex cases. In HF there is minimal involvement with dementia only cases due to lack of capacity. A dementia care team in Imperial and a dementia nurse in Chelsea and Westminster are present but collaboration between them and psychiatric / medical services has only recently started to happen.

There is some confusion regarding responsibilities of care in patients with dementia related to other physical diagnoses.

3.6 INTEGRATED CARE MODELS

General opinion was that dementia care would be improved with greater integration and collaboration between services. Praise was given to the KCW memory service model for emphasising community based care and working flexible with GPs (**P1**; **GP2**).

An ideal memory service would include:

> *A single point of referral where both the GP and the assessor will make a decision about what arm of the service the patient would sit in and once the diagnosis was made there would again be a crossover from one end of the service to another.* (**GP1**)
>
> *Social, district nursing, community matrons, community mental health team, home care all in one place so that they can access all in one place, with joined up care, reducing unconnected silos.*(**P1**)

Some ideas for improving integration were offered:

- A single point of referral for dementia care and diagnostics; with patients able to cross over between services and reliable information governance (**P1**;**GP1**;**GP3**;**N1**)
- A lay keyworker to navigate appointments and patient engagement with services, including voluntary sector (**GP1**)
- A dual frailty ward with joint elderly care and psychogeriatric ward rounds. A Watford pilot had promising results in regards to reducing need for residential placement, with an opportunity so save significant amounts of care budget (**P2**)
- Extension of the ‘virtual ward’ model as operated by Aglaja Dar in the Charing Cross OPAL service to other areas and dementia focussed (**P2**)
- A mechanism by which dementia investigations can be initiated via elderly care services (**N1**)
- Screening based in residential care (**G1**, **GP2**)
- A rapid advice line with advice from secondary care clinicians to support care homes to work with people with behavioural issues (**GP2**)
- Geriatricians or psycho-geriatricians to retain oversight of care throughout community and acute services, and to take ownership of admission and discharge decisions (**G1**)
- Increased strategic coordination of commissioning with a long term view and perhaps pan-London GP networking were advocated (**GP3**, **P2**.)

Reference was made to current integrated care pilots in North West London. Whilst it was recognised that these services offered good holistic care to those with complex needs; concerns were raised that the few patients targeted probably already had extensive multidisciplinary input and engaged GPs coordinating care, and the time spent per patent perhaps did not offer value for money. Thus this would run the risk of being an expensive way to 'reinvent the wheel.

> Also raised was the point that dementia had not been included in integrated care themes, perhaps due to lack of ability to advocate within the patient group (**G1**) '*There are all these ideas about integrated care – it sounds great but there's a whole load of stuff to do and I actually think they would have more impact if they sat down and said I want you to identify every single patient with dementia that comes into the door and I want them out the door within 60 minutes. There's a lot of work generated by the way that people are dealt with within the current system*(**GP1**).
>
> *You would discuss 5 cases in 2.5 hours with 30 people in the room and the ratio of man hours to yield of patient intervention was very very low. If these people were out delivering care then they probably would have had a much greater impact than sitting in that room for 2.5 hours* (**G1**)

The importance of good community and social support services was highlighted:

> *If you have a system designed for single problems, self-presenters and self-managers, if prevalence of dementia is going to go up self-management is going to be a problem. Unfortunately the things that we need to make things work aren't necessarily going to keep pace: people think geriatricians can wave a magic wand but there is nothing I can do myself almost everything I do is through other people. We do some medicine ie. medication review and picking up the odd diagnosis but a lot of the discharge planning and chronic disease management is entirely reliant upon other services and social support. I'm a very expensive way to provide on-going management, I am a better 1 stop quick review. Sometimes I see people more often than the people that need to which may just be social care providers. Sometimes we just need to get people up and moving, taking medication and getting decent food to eat, it's not rocket science, there's no point you coming back to clinic three times for me to say that over and over again.*

Conclusions:

Greater collaborative working between services is generally supported, but concerns are raised that entire new models of integrated care would not create as much output as strengthening existing services, especially the community support element, and collaboration between them would. Ideas proposed by clinicians include dual frailty and virtual wards to optimise in hospital care and early discharge, care coordination by a lay worker; extra telecare support for care homes; better designed memory services in HF with a single point of referral and triage.

3.7 CO-PRODUCTION/ ROLE OF VOLUNTARY SECTOR

Some clinicians expressed an interest in working more closely with the voluntary and community sector:

> *I would want more involvement with voluntary sector and also with private sector. Due to the local demographic with a large amount of wealthy residents we miss a trick by not getting involved more closely with individuals and organisations in the private sector, particularly with organisations that specialise in dementia care. I would improve referral pathways and diagnosis by involving community pharmacists/shopkeepers/librarians who notice more the loss of function.*

Difficulties of stigma and confidentiality regarding the latter were acknowledged. (**P1**)

> *I would like some carers involved in projects I've got coming up in terms of dementia admission packs I want to start using throughout hospitals as an identifier. Carers are asked to fill out a 'this is me' document; I think closer links with carers in the hospital would be really beneficial in terms of other services that are going on. Also to try and offer those services here –in terms of dementia friends sessions and training etc. I am pulled away from trying to do that kind of work because there's always a patient or always a meeting, so I would really like there to be closer links with the community, I think we would benefit massively in the hospital.* (**N1**)

> *They have a large role a lot of charities have a lot of political power and are very well financed. I'd like to see more collaboration with this sector. One thing I would like to see is more co-ordination and more clarity with these services because they all seem to be doing very similar things often overlapping and in one area one organisation may be well represented and in another the other organisation well represented. I don't know if they see each other as rivals or not but there needs to be more strategic exploration.* (**GP3**)

G3 mentioned that they had already worked closely with the Alzheimer's society to provide services specific to younger onset dementia patients across North-west London.

N1 expressed a view that there were insufficient dementia specific services: '*we have many diagnosed late, and we have very little on offer for people with dementia in terms of reducing levels of social isolation*.' **GP4** also felt that befriending services would be useful in reducing social isolation.

The role of voluntary sector in patient advocacy was also praised as promoting more holistic, less clinical, decision making (**GP4**).

Conclusions:

Clinicians expressed interest in working more closely with voluntary and charity sectors to inform better care with holistic decision-making, fill gaps in dementia care provided by traditional services; and ensure equitable access to support. The services already provided by Alzheimer's society and Age Uk, as well as various day centres and activity groups are highly valued, but the perception is that there is little strategic oversight of provision.

4 QUALITY OF CARE

4.1 QUALITY OF HOSPITAL CARE

Overall, clinicians felt that hospital care had improved since introduction of the dementia CQUIN. The ward environments were generally not seen as achieving a dementia friendly status, with little colour differentiation or non-clinical looking environments (**N1**, **GP2**, **G1**, **G3**). The work of the Imperial Dementia Care Team has included this: '*wards are now seeing benefits CQUIN targets have been met, and the referrals to the team have increased. Life Story work and work on managing delirium is incorporated into the pathway*' (**G2**, **P2**).

There is interest in expanding the activities available to patients with dementia and providing counselling and activity coordinators, but funding is currently limited.

> *In terms of the physical care I think we do a good job were good at maintaining peoples' skin integrity and nutrition. I think when looking at somebody's mental health and wellbeing we've got a way to go before we address those things.* (**N1**)

Innovation such as the 'my life' digital reminiscence software are useful but many patients will require someone to sit and talk them through using it.

Antipsychotic use was generally not seen to be problematic, at Chelsea and Westminster hospital an audit is due to take place (**N1**). **P2** expressed dissatisfaction with the quality of bank nursing staff and would like to see a bank of dementia trained nurses for 1:1 with a line manager.

Conclusions:

Quality of hospital care has improved with introduction of dementia CQUINS. There are no concerns raised regarding antipsychotic usage, and skin and nutritional care was reported to be good in Chelsea and Westminster. Continuing need for improving environments and increasing range of activities available in hospital were identified.

4.2 QUALITY OF MEMORY SERVICE CARE

The KCW memory service was recently awarded the national mental health team of the year award: key components included a focus not just on diagnosis but also on aftercare, a community based and flexible model where people can be seen at home and in GPS (**P1**).

Some frustration was expressed at the support given by the memory service in HF. Examples were cited where the team have been contacted for advice when a patient has been in crisis and have said there is little they can do as the problem is 'disease progression.' This was not felt to be very helpful by the GP in question. It was also felt that the HF memory service offered a 'one size fits all' treatment for the patient concentrating of medication and follow up rather than really addressing individual problems and establishing links with social services, occupational and other therapies. Examples were also given of requests for second opinion cardiology reviews which were felt to be inappropriate by the GP, causing unnecessary delays in diagnosis (**GP1**, **G3**). Such concerns have already been raised with commissioners who are reviewing contract plans, and may relate to difficulties in collaborative working with social services.

Conclusions:

The relatively new memory service in KCW has been recognised as providing excellent care. Difficulties have been noted with HF services, largely relating to poor links with social and community services, communication and delays in assessment.

4.3 QUALITY OF RESIDENTIAL CARE

Little was known about quality of residential care. In terms of provision, specialist homes for actors and RAF veterans were available. Some clinicians expressed the thought that care homes could be more engaged with dementia friendly environment, better staff training, cognitive stimulation training and/or activities being available (**GP2**, **P1**). One clinician mentioned often seeing patients dehydrated in extra care/ residential accommodation, perhaps secondary to staff resource (**GP4**). It was noted that some were reported to provide excellent care and it was not known whether there was a mechanism in place whereby others could learn from this (**G3**).

Conclusions:

Clinicians rarely had direct experience of care homes, the interviewees felt that quality of care varied, some were very good, but others could improve in terms of training to pick up dementia, deal with distressing behaviours and needs, and keeping residents hydrated.

4.4 QUALITY OF COMMUNITY CARE

Many expressed a desire that staff focussed on emphasising independence and dignity of individuals and increasing social interaction. '*Home carers, instead of going shopping, should go and sit down with patient and order shopping together in social interaction*' (**P1**). **P1** also expressed that it was difficult to afford good quality care home staff in London, and that their top priority would be to '*pay home carers a decent salary and give them a career structure and make them a valued part of the community*', '*they should have the same recognition and value in society that nurses do*.' There was also some interest in extra training as whilst in general it was felt that home care and support staff were confident in dealing with dementia, occasionally there would be issues such as care being withdrawn for a patient who was making racist comments with a lack of understanding or tolerance for this being part of the disease process. It was also felt that carers could be trained better in identification of dementia. (**GP1**)

One GP mentioned difficulty in obtaining extra care and support linked to legislation – the clinician felt that many clinicians were not aware of the power scheme of independent advocates (IMCA) for those who lacked capacity (**GP4**). More outreach support for those with dementia was desired, and reinforcement of advice regarding maintaining a dementia friendly environment for carers (**GP1**, **GP2**).

Conclusions:

Generally it was felt social care staff had a good understanding of dementia, but finding and retaining good staff was a challenge in London. They could be supported with extra training and encouraged to think of ways to preserve dignity and independence for patients. This knowledge, alongside how to create a dementia friendly environment, should be passed on to carers but it is not clear that this is consistently happening. Little awareness of availability of independent advocates between clinicians was reported.

5 ATTITUDE AND ENVIRONMENT

5.1 COMMUNITY ATTITUDES TOWARDS DEMENTIA/ DEMENTIA CARE

> *From a public consciousness point of view having memory trouble as you get older is still an expected thing; you see so many people where it's never been picked up and we start asking about cognition and the fact that someone hasn't been able to pay their bills or remember an appointment in 3 yrs doesn't strike anyone as abnormal.* (**G1**)

This opinion was echoed by others (**GP1**; **N1**).

Many clinicians noted that as part of an inner city urban population, with expensive house prices and living costs, families and communities are increasingly fragmented and unable to support those with dementia (**G2**; **P1**; **N1**; **GP1**). This leads to increased burden on care and later presentation or presentation in crisis which is more likely to escalate to a residential care placement. However, a couple of clinicians cited cultural attitudes in some ethnic minority groups such as Somali and Filipino where family cared for the patient until advanced stages, for one patient until she developed contractures and couldn't walk, before seeking help (**G1**; **GP1**). Some also felt that people were unlikely to seek diagnosis as there was little hope that any of the care offered would modify the disease or relieve suffering (**GP1**, **N1**).

The need for greater public awareness and education was also raised; with the idea that this would also encourage younger people to engage with primary prevention:

> *I would hope that people's individual views would change that if they have a relative with dementia that as they get older they want to get a fasting glucose and cholesterol. I'm not sure we can really change the attitude towards dementia until we have something to offer in terms of prevention or that really modifies the disease progress.* (**GP1**, **G2**)
>
> *It seems funny we have people at school and we don't teach them useful stuff such as understanding dementia and frailty. Unfortunately they are complex and superficially dull concepts…People have some personal experience but no understanding of it: get them in school, that's the time*. (**G1**)

Conclusions:

As an inner city area, patients are less likely to have social support from families leading to increased dependence on services and later presentation. Some ethnic minority groups offer much support but may access services later. A lack of public awareness of the significance and ability to treat dementia prevails which limits peoples' willingness to access treatment.

5.2 HEALTH PROFESSIONALS' ATTITUDE TOWARDS DEMENTIA/DEMENTIA CARE

Most clinicians emphasised the fact that dementia impact and presentation varied greatly from person to person and this needed to be addressed in the care they are given (**GP1**; **G1**; **G2**; **P1**; **N1**). A need to support patients' independence and do things 'with, rather than for' people was noted to achieve 'living well with dementia' (**P1**,**G3**). The link between early diagnosis and independence was noted in enabling risk mitigation; enabling a person to take control and make decisions regarding the future while they are still able such as taking holidays and living wills.

Interestingly, some interviewees observed occasional reluctance by health professionals to diagnose.

The reasons for not diagnosing in hospital have already been discussed, but there is a suggestion that it can be avoided even when appropriate:

> *Sometimes it's a battle on our side to get investigations done because it's just deemed as chronic confusion or they say it's a resolving delirium but actually there's a history of months of memory decline, so it's that something I've had some discussions about that have been quite difficult'* (**N1**) . *'There is an attitude amongst GPs in general which is basically what is the point when there is very little you can do.* (**GP1**)

Occasionally there would be reluctance of care staff to deal with behavioural issues, such as the example of care withdrawal from a patient with dementia who made racist comments (**GP1**).

Conclusions:

The majority of clinicians endorsed individualised care due to the large variation in presentation and need seen. There were examples cited of GPs who did not feel that effective care was available, care staff that found it difficult to deal with behavioural issues, and hospital clinicians being unwilling to initiate the diagnostic process.

5.3 PATIENTS' ATTITUDE TOWARDS DEMENTIA/ DEMENTIA CARE

GP1 and **N1** mentioned that the current demographic were particularly stoical and unlikely to seek extra support or join groups, exacerbating isolation and loneliness. It was also mentioned that many patients would not feel comfortable talking with their GP about problems and a behavioural or coping issue may be flagged sooner if they have somewhere to 'drop-in' informally (**N1**). The impression was that it was rare for people to move away from London once diagnosed most stated local. One clinician cited that on the rare occasion that a patient was relocated to be near family elsewhere in England this was a very difficult and lengthy process (**G1**).

P1 described a study in KCW carried out within the last few years that showed the ethnic mix of those diagnosed with dementia matched the community profile inferring little impact of ethnic specific beliefs on diagnostic rates. However,

> *We have reasonable BME populations this may be something that culturally they don't recognise as an illness you should take to the doctor, for example I've seen some Somali families where they just accept it, this is the way their mother or father is now.* (**GP1**)

Conclusions:

The current elderly demographic is stoical and less likely to seek help than younger patients; thus may be better reached by outreach and informal services. Patients were likely to stay in borough once diagnosed. There are mixed reports as to the impact of BME beliefs on diagnosis.

5.4 DEMENTIA FRIENDLY ENVIRONMENTS

Currently, **P1** and **P2** did not feel that their patient base was different to surrounding areas. However, it was mentioned that in HF people tended to be seen and diagnosed at more advanced stages (**GP1**) whereas in KCW people were diagnosed early (**GP1**, **GP2**, **P1**). A significant proportion of people who were seen in hospital were thought to have cognitive impairment '*1/3 of my inpatients have dementia diagnosis, 2/3 should have a diagnosis of dementia*' (**G1**).

In general, it was agreed that numbers were to increase in the coming years secondary to an ageing population in general, although some interviewees felt that the impact would be less than expected due to:

1. Increasing preventative work around cardiovascular disease (**GP1**;**G2**)
2. Increased fitness levels in those that do survive longer (**G1**)
3. Potential new drugs and treatments for dementia (**GP3**)
4. A shift of current working age adults out of central London due to rising house prices and living costs or to seek a quieter environment for retirement (**N1**)

Conclusions:

The impression was that HF tended to have later stage diagnoses and KCW earlier diagnosis. Many patients in hospital were observed to have memory problems, a significant proportion undiagnosed. Clinicians felt that their patient base was likely to increase due to ageing population, but that preventive work, better fitness levels and moving out of London in the coming cohort may affect the impact of this.

6 DISCUSSION:

Whilst the opinions of clinicians as demonstrated here are not representative of the entire picture and will inevitably contain some bias, they provide rich and varied viewpoints to understand both the factors influencing dementia care and clinicians' roles with in it.

The areas for which there were most consensus were:

- the need for a single point of referral for dementia diagnosis
- a lack of cohesion/communication between different specialties, more pronounced currently in HF than in KCW
- the important contribution of voluntary sector and carers

This analysis has allowed some general reflection in terms of what the important factors in dementia are as well as highlighting specific issues relating to current service provision

7 IMPLICATIONS FOR FUTURE STRATEGY:

Recommendations based upon this report would be:

- Review ways of increasing cohesion and communication between services.
- Memory service in HF to have a stronger community and social care presence, possibly modelling upon the KCW service
- Clarify diagnostic pathways with 'one front door' and possibility to refer straight from hospital with GP acknowledgement rather than only via GP
- Improve links with voluntary sector, consider strategic commissioning and provision of more admiral nurses
- Review quality and supply of residential care
- Consider ways of providing extra support for carers
- Consider improving in-hospital care from point of admission for those known to have dementia; (it is noted that KCW are piloting implementing a nurse in A+E for this purpose.)
- Consider increased provision of training in managing difficult behaviour and spotting warning signs for paid and unpaid carers