Mapping Dementia Services in the South West

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Authors: Dr Sarah Robens, Tobit Emmens, Sarah Ross, Professor Chris Dickens

Acknowledgements: Dr Nick Cartmell, Dr Iain Lang and Ben Wheeler

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1 Background

There are 750,000 people living with dementia in the UK (2011 prevalence), and this is expected to rise to over a million by 2021. The costs of caring for this population have been estimated currently to be around £8 billion for direct healthcare, rising to over £20 billion if full societal costs are taken into consideration, which is more than the combined costs of cancer and heart disease. The majority of these costs are for long term residential care (40% of total costs) and informal carers (55% of total costs), with only 5% of costs going on primary and secondary care (Health Foundation 2011). Since the prevalence of dementia increases sharply with age, these costs are set to increase sharply in coming years due to the aging of the population.

Care for people with dementia frequently falls short of best practice, as outlined in a number of high profile government reports and recent clinical guidance documents. Dementia sufferers and their carers frequently do not access recommended care and support in a timely fashion, and, when they do access care, the varying components of health and social care are fragmented and poorly coordinated. As a result dementia sufferers and their carers experiences of care are poor, outcomes are worse and health and social care costs are greater than necessary. In 2007 and 2010 the National Audit Office concluded that dementia services offered poor value for money due to patchy implementation of services, poor coordination of care, leading to avoidable hospital admission, prolonged stay in hospital and increased use of residential care. Consequently, there is considerable scope to improve the quality and efficiency of dementia care.

The overarching aim of our work is to improve the quality of care and to improve outcomes for people with dementia and their carers, by ensuring that care is appropriate to the level of need, equitable across the local area, easily accessible and well-coordinated. From the perspective of service users, their carers, healthcare providers and even NHS commissioners, it is not clear what services are being provided and by whom.

As a first necessary step to improving the availability, accessibility, equitability and coordination of care for people with dementia in the South West Peninsula, where the needs for dementia services are particularly marked due to the higher than average age compared to the UK as a whole, this project aims to identify and describe current service provision for people with dementia and their carers.

The potential health gains and benefits arising from this project include:
1) A detailed map of existing dementia services, which will be useful to:
    i)   service users (to identify local sources of care and to see what services are offered),
    ii)   service providers (to assist in the coordination of care) and
    iii) service commissioners (to increase understanding on current levels of service provision, to identify areas of need and to inform future service developments).
2) A better understanding of the processes and experiences of dementia care, particularly the nature of care provided and the accessibility of and barriers to the integration of care, which will help to identify best practice.
3) Details on patient outcomes, and how this data relates to service provision and different processes of care, which will help

i) identify areas of service need,

ii) inform discussion on the most effective models of local service delivery, and

iii) provide a baseline against which future service developments can be evaluated.

2 Aims

Aim 1: Service Identification

To develop a comprehensive map of service provision for people with dementia and their carers across the South West peninsula.

Specifically we will aim to

i) Identify all services (statutory and non-statutory) provided within the South West Peninsula, which are specifically for people with dementia and their carers.

ii) Contact each of these services to confirm their existence, source of financial support, establish details of patient eligibility, levels of service provision and to obtain a description of the services provided.

iii) From direct contact with services, to gather a secondary list of additional service providers and organisations with which the index services interact to provide care for people with dementia and their carers. These additional services may be dementia specific but not identified in our original data searches, or (more likely) are generic services that provide important care for people with dementia and their carers. We considered this additional stage would add value to the mapping exercise, since much care provided to dementia sufferers is not dementia specific.

iv) Develop an interactive geographic map of dementia services to enable service users, providers and carers to search for local services (by service name, type and service provided).

Aim 2: Qualitative Research

To better understand the processes and the nature of care provided to people with dementia and their carers by:

i) Finding examples of what works and what does not.
ii) Exploring the accessibility of and barriers to the integration of care.
iii) Collecting patient stories around the breakdown in care.

Aim 3: Outcomes Mapping

To investigate potential to develop a map of dementia outcomes in the South West, to:
i) identify areas of excellent dementia outcomes across the Peninsula
ii) identify areas of poor dementia outcomes across the Peninsula, and
iii) explore how / if dementia outcomes relates to service provision which could inform future planning and evaluation of dementia services.

3 Methodology

3.1 Service Identification Methodology

The South West Peninsula boundaries were defined as being within the South West Academic Health Science Network geography of Devon, Cornwall and Somerset.

Mapping criteria included all statutory and non-statutory health and social care services from the public sector, private sector and third sector that would be useful for people with dementia and their carers.

The mapping process began in East Devon to establish mapping methods, before rolling out to the rest of Devon, Cornwall and Somerset. Geographical regions within Devon were identified using a combination of Local Authority (LA) and CCG boundaries to divide the county roughly into North, South, East and West localities. CCG geographical boundaries were not used since this information was not readily accessible at the time of mapping.

The service identification took place in the following three stages:

Stage I: A brief scoping review to identify existing service maps and directories.
* Scoping existing maps and directories
  During this stage, we gathered evidence on the types of dementia services to inform a service classification system, which was later revised during the project cycle.

* **Criteria were set for the types of services to be included in the search.**
  The following categories of provision for dementia services were established:
  ➢ Health and Social Care
  ➢ Statutory and Non-Statutory
  ➢ Public Sector, Private Sector and Third Sector
  ➢ Services located within Devon, Cornwall and Somerset
  ➢ Dementia-specific services
  ➢ Generic services for older people (if snowballed)

Stage II: Service identification
* **Services were identified using online directories and through professional networks.**
  We searched existing databases and directories of health and social care provision, for example, those held by local councils. Collaborators among NHS service commissioners and providers in the voluntary sector were also consulted. Shortlisted services were added to a research database, including basic information only such as service name, organisation and contact details.

We recognised that existing directories and service maps would only list a proportion of services relevant to people with dementia and their carers. In addition to the dementia specific services, we anticipated that there would be a considerable number of more generic services that were useful to people with dementia, but not limited to people with dementia, for example services aimed at older people. This created a methodological dilemma, in that we could limit our search to dementia specific services (and therefore fail to include a large number of useful generic services), or we could create a map that included all generic services (which would be over inclusive). We decided to manage this problem by adopting a "snow-balling" approach, whereby each service surveyed

was asked to identify other local services with whom they interact (dementia specific or otherwise). This step was considered to add value since much care for people with dementia and their carers is provided by non-dementia specific services, yet we avoided listing generic services that were not actively providing care and support for people with dementia. The initial aim was to reach saturation until no further services were identified. In practice, due to time constraints, saturation was only reached for the East Devon LA region where we piloted the mapping methodology.

- **Telephone interview with the service coordinator took place.**
  A survey and telephone interview guide was designed in consultation with the project steering group and CCG representatives (see Appendix I). The telephone survey interview contained 37 questions and took an average of 33 minutes to complete per interview. After completing the telephone interviews in East Devon, we shortened the survey; this reduced the time taken to complete each interview to approximately 15 minutes.

  For each service identified, telephone contact was established (or attempted). Basic information gathered from stage III was verified by telephone to ensure that service details published online were up to date. Further data about the service was collected using a telephone survey interview method, during which service coordinators were asked to identify other services and care organisations with which they interact, or for which they had personal knowledge that such organisations provided support for people with dementia and their carers.

- **Data management**
  A database was designed in MS Excel to record services identified and the different categories of service function provided each service. This database also allowed for the logging of all calls using a customer relations management method.

  Data was collected in written format and then transcribed from paper copies of the survey topic guide in to the MS Excel spreadsheet. Sections of data from this spreadsheet were used as a data source for the interactive map and outcomes mapping analysis.

  Services in the database were defined to determine a) whether they were dementia specific or generic services and b) what the primary function type was. Two members of the research team defined services independently before agreeing upon final definitions to ensure inter-rater reliability.

Stage III: Service mapping
  Raw data from stage II was cleaned and prepared for Geographic Information System (GIS) mapping. Using ArcGIS software, data was imported, joined and related to other data sets (including LSOAs, Deprivation measures, population and census data and outcome data). New GIS data files (shape files) were created to view and analyse the mapped data.

3.2 Qualitative research methodology

Qualitative research was carried out to find out what support was needed, what was being used and how it was being used by people using services, carers and other stakeholders.   The qualitative research focused on one particular geographical area (East Devon) in order to be able to better understand the dynamics of service use across one area thus highlighting points for use in wider comparison, rather than collect broader data across the whole Peninsula.

The qualitative research stages were as follows:

1) Create interview pro-forma (See Appendix III)

The topic guide for the qualitative interviews was drawn up by members of the projects team with the aim of eliciting patients' and carers' experiences and perspective on their care, particularly what experiences of care they had, what they considered worked well, and what did not work well.

The topic guide was amended half way through the qualitative interview stage to help the researchers prompt the chronology of the care pathway from first detecting there was a problem to post diagnosis (Appendix II). This facilitated interviewees to remember the types of support and services they had accessed along the pathway.

2) Identify sample of service providers to be interviewed

During the telephone survey, all memory café service coordinators were asked about their willingness to be part of a follow-up interviewing. Of those who reported a willingness to take part, 12 were sampled from East Devon. These 12 were those who responded to the request to attend sessions during a particular time-frame. The decision was made to concentrate the sample of East Devon so as to have a more comparable sample across one area rather than a more dilute set of experiences from across the whole region.

3) Set-up observation and interview sessions

The interviewer spoke to the memory café facilitators to arrange a time that was most convenient to them. This depended on planned activities or speakers.

4) Carry out interviews

Interviewees' agreement to taking part in an interview was taken by the research team as implicit consent. Verbal reassurance was provided to interviewees that their comments would be anonymised.

Semi structured interviews were carried out during Memory Café sessions, with people with dementia, carers and service coordinators. Initially these interviews took place at tables within the main group, but sometimes people were interviewed in a separate room because of noise and other activities taking place. Interviews varied in length from 10 – 40 minutes.

Interviews with stakeholders were recorded using written notes, rather than audio recording which would have been difficult to hear in a noisy setting, and might also have prevented discussion of sensitive topics.

5) Analyse findings

Notes and observational notes were written up and a thematic analysis of the notes was carried out

3.3 Service and Outcomes mapping methodology

Observed spatial variations in health have long been of interest to researchers (Durkheim, 1951, Pearce et al., 2006). Understanding what it is about places that might be important in explaining such variations remains an ongoing challenge to health researchers.

Geographic data that supports health research can be categorized as follows:

- Data about health care capacities, such as health facilities, employment, and administration.
- Data about the population and their health conditions and health care needs.
- Data about the environment, both natural and social, that affect people's health.
- Data about transportation and address location, which are essential in understanding accessibility for care, dissemination of medical supplies, transmission of infectious diseases, distribution of patients, and many other relationships among data of the above three categories.

In addition to producing a range of maps with clickable links to different services, (a 'find my nearest' solution), we also wanted to explore the spatial variation of mapped services alongside other mapped determinates of health, such as social isolation, deprivation, social fragmentation, and outcomes. Our aim was to gain a better understanding of the equity of dementia care (or lack thereof) and the possible impact of variations in service provision on dementia outcomes.

For these purposes, we collected or located data as follows:
- Service data about facilities, opening times, numbers served and other key facts, from the dementia services mapping exercise.
- Census and population data, from the UK Data Service (http://census.ukdataservice.ac.uk/get-data)
- Indices of Deprivation (IMD, Carstairs, Towsend), Rurality and Social Fragmentation from the UK Data Service (http://census.ukdataservice.ac.uk/get-data)
- Hospital Episode Statistic data for unplanned admissions coded as 'dementia' provided by the SW AHSN via the Lightfoot Solutions UK HES Data Portal.

These data were collected, and coded into an Excel spread sheet, and prepared for spatial analysis using ARCGIS and using the LSOA (Lower Super Output Area) or postcode as our geocoded unit.

To test the mapping process, and to conduct a preliminary analysis and plotting of service data, we used a modified Dementia Services dataset which included the Service Name, City / Town and postcode and the service type.

Using standard statistical and GIS methods we prepared HES data to be plotted in two ways:
1. A raw data plot, with admissions shown at the level of the LSOA
2. By creating a 'Standardised Admission Rate' (SAR) of the admission data and plotting it at the level of the LSOA

Hospital admissions for dementia, extracted from Hospital Episode Statistics, were mapped according to the Lower-layer Super Output Area (LSOA) of residence of each patient. Using population counts from the 2011 Census, admission rates were indirectly standardised by sex and age group, using the regional population as the standard. This process generated Standardised Admission Ratios (SARs),

where a value of 1 indicates that the admission rate in that LSOA is equal to the rate for the whole region, having accounted for the LSOA population age/sex structure. A value of 1.2 would indicate an admission rate 20% higher than that expected, whilst one of 0.8 would indicate a rate 20% lower than that expected. The map of SARs gives an indication of the geographical variation in admission rates, but is limited by small numbers in some areas.

We did this in order to make some preliminary and exploratory investigations into whether the observed outcome, which in this case is a hospital admission, had any relationship to a range of variables, including service provision, deprivation or social fragmentation.

We wanted to test which 'predictors' (e.g. Deprivation, Age and Age Profiles, Proxies for social and geographical isolation), were associated with a number of dementia outcomes (Dementia Admissions from Hospital Episode Statistics (Primary and Secondary), Referral Rates.

4 Results – Service Mapping (Aim 1)

- In general, we had a positive response from service coordinators about the Dementia Mapping research project.

- Only one service in Devon declined to take part in the telephone survey. This was because they did not want their well-attended charitably funded service to be responsible for the closure of the local community hospital. The service coordinator did not want to be seen to be providing a service that 'statutory services should be providing' and therefore did not want to be included in statistics that might draw funds away from statutory services.

- Due to the multitude and diversity of services provided, in some cases, we worked with providers to gather data from a single person rather than interviewing individual staff from each services. For example, for the 42 Alzheimer's Society services in Devon and Cornwall a single person filled in the data collection spreadsheet. Although this data lacked the richness of telephone survey data, the pre-filled data spreadsheet saved considerable time during stage II of the service identification phase.

4.1 Scoping review of existing directories

- Five online directories offered the most comprehensive service information: Devon County Council (DCC) Community Directory, Dementia Roadmap, Alzheimer's Society, Memory and Alzheimer's Cafés UK Directory (www.memorycafes.org.uk) and Dementia Care Devon.

- Two out of the five directories, The Dementia Roadmap and Alzheimer's Society, used a geographic mapping function within their directories, linking postcode data to Google Maps.

- The DCC Community Directory appeared to be the most useful for service identification with a sophisticated search function. For example, it was possible to search services by key word 'dementia' and the results appeared in order of geographic proximity (distance in miles) from the town being searched. However, the DCC Community Directory was not always up to date and sometimes contained incorrect information.

- The Dementia Roadmap directory sometimes contained higher quality information than the DCC directory and also listed services that were not in the DCC directory; therefore it was essential to use both directories simultaneously until our search was exhausted.

- The Devon Senior Voice directory was found to be less up to date than the other directories, so was not used to inform this service mapping exercise.

- All memory cafes listed on www.memorycafes.org.uk. In addition, a list of 47 memory cafes in Devon created by David Light was downloaded from www.carerspathways.org.uk. We later received an updated memory cafe list (October 2014) from a contact at a memory café. This list contained details of 49 memory cafes.

- The Alzheimer's Society service directory provided information relating to services organised by the Alzheimer's Society, and so provided important data that complemented information on statutory service provision.

4.2 Service categorisation

- Service categories were chosen by the research team and based on a rapid review of a small sample of services identified during the scoping review stage. These categories were then used in the telephone interview guide as per question 2.4 (see Appendix II).

- Service categories used in the telephone survey included:
  - Befriending
  - Memory Café
  - Music Group
  - Information & Advice
  - Carer Support
  - Transport Service
  - Home Visits
  - Day Care
  - Social Activities
  - Respite Care
  - Education
  - Assessment
  - Other

- As the service mapping progressed, the 'Assessment' category was redefined into two new categories:
  - Clinical Assessment & Diagnosis
  - Other Assessment

- 'Home Visits' could be further defined as any one or more of the following functions: 'assessment', 'treatment', 'befriending' or 'personal care'. If the mapping study were to be repeated, a separate category for 'Personal Care' should be added to the database.

- The 'Other' category allowed for a free text response from the telephone survey and included the following categories:
  - Advocacy & Liaison
  - Carers Assessment
  - Cognitive Stimulation Therapy
  - Daily Living Prescriptions
  - Enabling Service
  - Equipment Loan
  - Form filling
  - Massage
  - Intergenerational Project
  - Lunch Club
  - Medical Checks
  - Medication telephone reminders
  - Needs Assessment
  - Personal Care
  - Reminiscence Group

- ➢ Short Breaks
- ➢ Sitting Service
- ➢ Social Outings
- ➢ Telephone Befriending
- ➢ Telephone Helpline
- ➢ Therapeutic Activities
- ➢ Transport to Service
- ➢ Treatment & Medication

4.3   Overview of services identified and mapped

Service were identified across Devon, Cornwall and Somerset, as planned. Figure 1 shows total services mapped by geographic location
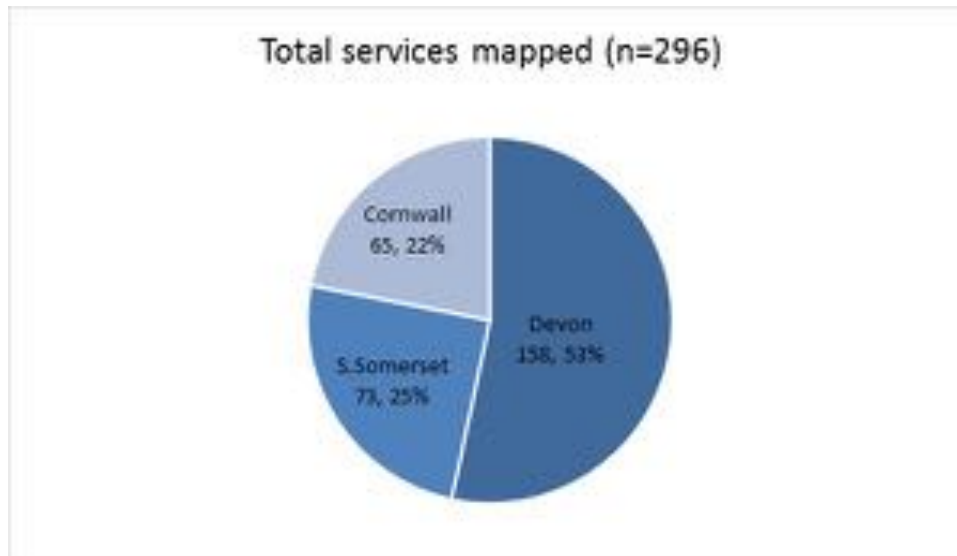

Figure 1: Total Services Mapped

- The most prevalent types of support provided by all services were:
    - ➢ **Information & Advice** (164/296; 55%)
    - ➢ **Social Activities** (161/296; 54%)
    - ➢ **Carer Support** (136/296; 46%)

- The least prevalent types of support provided by all services were:
    - ➢ **Transport** (35/296; 12%)
    - ➢ **Respite Care** (29/296; 10%)
    - ➢ **Befriending** (28/296; 9%)

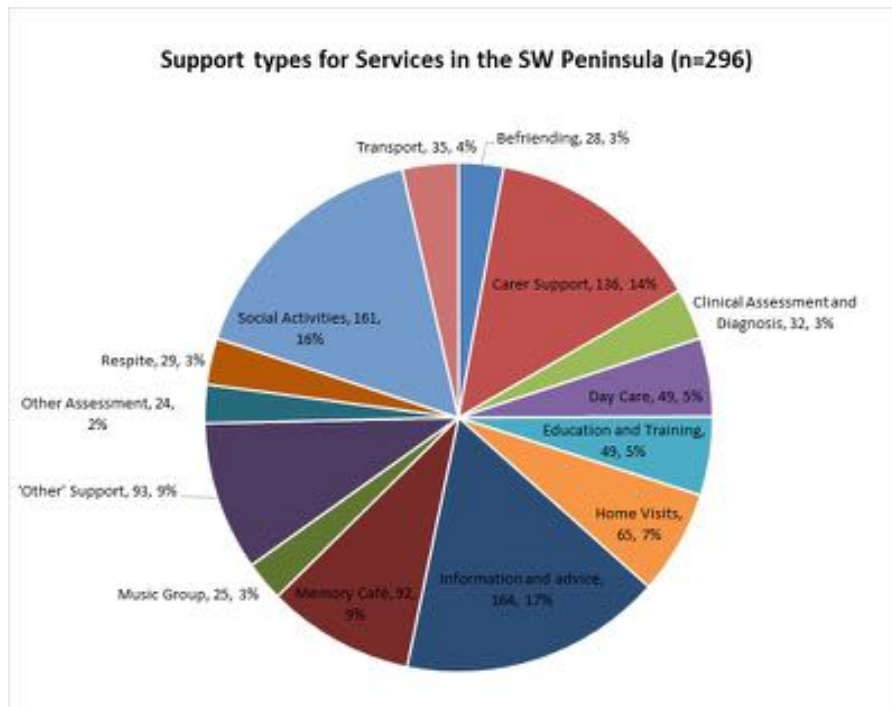**Figure 2 shows support types for services in the SW peninsula**

Figure 2: Support Services in SW Peninsula

- Descriptions of 'Other Support' provided were collected during the telephone survey interviews.
- 'Other Support' was defined as not fitting any of the pre-defined service types as listed on the telephone survey sheet (see Appendix II, 2.4)
- A total of 93 services reported that they provided other support functions; some of these services provided multiple other support functions. See Figure 3
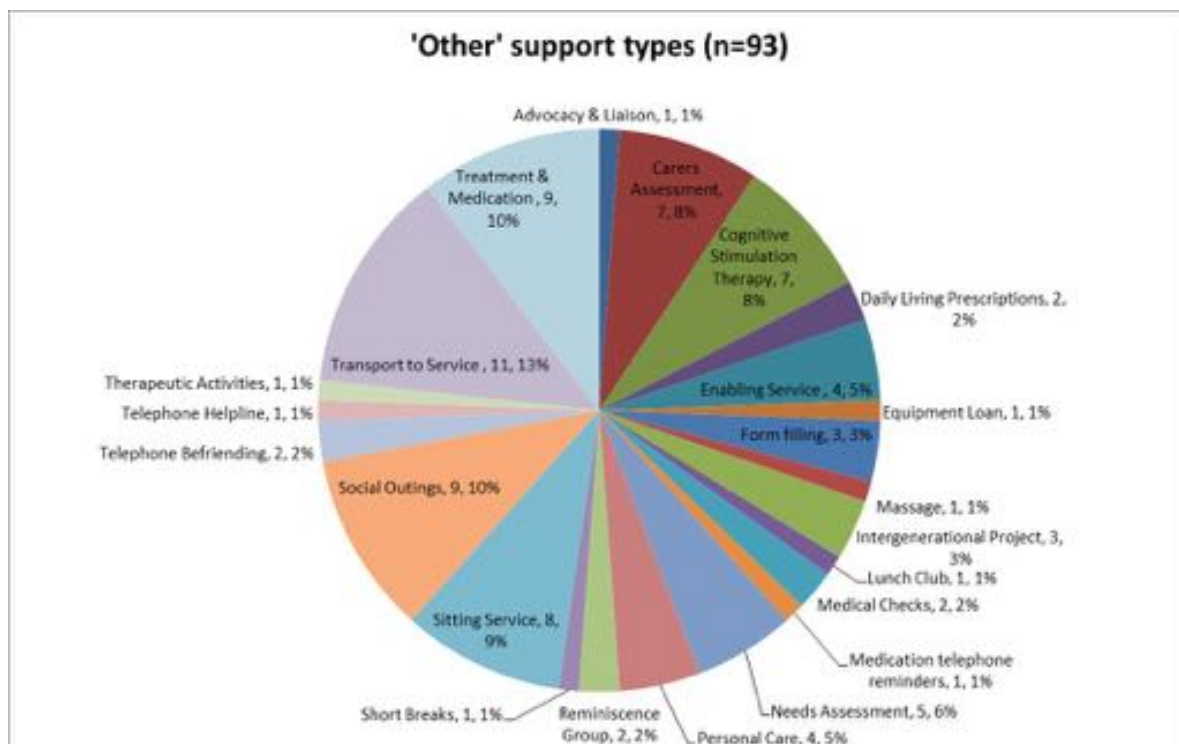

Figure 3: Other Support Services

4.4 Memory Cafes

Memory café services provide the three most prevalent functions across all 296 dementia services mapped; Information & Advice, Social Activities and Carer Support. Detailed analyses have therefore been carried out for memory cafés in section 4.4.

4.4.1 Geographic spread

- 54% (50/92) of all memory cafes mapped were in Devon
- 36% (33/92) of all memory cafes mapped were in Cornwall
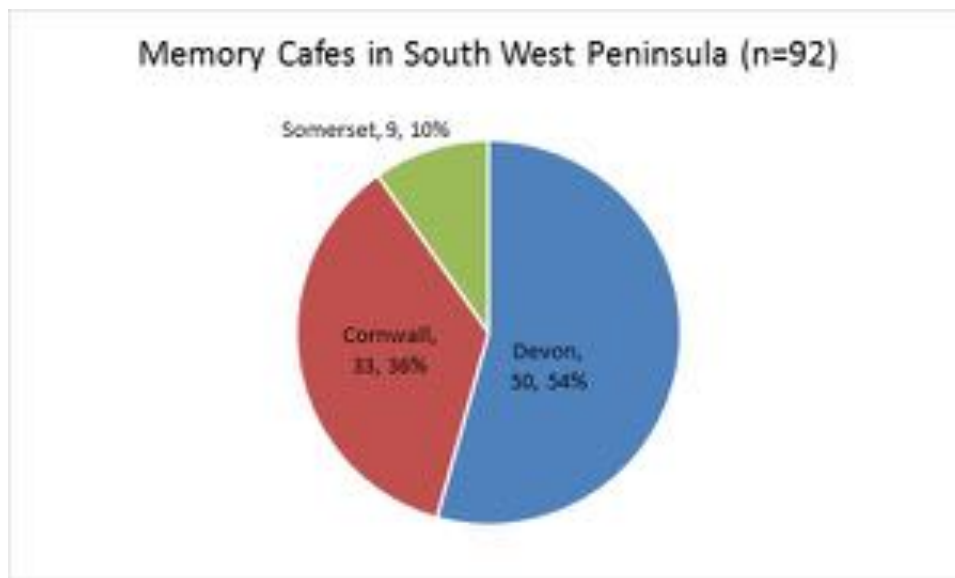- 10% (9/92) of all memory cafes mapped were in Somerset

Figure 4: Memory cafes in the South West Peninsula

4.4.2 Service functions

- The key service functions provided by all memory cafes in the South West peninsula include: Social Activities (57/92), Information & Advice (49/92) and Carer Support (43/92).
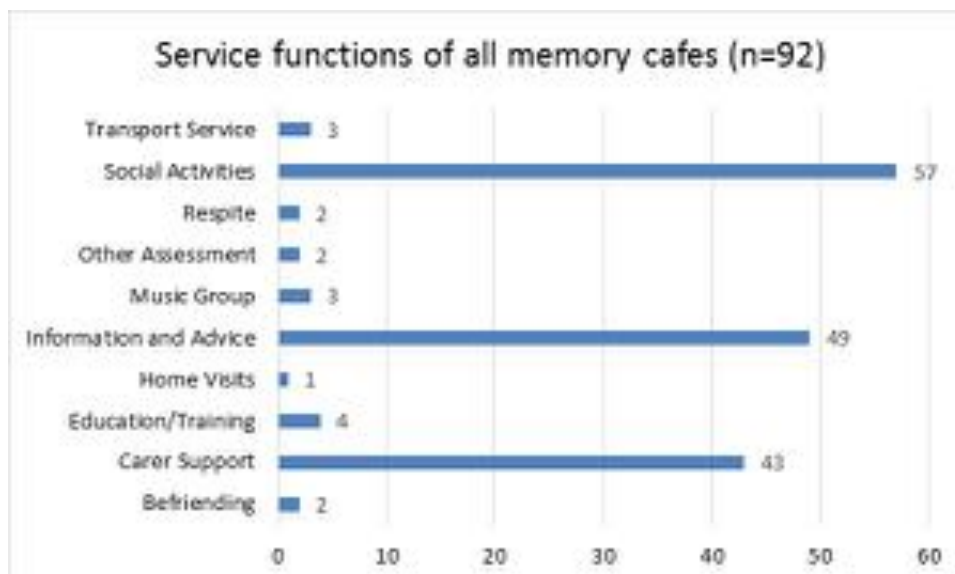

Figure 5: Service functions of all memory cafes

4.4.3 Client base

- We obtained client eligibility data from 25/92 memory cafes (see figure 6). We also gained insight about the type of clients attending memory cafes following qualitative visits to a sample of memory cafes in Devon.
- The majority of memory cafes provided support for people of all ages experiencing memory problems or early stage dementia and their carers, relatives or nominated support.
- A minority of memory cafes provided support only for people with a diagnosis of dementia.
- One memory café in Devon provided support for younger people with dementia.
- Not all memory cafes provided exclusion criteria, but of the 15 that did, 5 of these said they had to exclude people with end stage dementia and also challenging behaviour.
- Two of these memory cafes which specified exclusion criteria also said that carers needed to attend because volunteers were not trained to provide personal care.

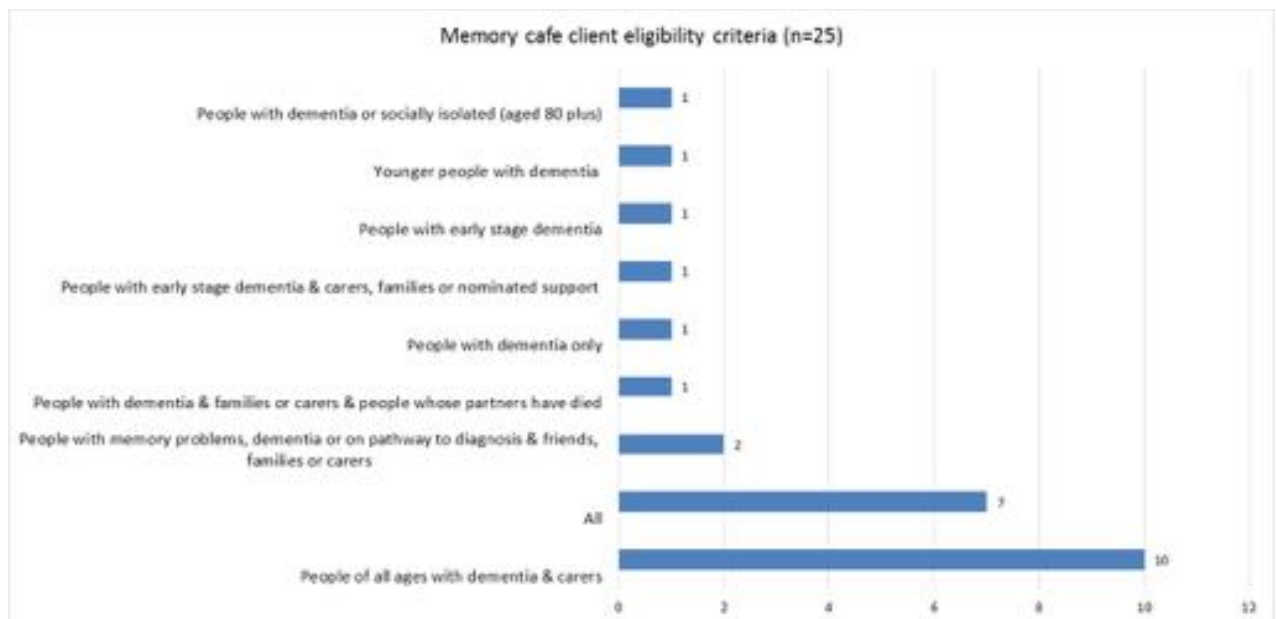**Figure 6 shows the eligibility criteria of memory café clients.**

Figure 6: Memory café client eligibility

4.4.4 Capacity and attendance numbers

- We collected maximum capacity data for 67% (62/92) of memory cafes in the SW Peninsula.
- 49 of these 62 memory cafes reported having a maximum capacity. 13 of these 62 memory cafes reported no maximum capacity.
- We collected data for estimated attendance numbers for 59% (54/92) of memory cafes. See table 1 for results.
- The average maximum capacity was 33 people per session, ranging from 10 to 70 people. **See Table 1**
- The average number of clients attending memory cafes in the SW peninsula was 17 people per session, ranging from 3 to 45 people. **See Table 1**

Memory Café - Number of Clients	Mean	Range	Median	Mode
Maximum capacity per session (n=49)	33 (SD 15)	Min 10; Max 70	30	30
Estimated attendance numbers per session (n=54)	17 (SD 11)	Min 3; Max 45	15	8

Table 1

- We collected both maximum capacity <u>and</u> estimated attendance data for 58% (53/92) of memory cafes. 40 of these 53 memory cafes reported having a maximum capacity. 13 of these 53 memory cafes reported no maximum capacity.
- Where we had good quality data on both variables (maximum capacity and estimated attendance), we were then able to infer how many places were available per session and which services were close to reaching maximum capacity. See table 2

Table 2 shows data for all memory cafes where we had data on both capacity and attendance:

Memory Café (n=40)	Maximum Capacity	Average attendance per session	Available places left per session	No. of days open per week	Total visits per month (4.33 weeks)
Babbacombe*	50	21	29	1	91
Barnstaple	50	35	15	0.25	35
Bovey Tracey (Activity Group)	10	8	2	0.25	8
Bovey Tracey	30	13	17	0.25	13
Brixham	50	9	41	1	39
Budleigh Salterton*	25	20	5	0.5	40
Camborne	30	19	11	0.25	19
Cheriton & Teign Valley	20	18	2	0.5	36
Chulmleigh	10	3	7	0.25	3
Crediton	12	10	2	0.25	10
Crownhill, Plymouth	30	15	15	0.5	30
Exeter (Alzheimer's Society)	30	13	17	0.25	13
Exeter, Heavitree*	30	12	18	1	52
Exmouth*	50	45	5	0.25	45
Ex-Service Veterans, Plymouth	30	13	17	0.5	26
Frome	30	10	20	0.25	10
Hatherleigh	20	6	14	0.25	6
Hemyock	16	9	7	0.25	9
Kingsbridge	30	5	25	0.5	10
Langport	20	8	12	1	35
Newton Abbot/ Kingsteignton	30	11	19	0.25	11
Northam	50	20	30	0.25	20
Okehampton	20	6	14	0.25	6
Ottery St Mary	20	15	5	0.25	15

Paignton*	50	19	31	1	82
Plympton, Plymouth*	30	30	0	0.5	60
Plymstock, Plymouth	30	11	19	0.5	22
Redruth	30	19	11	0.25	19
Saltash	30	13	17	0.25	13
Seaton*	50	45	5	0.25	45
Sidmouth & Sid Valley*	50	45	5	1	195
South Molton	28	21	7	0.25	21
Tavistock*	50	40	10	0.5	80
Teignmouth	32	15	17	0.25	15
Teignmouth Old Java Cafe	10	7	3	1	30
Tiverton	12	8	4	0.5	16
Topsham	12	10	2	0.25	10
Totnes*	70	45	25	0.25	45
Winkleigh	22	12	10	0.25	12
Yelverton	40	20	20	0.5	40

Table 2, * donates the most frequently attended memory cafes

- The majority (88%) of memory cafés opened for 2 hours.
- 4% open for 1.5 hours; 1% open for 1.75 hours; 6% unknown
- 47% (43/92) of memory cafes operated on a fortnightly basis.
- 43% (40/92) operated on a monthly basis.
- 8% (7/92) operated on a weekly basis.
- 2% (2/92) operated on a twice weekly basis.
- Weekly and twice-weekly memory cafes were located in the following towns:
  - Babbacombe, Devon
  - Brixham, Devon
  - Crediton, Devon
  - Exeter, Devon
  - Langport, Somerset
  - Paignton, Devon
  - Sidmouth & Sid Valley, Devon
  - St Mary's, Isles of Scilly
  - Teignmouth, Devon

- From the sample of most frequented memory cafes, **Plympton**, **Budleigh Salterton**, **Exmouth**, **Seaton** and **Sidmouth & Sid Valley** are at capacity or close to reaching their maximum capacity. All 5 memory cafes were included in our qualitative research sample.
- According to our data, the **Sidmouth & Sid Valley Memory Café** appears to be the most accessed and close to capacity memory café across the South West peninsula with an average of 195 visits per month compared to an average of 32 visits per month.
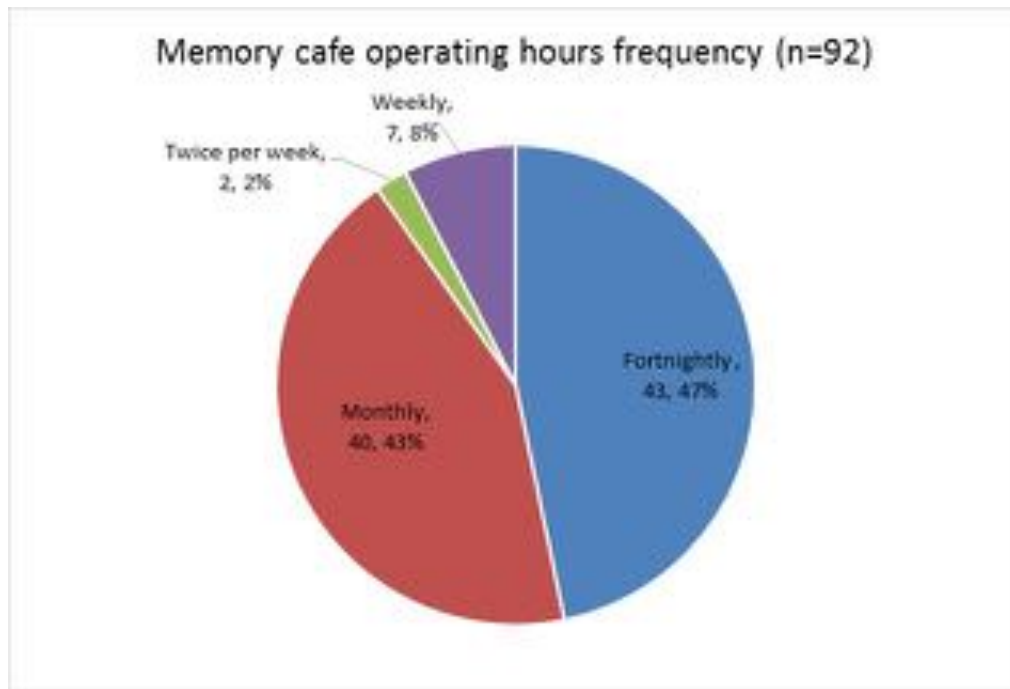- **Figure 7 shows all memory café operating hours frequency**

Figure 7: Memory café operating hours frequency

4.4.5   Other observations
- There appeared to be no standard service model for memory cafes apart from the length of session time.
- Some memory cafes reported that they provide a structured session with activities and speakers whilst others provide an informal social interaction session.
- Alzheimer's Society have recently changed the name of a number of their memory cafes to 'Activity Group' or 'Activity Café'.
- Some people will attend more than one memory café, for example Honiton and Seaton.

4.4.6   Outcome measurements
- 34% (31/92) of memory cafes reported that they collected outcome measurements.
- 28% (26/92) of memory cafes reported that they did not collect outcome measurements.
- 38% (35/92) of memory cafes were not asked whether they collected outcome measurements.
- Types of outcome measurements collected included:
  - ➢ Carer activity data
  - ➢ Edinburgh Warwick Mental Wellbeing Scale
  - ➢ Friendship scale questionnaires
  - ➢ Record of interaction
  - ➢ Satisfaction questionnaires
  - ➢ Service user evaluation questionnaires
  - ➢ Wellbeing questionnaires

4.4.7 Snowballed services

- 120 additional services were identified across the South West peninsula through the snowball sampling approach but not mapped due to time constraints. By the end of the project, a total of 416 services were identified (i.e. from directories and snowballed services). **See figure 8**

- Snowball sampling added value to the dataset since this service information was not easily accessible using existing online data sources. This has important implications for health & social care professionals whose role includes signposting people for post-diagnostic support.

- Many of our mapped services sample (n=296) were also identified through the snowball technique.

- The majority of unmapped snowball services were identified late in the project, for example during the data entry stage of telephone interviews and during the final qualitative research stage.

- The area within the SW Peninsula that included the largest number of snowballed services within the mapped sample and was closest to reaching saturation point was the East Devon local authority area.
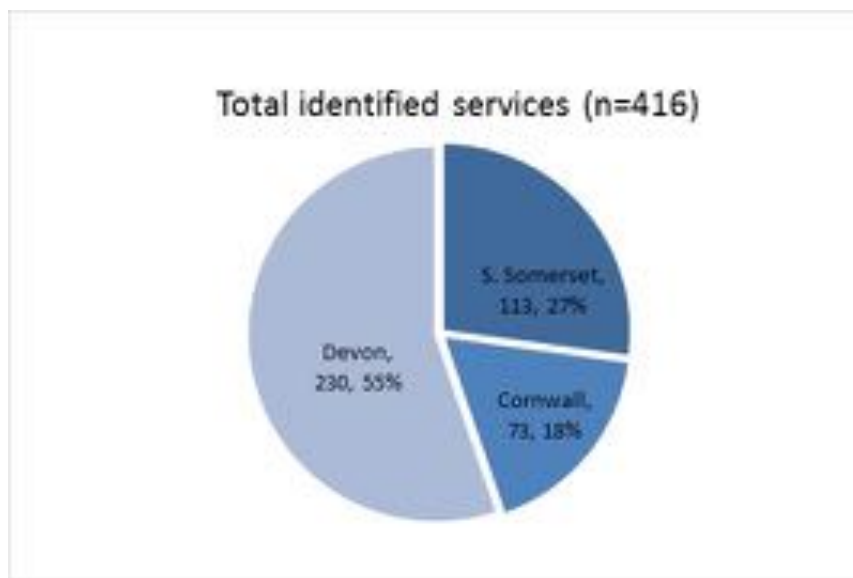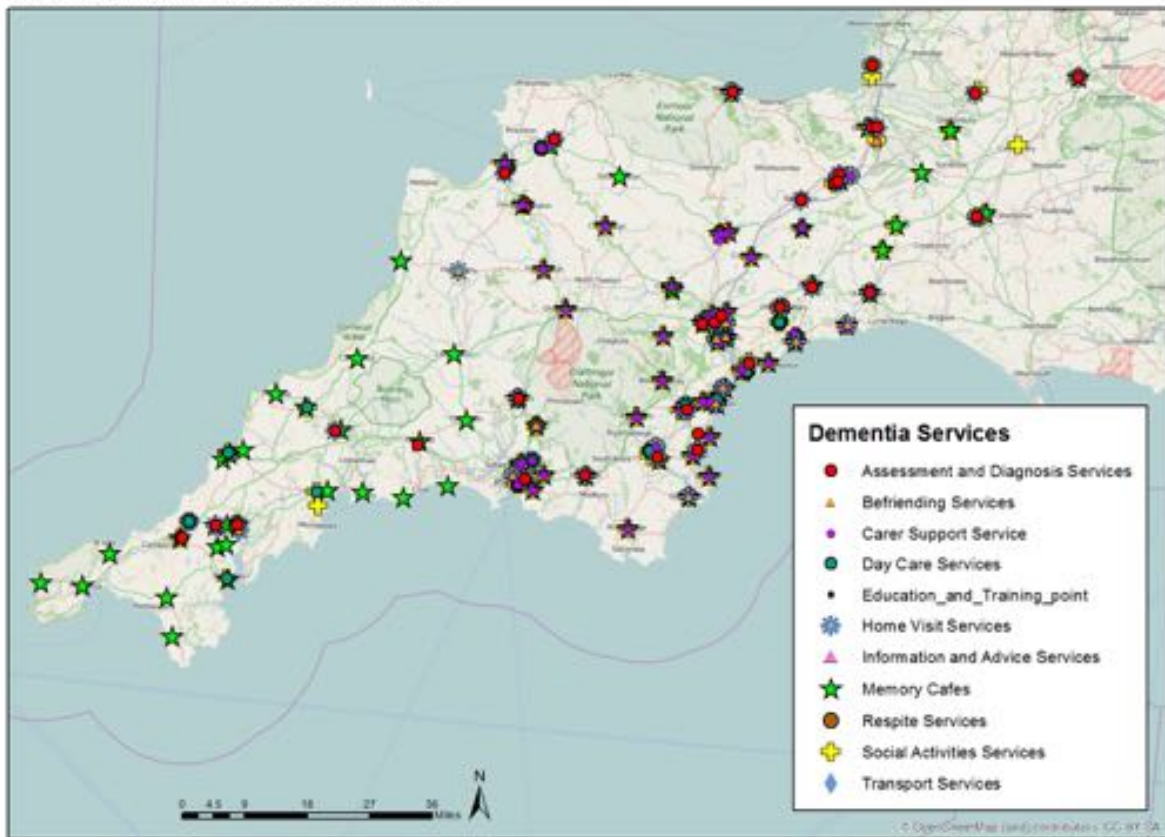

Figure 8: Total identified services

The Following maps show where the dementia services we identified are.

Dementia Mapping Project
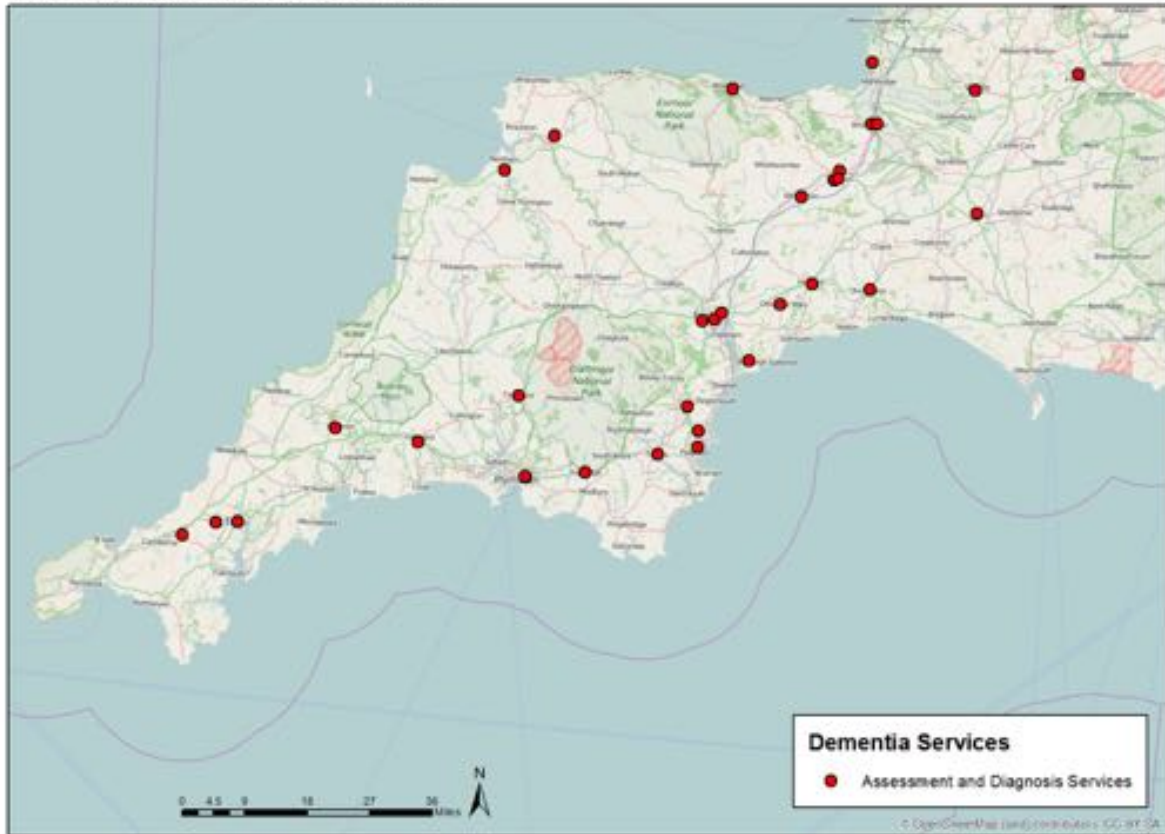Prof Chris Dickens, Tobit Emmens, Sarah Ross, Dr Sarah Robens

Map 1: All Services

It is clear from this map that, on the whole, there is reasonable geographical coverage of all services across the Peninsula. It is clear that most services cluster around the more densely populated areas, especially Exeter, Plymouth and the South coast of Devon.

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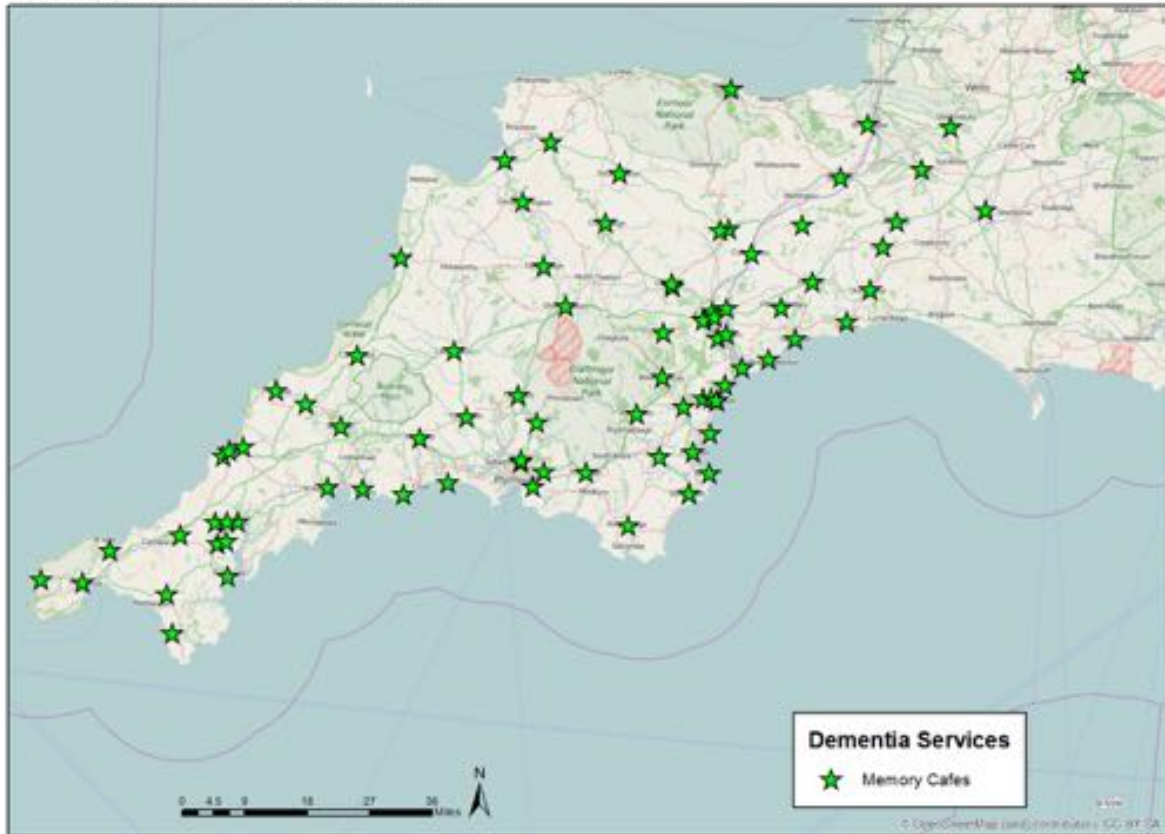**Dementia Services**
● Assessment and Diagnosis Services

Map 2: Assessment Services

Map 2 show where the assessment and diagnostic services we identified are. This map shows large areas of the South West Peninsula where there are no assessment and diagnostic services, however, we recognise that NHS Diagnostic services are often co-located with Acute hospitals.

Dementia Mapping Project
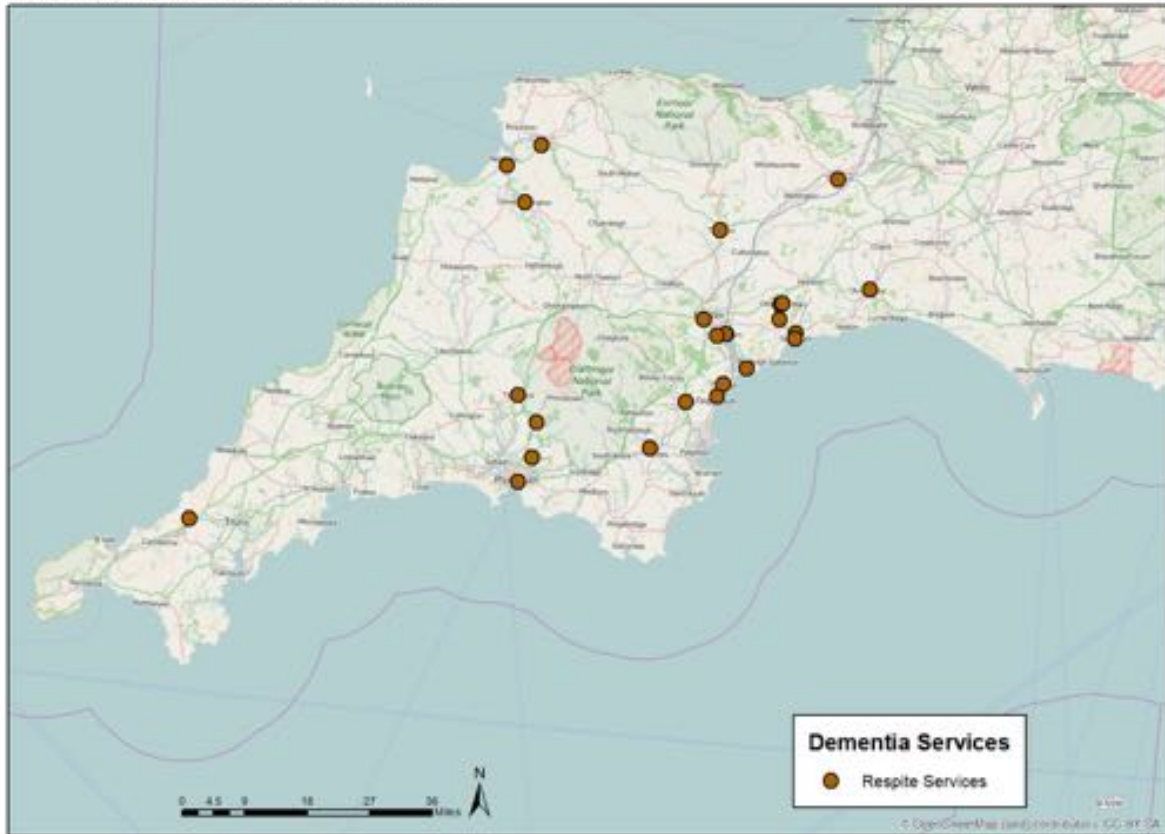Prof Chris Dickens, Tobit Emmens, Sarah Ross, Dr Sarah Robens

Map 3: Memory Cafes

It is clear from map 3 that throughout Devon, Cornwall and Somerset, with the exception of North West Devon and North Somerset that there is widespread provision of memory cafes. However, we noted from the results in section 4.4.4 and figure 7 that only 10% of these are open weekly, 47% are open fortnightly, and 43% are only open once a month.
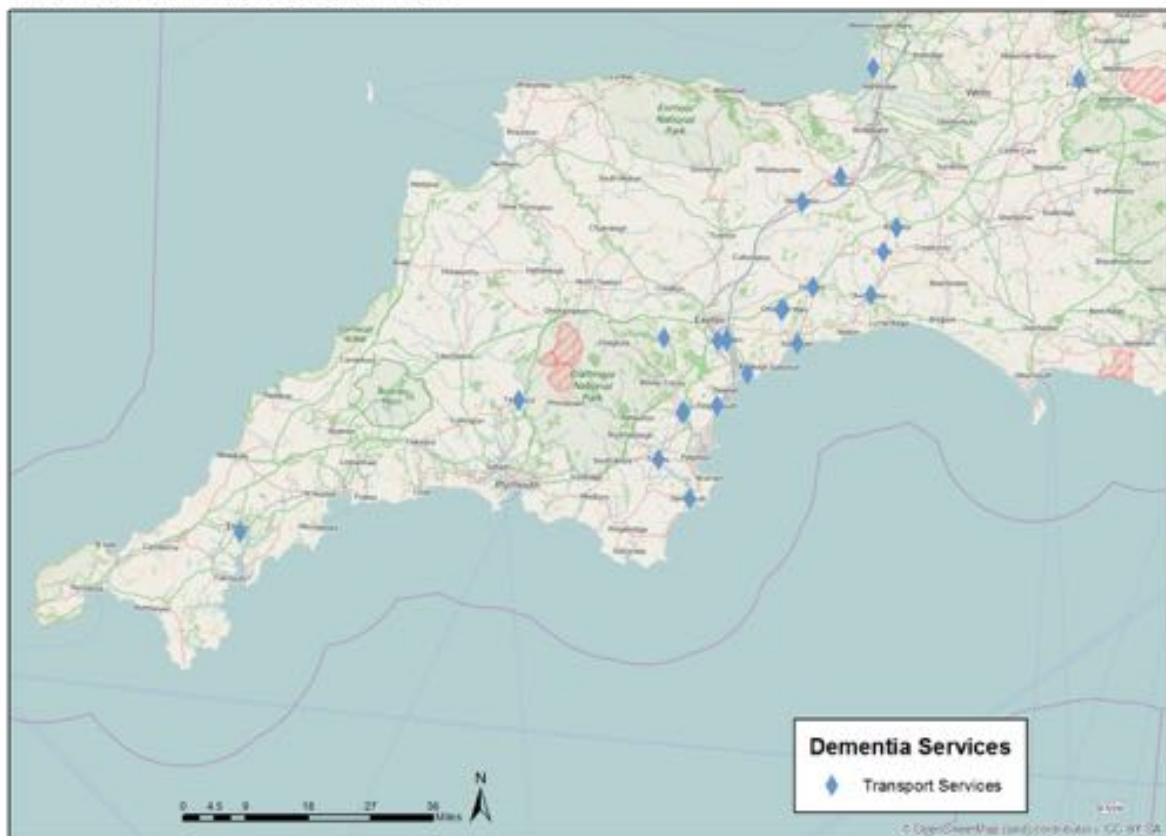
Map 4: Respite Services

Map 4 illustrates that the respite services we were able to identify and map are limited to the East Devon Coast and South Devon. Our data would indicate that respite services in Cornwall are restricted to a single provider in Redruth and in Somerset, a single service in Taunton. It may be that other services exist, however, these were not easily identifiable.

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Map 5: Transport Services

Similarly to respite services, it is clear that the majority of those easily identifiable transport services appear to be geographically limited to South Devon.

4.5 Services in Devon

4.5.1 Service Mapping

- Sources of information used for identifying services in Devon were:
  - ➢ Devon County Council Community Directory
  - ➢ Dementia Roadmap website
  - ➢ Alzheimer's Society website
  - ➢ www.memorycafes.org.uk
  - ➢ Dementia Care Devon website

- A total of 158 services were mapped across Devon.

- 73 additional services were identified by the snowball sampling approach in the later stages of the project and were not mapped due to time constraints (20 of these snowball services were identified during the qualitative stage). These services included domiciliary care services, carer support, befriending groups, day care services, luncheon clubs, peer support groups, voluntary car services and a memory pub.

4.5.2 Funding

- 39 services in Devon reported that they received funding from more than one source.
  - ➢ 60% (95/158) of services receive Third Sector funding
  - ➢ 60% (95/158) of services receive Statutory Sector funding
  - ➢ 14% (22/158) of services receive Private Sector funding
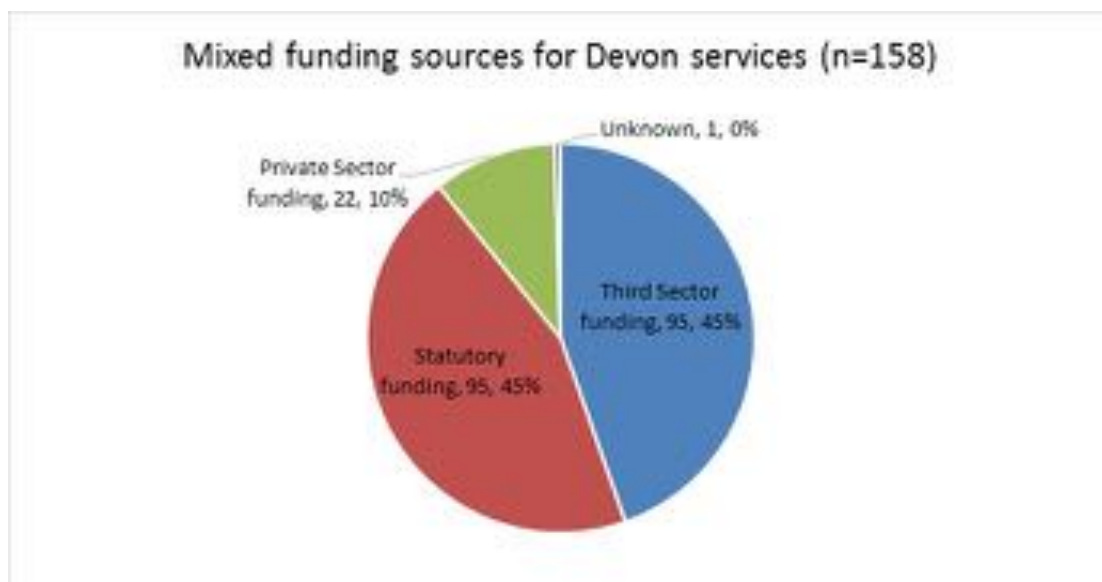 - ➢ 1% (2/158) of services funding stream is unknown

Figure 9: Funding sources for services in Devon

- 48% (24/50) of **memory cafes** in Devon reported that they received income from fundraising activity only, for example from the following revenue streams:
  - ➢ Donations – business and private
  - ➢ Charity grant applications

- Legacies
- Rotary Club
- Raffles
- Sponsorships

- 40% (20/50) of memory cafes in Devon received funding from a combination of voluntary income and statutory funding.

4.5.3 Type of support provided

- Most prevalent types of support provided by services in Devon were:
  - **Information & Advice** (19%)
  - **Social Activities** (19%)
  - **Carer Support** (17%)

- Types of support that appear to be lacking include:
  - Respite Care (5%)
  - Education/ Training (4%)
  - Day Care (3%)
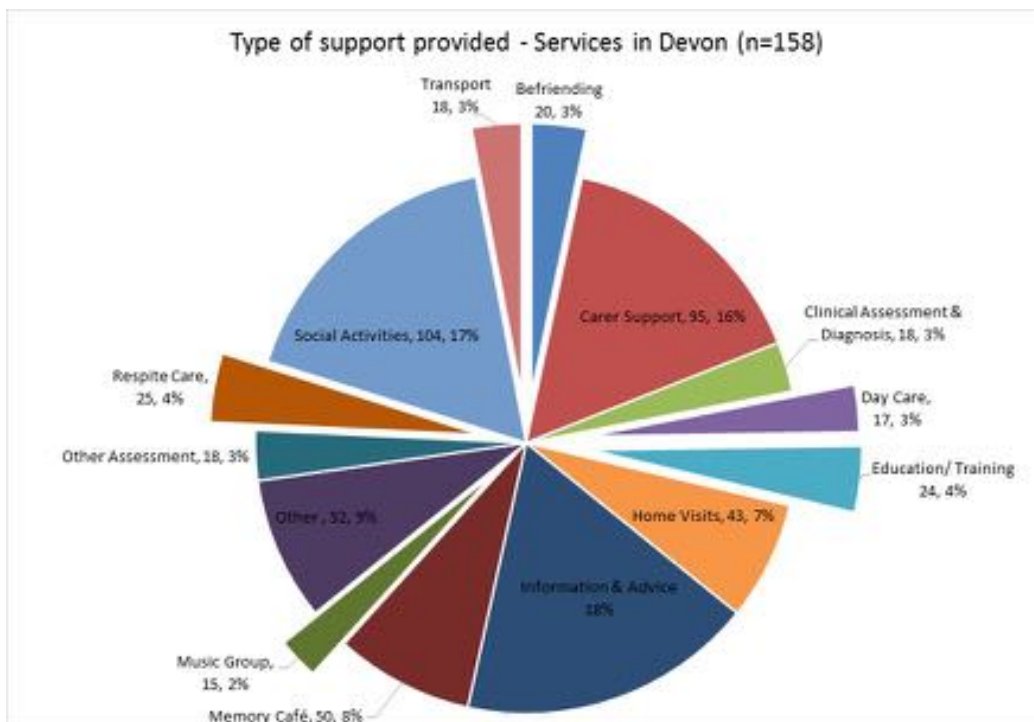 - Transport (3%)
  - Music Group (3%)

Figure 10: Type of support provided by services in Devon

4.5.4 Functions of Services in Devon

- 70% (110/158) of services were defined as dementia specific.

- 30% (48/158) of services were defined as generic (usually aimed at older people).

- Memory Cafés were defined as having a primary function of either social interaction (n=48) or activity group (n=2). We learnt during the qualitative analysis that many people attend memory cafes for peer support which could be a secondary function of memory cafes.
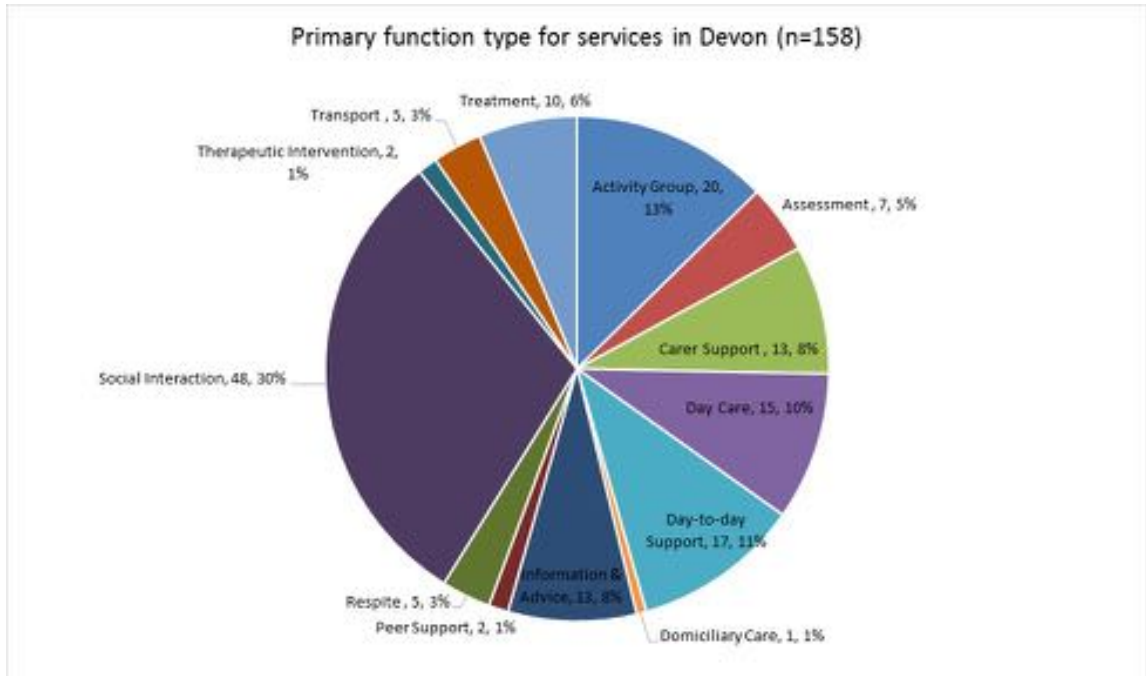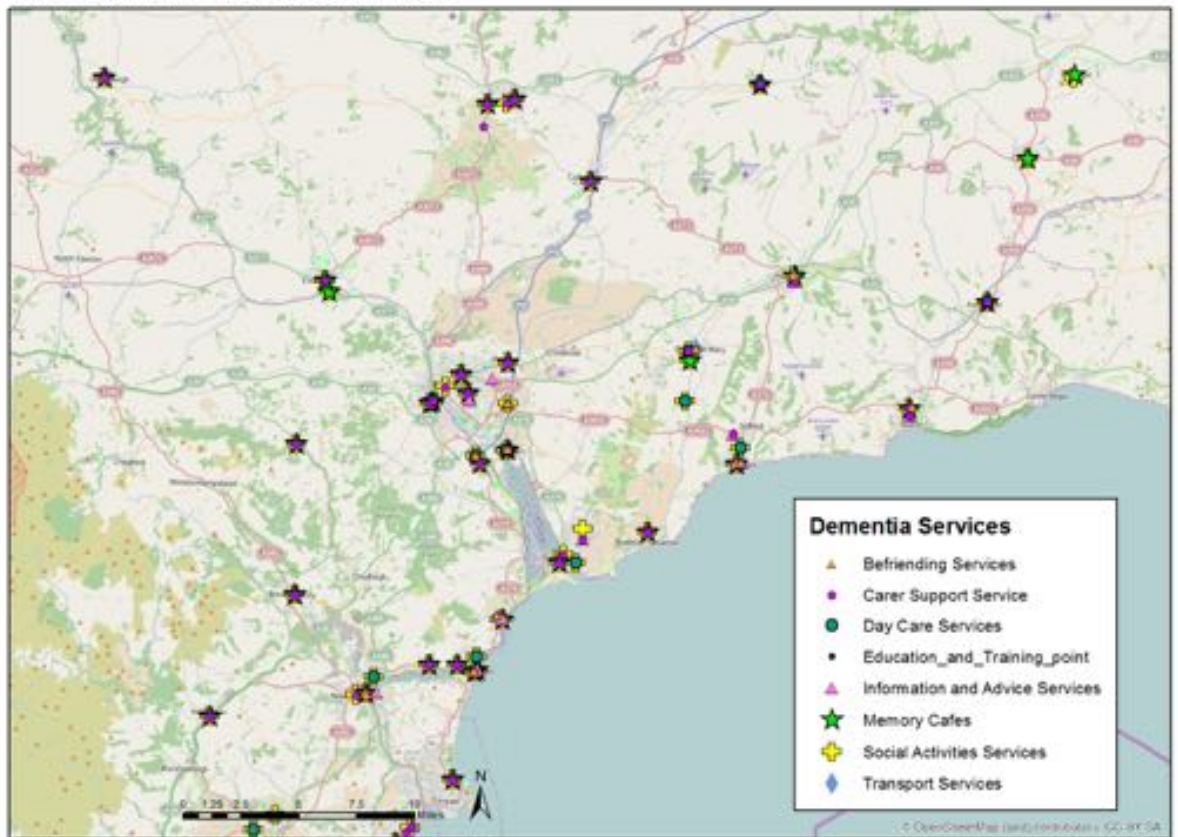

Figure 11: Primary function type for services in Devon

- The most prevalent primary function type of services in Devon were:
    - ➤ **Social Interaction** (48/158; 30%)
    - ➤ **Activity Group** (20/158; 13%)
    - ➤ **Day-to-day Support** (17/158; 11%)

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Map 6: Devon (Exeter and East) Services

4.6 Services in Somerset

4.6.1 Service Mapping
- Sources of information used for identifying services in Somerset were:
  - ➢ Somerset County Council website
  - ➢ Somerset Care website
  - ➢ Alzheimer's Society website
  - ➢ Compass Carers website

- A total of 73 services were mapped across Somerset.

- 42 additional services were identified by the snowball sampling approach but not mapped due to time constraints. These services included day care services, activity groups as well as information & advice services and specialist nursing services

4.6.2 Funding
- One service in Somerset reported that they received funding from more than one source.
  - ➢ 29% (21/73) of services receive Third Sector funding
  - ➢ 59% (43/73) of services receive Statutory Sector funding
  - ➢ 8% (6/73) of services receive Private Sector funding
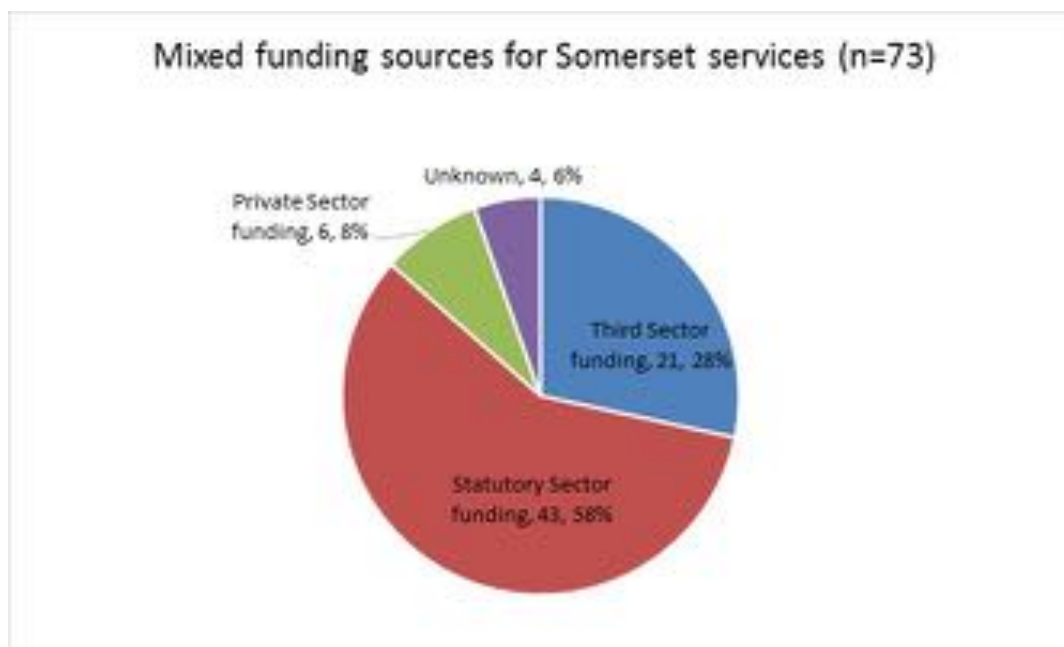 - ➢ 5%(4/73) of services funding stream is unknown

Figure 12: Funding sources for services in Somerset

4.6.3 Type of support provided
- Most prevalent types of support provided by services in Somerset were:
  - ➢ **Information & Advice** (19%)
  - ➢ **Social Activities** (16%)
  - ➢ **Carer Support** (11%)

- Types of support that appear to be lacking include:
  - Memory Café (4%)
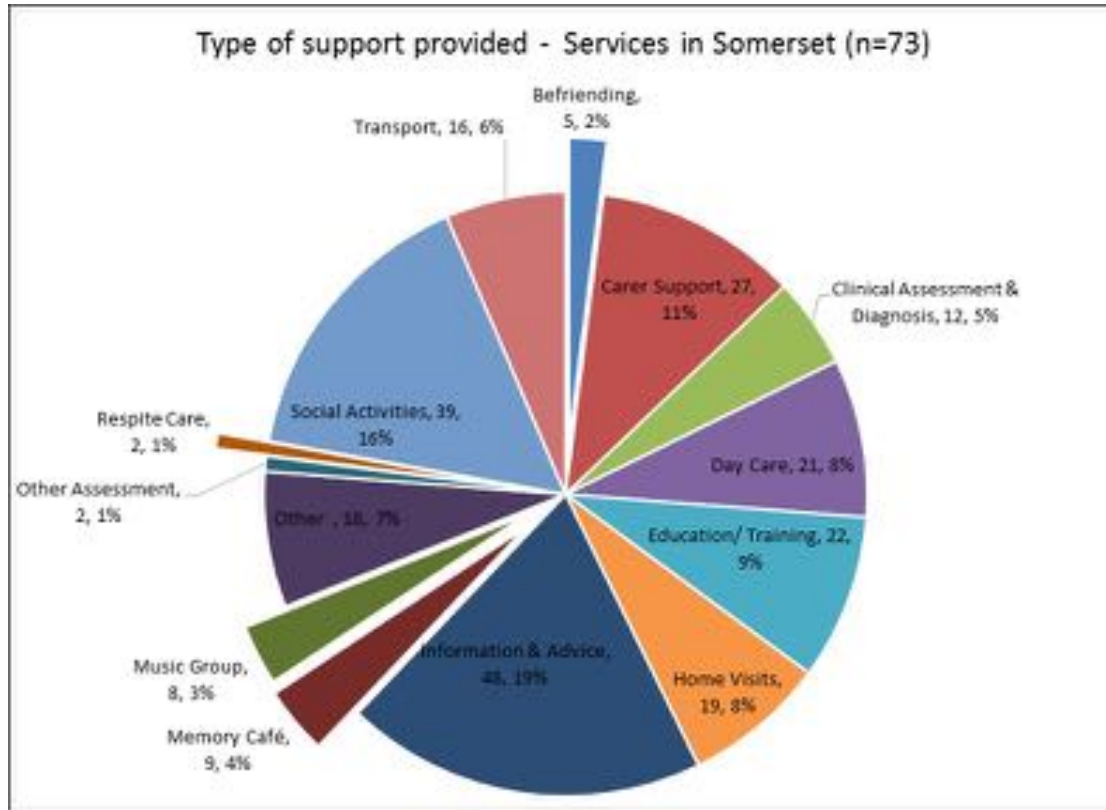 - Music Group (3%)
  - Befriending (2%)
  - Respite Care (1%)

Figure 13: Type of support provided by services in Somerset

4.6.4 Functions of Services in Somerset
- 49% (36/73) of services were defined as dementia specific.
- 51% (37/73) of services not defined as either dementia specific or generic due to insufficient data.
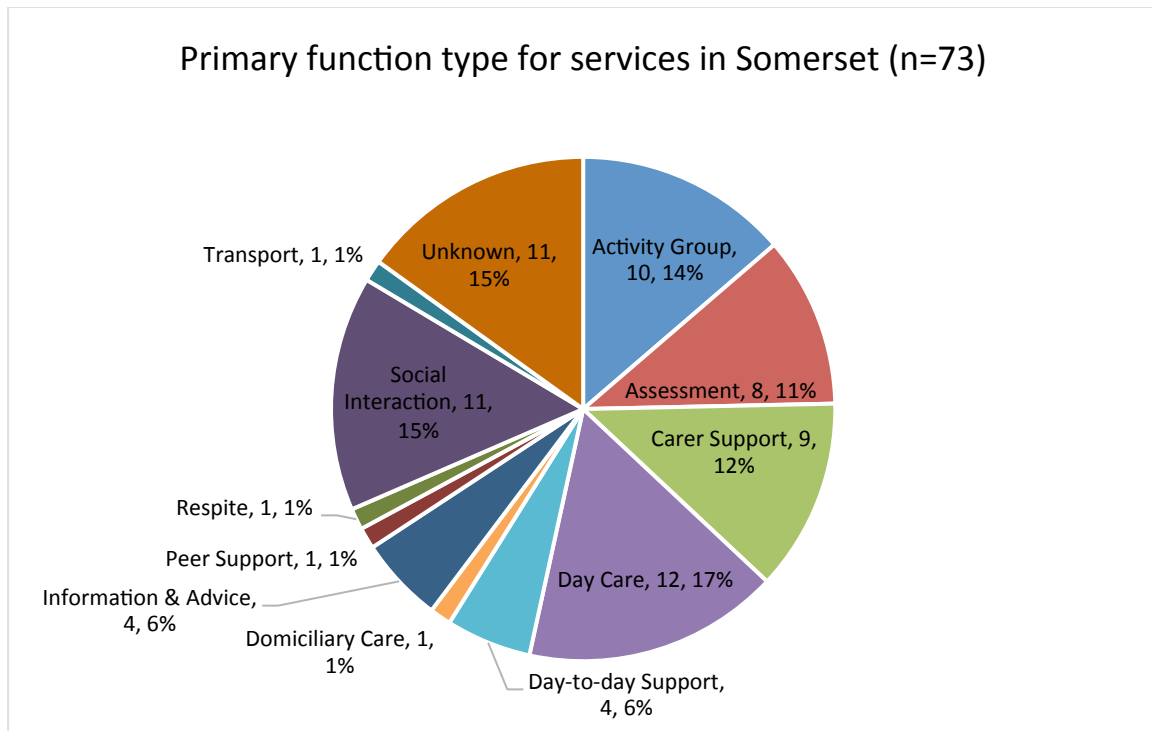
Primary function type for services in Somerset (n=73)

- Activity Group, 10, 14%
- Assessment, 8, 11%
- Carer Support, 9, 12%
- Day Care, 12, 17%
- Day-to-day Support, 4, 6%
- Domiciliary Care, 1, 1%
- Information & Advice, 4, 6%
- Peer Support, 1, 1%
- Respite, 1, 1%
- Social Interaction, 11, 15%
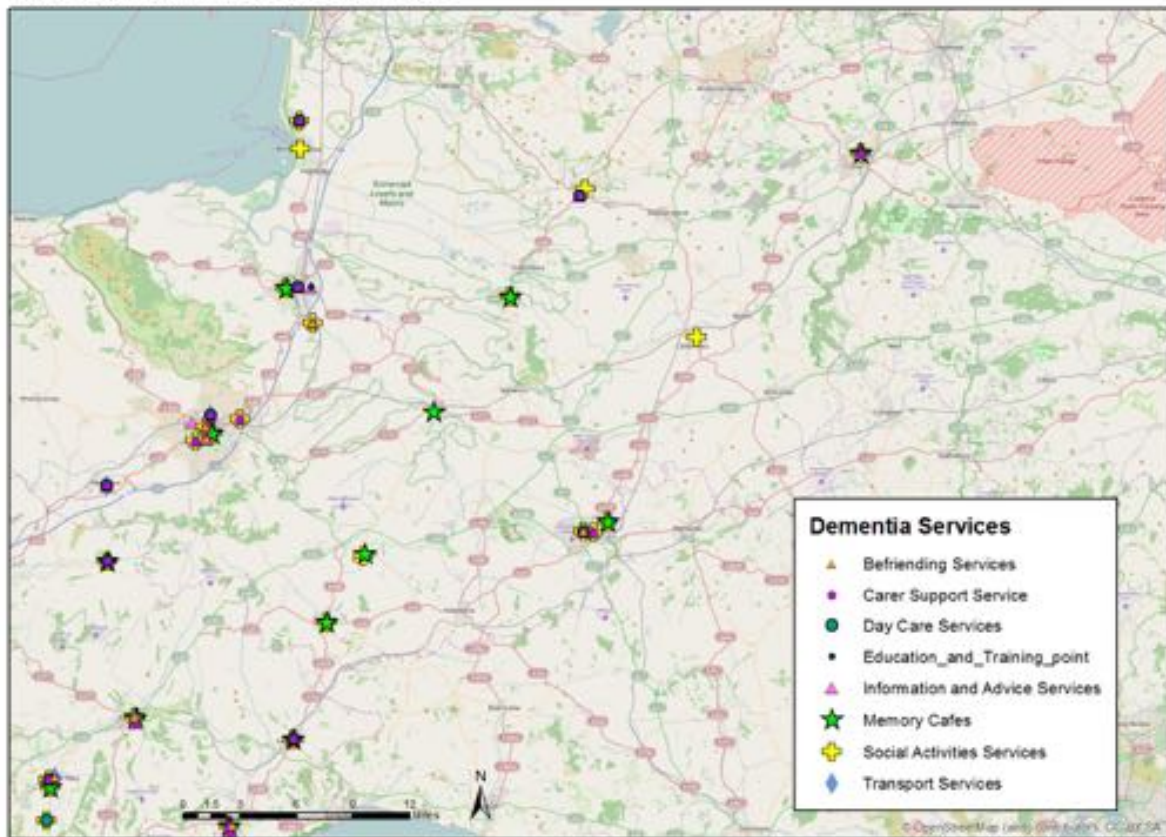- Transport, 1, 1%
- Unknown, 11, 15%

Figure 14: Primary function type for services in Somerset

- The most prevalent primary function type of services in Somerset were:
  - ➢ **Day Care** (12/73; 16%)
  - ➢ **Social Interaction** (11/73; 15%)
  - ➢ **Activity Group** (14%)

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Map 7: Somerset Services

4.7   Services in Cornwall

4.7.1   Service Mapping

- Sources of information used for identifying services in Cornwall were:
  - ➢ Cornwall County Council website
  - ➢ Alzheimer's Society website

- A total of 65 services were mapped across Cornwall

- 8 additional services were identified by the snowball sampling approach but not mapped due to time constraints. These services included: befriending groups, mental health support, church groups, carer support and telecare services.

4.7.2   Funding

Three services in Cornwall reported that they received funding from more than one source.

- ➢ 9% (6/65) of services receive Third Sector funding
- ➢ 12% (8/65) of services receive Statutory Sector funding
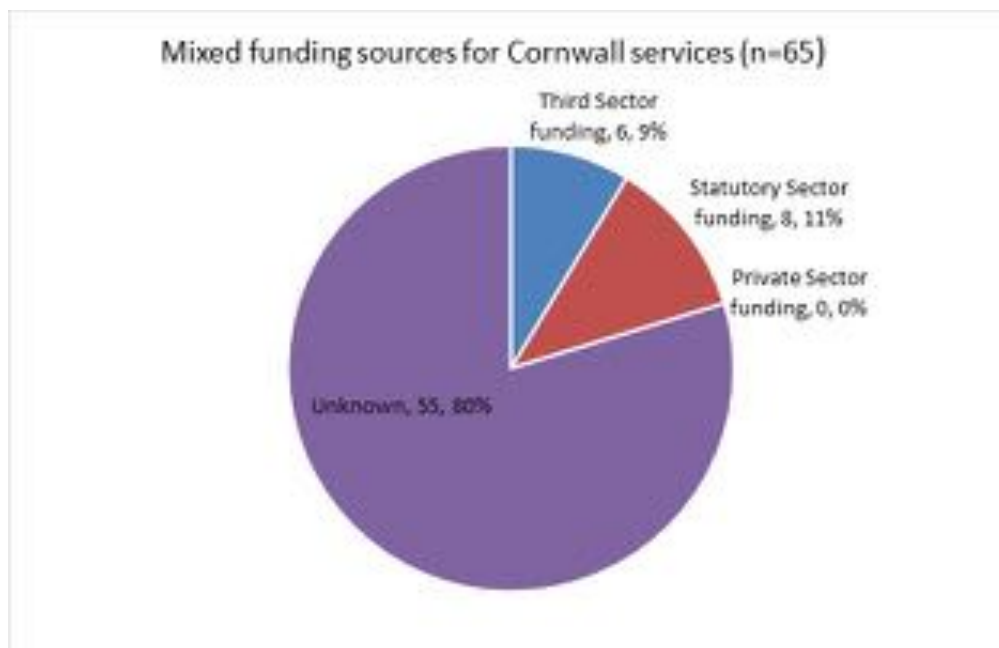- ➢ 85% (55/65) of services funding stream is unknown

Figure 15: Funding sources for services in Cornwall

4.7.3   Type of support provided

- Most prevalent types of support provided by services in Cornwall were:
  - ➢ **Memory Cafe** (29%)
  - ➢ **Social Activities** (16%)
  - ➢ **Carer Support** (12%)

- Types of support that appear to be lacking include:
  - ➢ Clinical Assessment & Diagnosis (3%)
  - ➢ Befriending (2%)

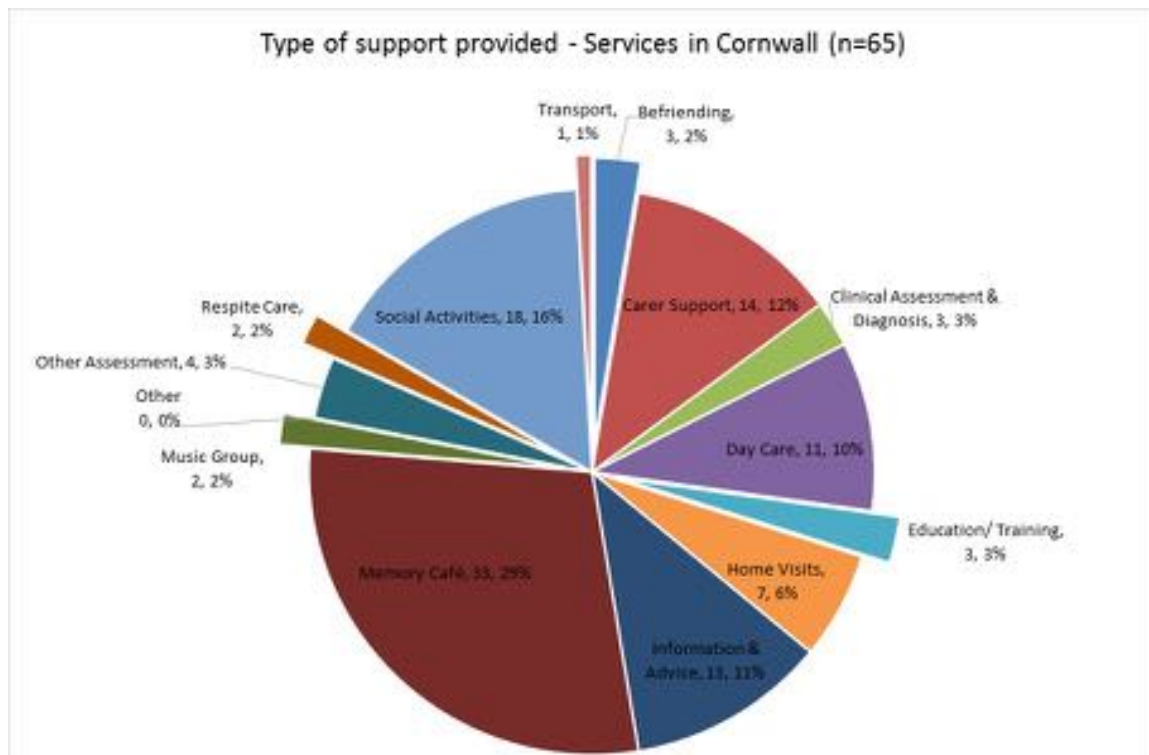➢ Education/ Training (3%)
➢ Music Group (2%)
➢ Transport (1%)

Figure 16: Type of support provided by services in Cornwall

4.7.4 Functions of Services in Cornwall
- 72% (47/65) of services were defined as dementia specific.
- 28% (18/65) of services not defined as either dementia specific or generic due to insufficient data
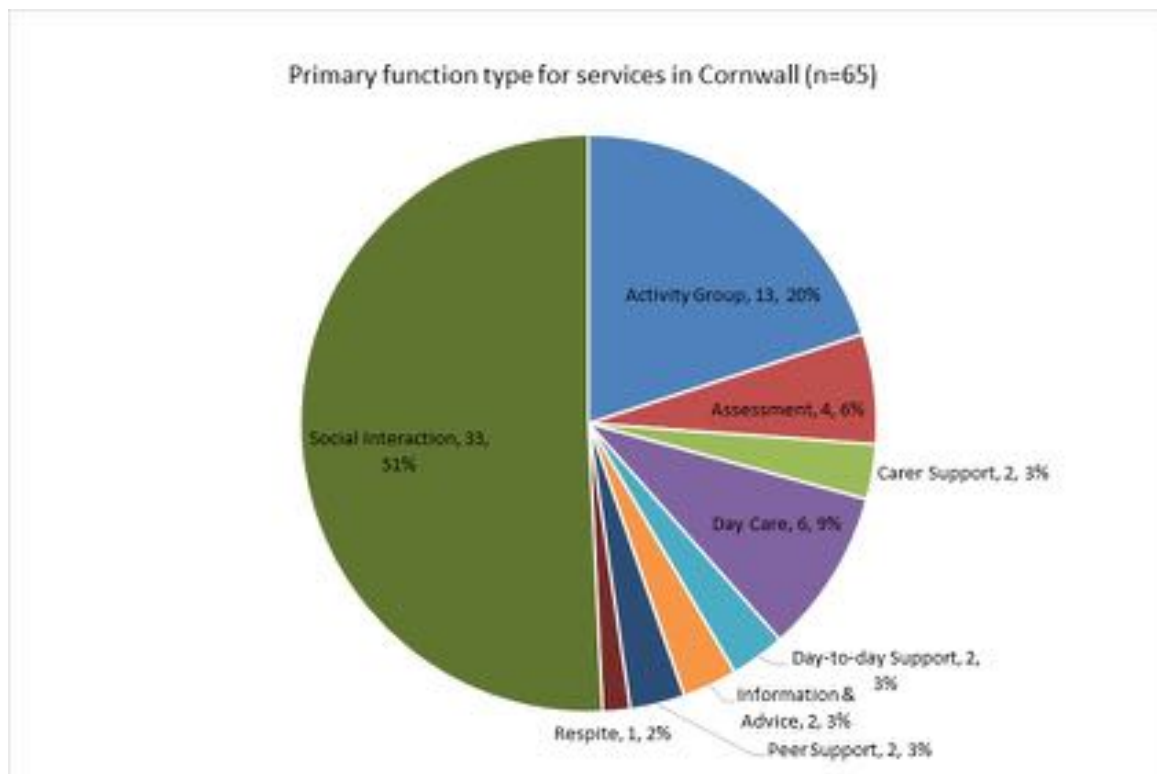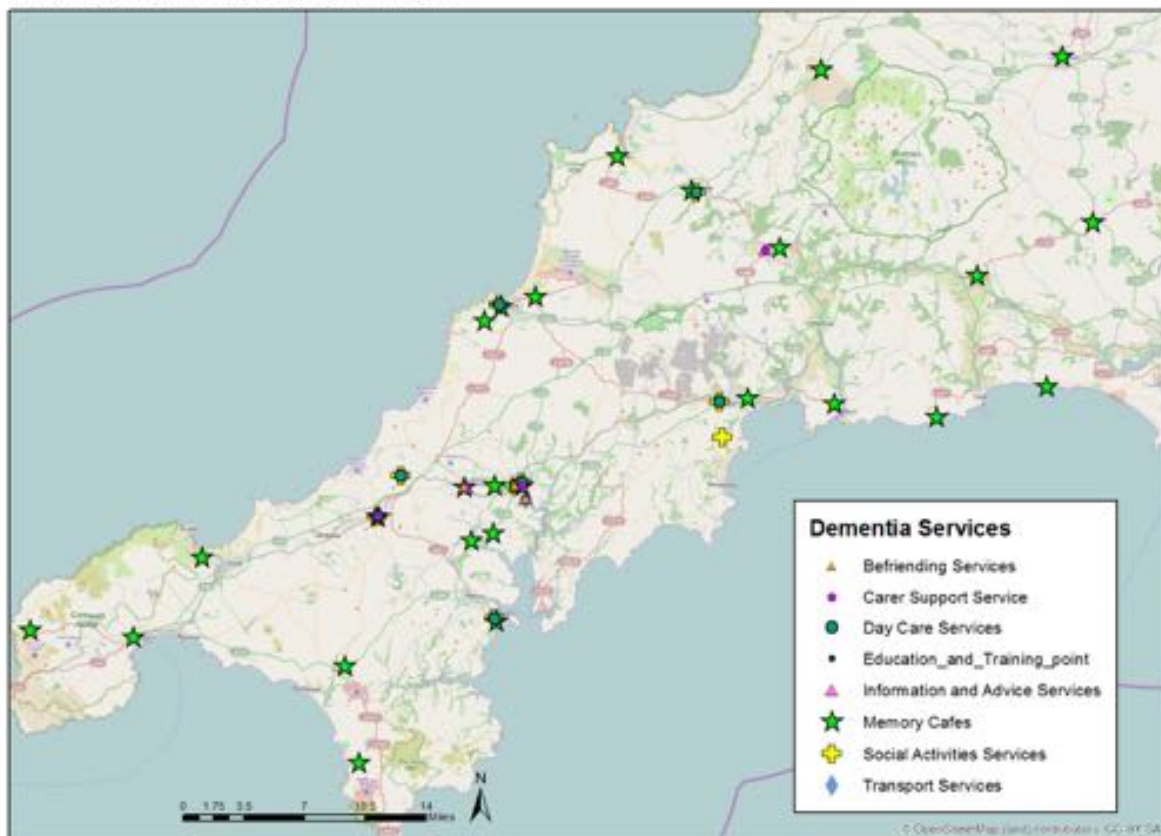
Figure 17: Primary function type for services in Cornwall

- The most prevalent primary function type of services in Cornwall were:
  - ➢ **Social Interaction** (33/65; 51%)
  - ➢ **Activity Group** (13/65; 20%)
  - ➢ **Day Care** (6/65; 9%)

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Dementia Services

▲ Befriending Services
• Carer Support Service
● Day Care Services
• Education_and_Training_point
▲ Information and Advice Services
★ Memory Cafes
✚ Social Activities Services
◆ Transport Services

Map 8: Cornwall Services

4.8 Key Observations

__Sources of information__

- Local Authority community service directories were generally the most useful sources of information for health and social care service information, however these directories were not always kept up to date.

- One of the most reliable online directories as a source of information was the website www.memorycafes.org.uk which includes a useful function for services to register and amend their own listings.

__Service overview__

- 53% of services were mapped in Devon, 25% in Somerset and 22% in Cornwall.

- The most prevalent types of support provided by services across the SW peninsula were: **Information & Advice; Social Activities** and **Carer Support.**

- The least prevalent types of support provided by services across the SW peninsula were: **Transport; Respite Care** and **Befriending.**

__Memory cafes__

- 92 memory cafes were mapped across the SW peninsula. 54% of memory cafes were located in Devon, 36% in Cornwall and 10% in Somerset.

- Key service functions provided by memory cafes were: **Social Activities, Information & Advice** and **Carer Support**.

- A minority of memory cafes also provided support for socially isolated older people who didn't experience any memory problems.

- Several memory cafes excluded people with end stage dementia or challenging behaviour.

- The average maximum capacity for memory cafes across the SW peninsula was 33 people per session and capacity ranged from 10 to 70 people.

- The average number of people attending memory cafes across the SW peninsula was **17 people per session** and ranged from 3 to 45 people.

- Types of service support that are less prevalent in Devon are: Respite Care, Education, Day Care, Transport and Music Groups.

- Types of service support that are less prevalent in Somerset are: Memory Café, Music Group, Befriending and Respite Care.

- Types of service support that appear to be less prevalent in Cornwall are: Clinical Assessment, Befriending, Education, Music Group and Transport.

DATA download links

MAPS download links

5 Results - Qualitative Research (Aim 2)

5.1 Sample & Setting

- A purposive approach was taken for the sampling of the sites for the qualitative work. During the survey work, café's were asked if they would be happy for someone to visit to carry out interviews, and the initial sample of 12 were those sites who agreed to this in East Devon and who had a café taking place within the timeframe available. Some sites had additional activities taking place at which interviewing would not be suitable, and they were not included. Two visits were unsuccessful because the interviewer was given the wrong time and place for the café. Due to time and resource constraints, replacements could not be found.
- 1/12 memory cafes declined a visit due to the service already being involved in similar research.
- 2/12 visits to memory cafes were unsuccessful due to incorrect information provided during the mapping process. For example, incorrect opening times and an out of date venue address.
- 9 memory cafes were visited and 47 stakeholder interviews took place.
- 1 specialist dementia assessment and day centre was also visited.
- The most prevalent group of interviewees at the memory cafes were the female carers of a husband or partner with dementia (14/47; 30%)
- In contrast, we interviewed only 1/47 (2%) of men with the caring responsibility for their wife.
- We interviewed 4 adult children (2 men; 2 women) with some caring responsibility for their parent with dementia.
- 7/47 (15%) of people we interviewed were men with early stage dementia and who were able to participate in the interviews. 1/47 (2%) of women in our interview sample with early stage dementia.
- Figure 18 shows which type of stakeholder were interviewed.

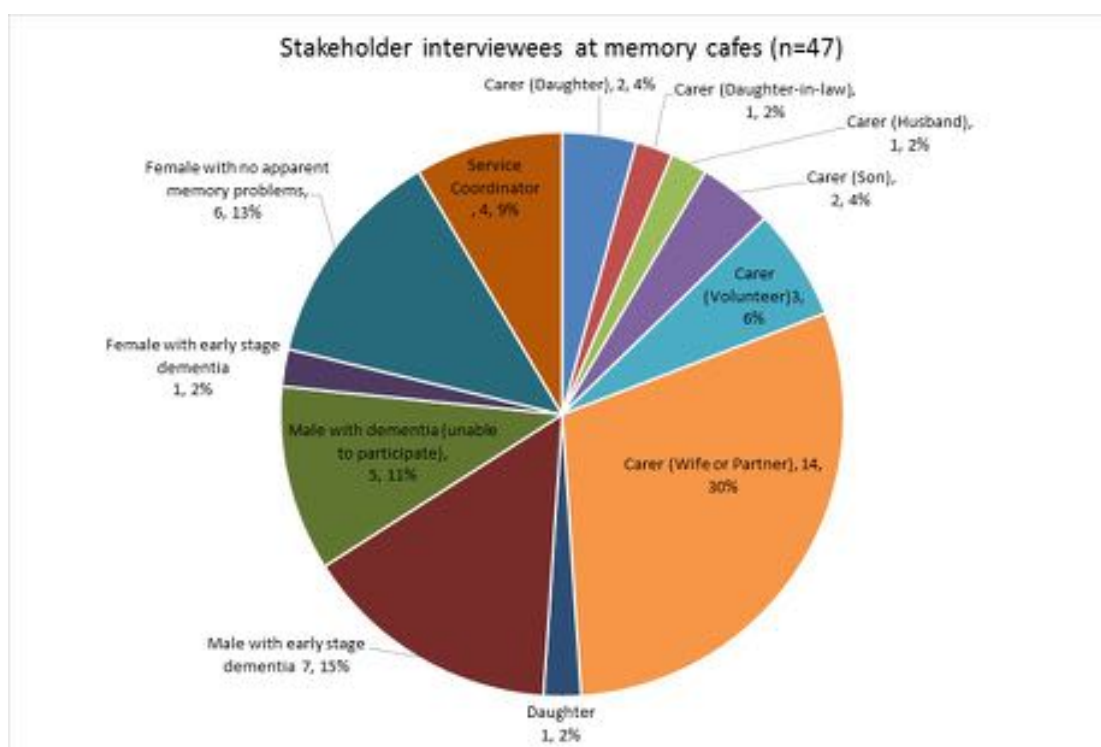Stakeholder interviewees at memory cafes (n=47)

Figure 18: Stakeholder interviewee type

Where couples were interviewed, it was not known to the interviewer at the beginning of each interview which partner had dementia, nor the stage of their condition. Five males with dementia were present with their partners during the interview process, but were unable to participate meaningfully in the discussion due to the severity of their condition.

5.2 Qualitative Findings

The conversations at Memory Cafés produced some very interesting findings about personal experiences of services and support in East Devon, and despite the fact the respondents were providing their own individual stories, unifying themes did emerge. The majority of the conversations were with carers, and as such, what the findings provide is the view of carers about how they can and do support their loved ones and themselves.

A particularly striking feature of the discussions around support use was the lack of commonality in the types of support respondents reported using. This is even more striking considering that these memory cafes were mainly from the same geographical area (East Devon) and that there was limited commonality between experiences of respondents even within the same memory café. The list of services and organizations accessed is long and includes the following:

- Different hospitals
- Care Agencies
- Devon Carers
- Various day centres
- GP
- Support groups
- Memory cafes
- Time for Life
- Take a Break
- Dementia Advisors
- Devon Memory Service
- Alzheimer's Society
- Age UK
- OPMH
- Helping Hands

People appear to be bewildered by the number and varying functions of different organizations, how to find them, how to interact with them, and the different structural systems they all use. On the one hand, some people find it difficult to find the support they need but on the other hand "loads of people arrive and you don't know who they are and nothing happens. You're left with piles of paperwork and you don't know what's going on. Nothing is going on" (Carer).

In terms of support, carers report how "good" care requires continuity of care, in particular having someone who is familiar with the person with dementia so that they can respond to them in a way that is meaningful to both the person with dementia and the carer. Memory Café's provide a level of support in terms of giving people somewhere to

gather information from each other and the volunteers, but also just to share experiences and the burden of caring. They also provide that link with familiarity as the same people attend regularly and get to know and understand each other. Key to any type of support working is access, and for many, a lack of transport can result in becoming very isolated. Memory cafes or sessions which provide transport are very welcomed.

Through omission as much as through being mentioned, it was clear that post-diagnosis support was missing. The questions about what happened post diagnosis did not produce responses about signposting by professionals, rather, a sense that there was a diagnosis and then usually nothing. Diagnosis was reported through GP, through Memory Assessment Centres and also through other specialists in hospital when attending for physical health problems. Again, there appeared to be no clear pathway of diagnosis leading to sign-posting. GPs were not reported as providing post-diagnosis support, and there were some negative experiences of GP perspectives, with one respondent reporting that a GP said "I deal with medical issues, not social ones."

The involvement of the Older Persons Mental Health NHS service was welcomed, but reports were made of appointments being cancelled, a lack of continuity of staff and limited follow-up. In terms of crisis support, only one respondent knew what they would do in the case of a crisis, with most of the others having no idea at all as to what they would do. When crises were experienced, people tended to turn to family or friends, but usually emergency services would be called.

A particular area of crisis mentioned frequently was when the carer themselves became ill and was unable to continue to care. Given the age of the carers themselves, this is something that is highly likely to happen, and something which is of great concern to the carers. For those who had experienced this situation, they reported the huge anxiety it caused both them and their loved one, and how they either just had to hope that the person they cared for would be alright, or call on neighbours, family and friends to help. They also tended to highlight that the situation made the person they care for get worse through the anxiety and uncertainty.

This worry about their own health and what to do if something were to happen to them was just one of the burdens mentioned by carers. Generally, they report how being relied upon is a "huge worry". They also talk of the frustrations of working with professionals who don't always listen to them, and how the focus on listening to the person with dementia can result in additional caring burdens. For example one son said that his Mother had told health workers that they didn't need any help at home because her son could manage perfectly well, whilst the son himself was struggling and did need support.

"We'd rather be left alone, but we need the help", is something said by one carer but a thought also voiced by others. Accepting help is difficult, partly because people want to feel they can manage and by admitting you need help you are saying that things are not good, but partly also because by asking for help people realize that it means having to deal with organizational frustrations and costs. People talked of how difficult it is to deal with the paperwork, the lack of continuity of care, the different people to contact and, importantly, the financial cost.

These organizational issues were mentioned by many respondents. Paperwork is found to be very difficult to complete, and there were a number of comments made about it

being difficult to understand why some people get funding for some things and some don't. This disparity in care and support is bewildering to many.

This was a small qualitative study, but it highlights some of the similarities in experiences between carers. In particular, the confusion around the different services and support available and how to access them is clear. The experience appears to be that memory cafes are important because they provide familiarity for both carer and the person with dementia, somewhere where they can go to share the difficulties of day-to-day life with people who know them.

5.3 Key Observations

- There is a lack of commonality in the types of support accessed.

- People are bewildered by the different organisations providing support.

- Carers report that 'good care' requires continuity of care.

- Memory cafes are greatly valued as a place to share experiences and the burden of caring.

- A lack of transport can result in people becoming very isolated. Memory cafes that provide transport are welcomed.

- There is little post-diagnosis support and no clear pathway of diagnosis leading to sign-posting.

- The involvement of the Older Persons Mental Health NHS service was welcomed but reports were made of appointments being cancelled, a lack of continuity of staff and limited follow-up.

- A particular area of crisis mentioned frequently was when the carer themselves became ill and was unable to continue to care.

- Carers reported their frustrations of working with professionals who don't always listen to them.

- Carers spoke about organizational frustrations for example, how difficult it is to deal with the paperwork, the lack of continuity of care, the different people to contact and the cost of care.

6 Results - Outcomes Mapping (Aim 3)

6.1 Overview

Early on in this process we discovered that there was a paucity of outcome data available. We discussed this with our steering group, with the AHSN and with healthcare commissioners what would be the best outcomes to map. It became apparent that standardised outcomes for people with dementia were not routinely recorded apart from hospital admissions and death. Acknowledging the limitations of these outcomes (its lack of sensitivity and lack of patient / carer perspective), we agreed to focus on a single outcome measure. This was HES admission data for unplanned admissions which had a primary or secondary coding of dementia This HES data was provided by the SW AHSN using the Lightfoot service.

Access to outcomes data on patients diagnosed with dementia and the costs of services were obtained   from commissioners. It was agreed that our primary outcome was to be hospital admission data. Whilst hospital admission rates for people with dementia is not a sensitive measure of outcome, it was the only measure of outcomes that is routinely recorded. Further we planned to find and map additional outcome data using the following process:
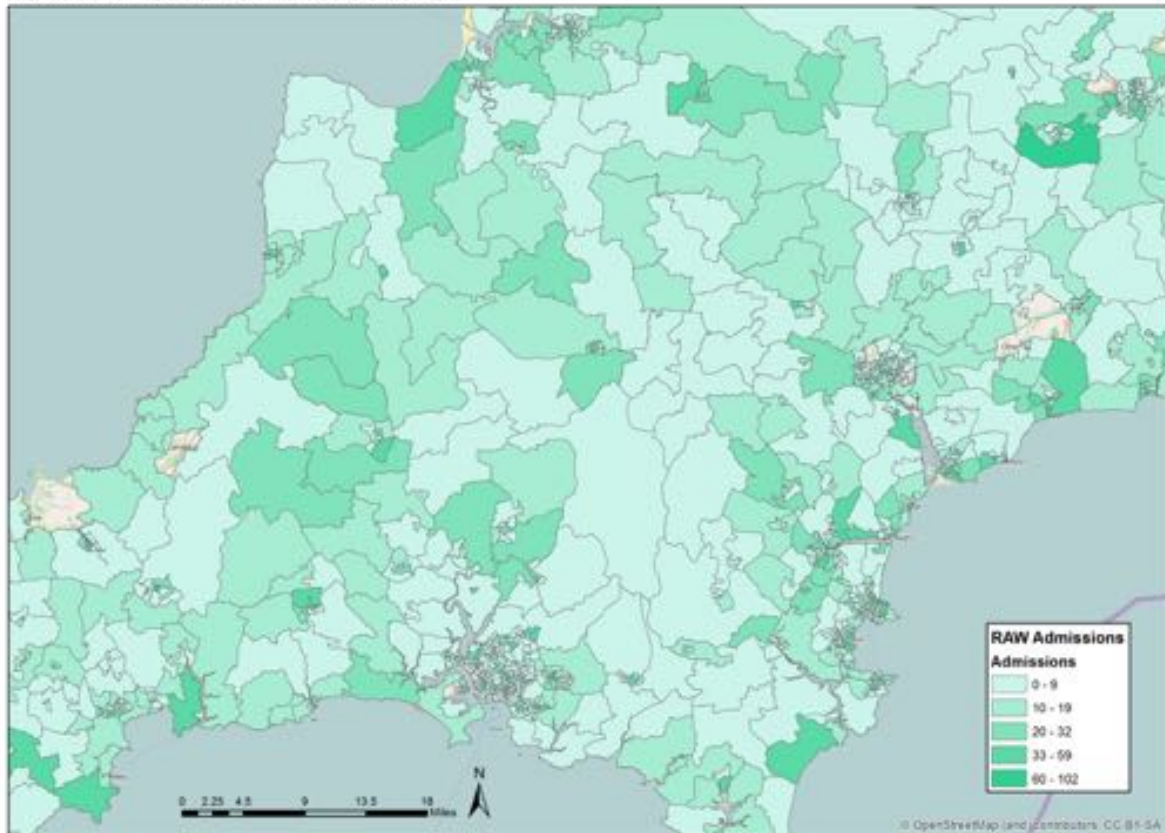
1) Classify outcome data collected from services according to type
2) Negotiate access to and gather general dementia outcome data from the region
3) Map outcome data to the region
4) Identify gaps in data
5) Look for evidence that could be used to fill those gaps

The following maps show raw data for admissions (Map 9) and then data standardised for population density, age and gender for urgent hospital admissions Map 10. In both cases, the darker the colour the higher the rate.

6.2 Findings

Map 9: Map of raw admission data

What this map shows is that most urgent hospital admissions for people with dementia come from areas where there is high population density and in areas where mean age of the population is highest. While further work is needed here, it could be that this tells us where the highest density of patients with dementia are.
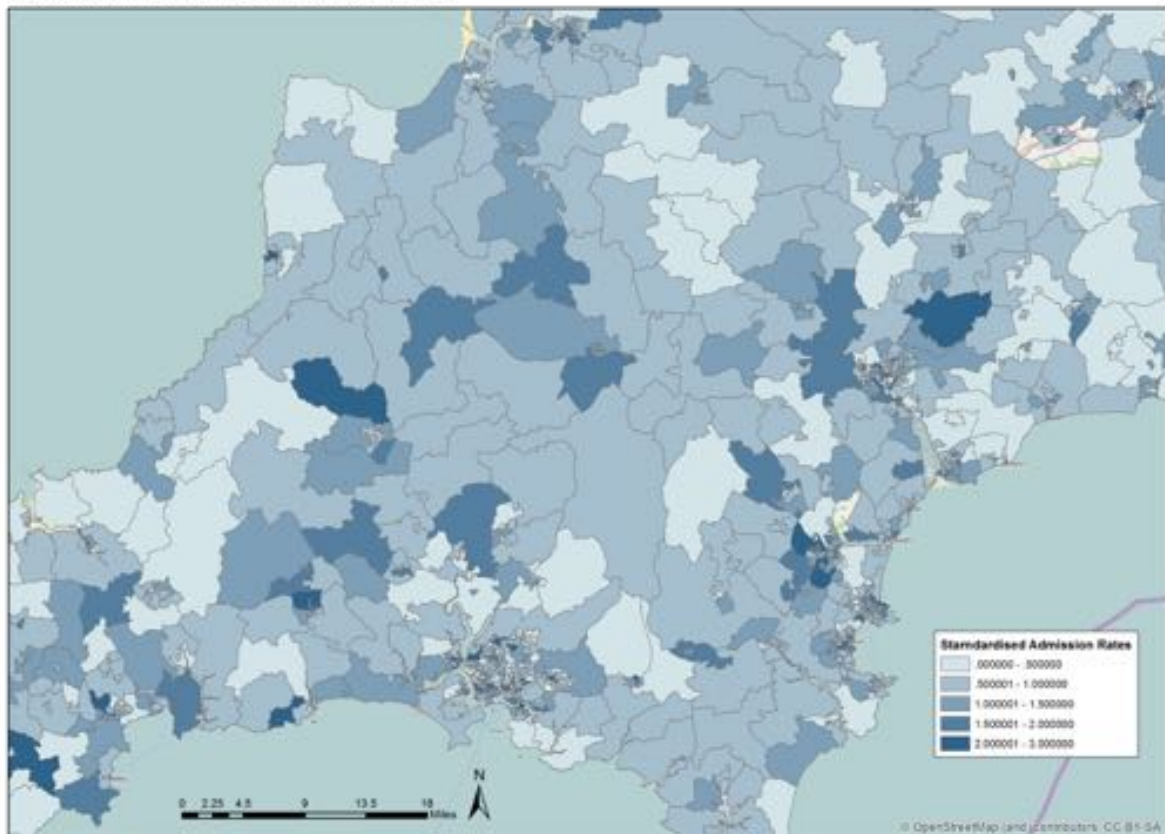
This raw data shows large numbers of admission for clearly defined geographical areas such as dense urban populations, i.e. in Exeter, Plymouth, Taunton and Yeovil, and areas where the average age is considerably higher, i.e. East Devon and South Devon coastal town.

When the same data is standardised for population density, age and gender the map (Map 10) tells a different story; those places that have high numbers of admissions don't necessarily have high exceptionally admission rates. This map controls for difference in population density, mean age and variations in gender mix, and provides more directly comparable data.

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Map 10: Map of Standardised Rates

On this map, a value of 1 indicates the expected rate, less than 1 means fewer admissions than expected and greater than 1 indicates more admissions than expected.
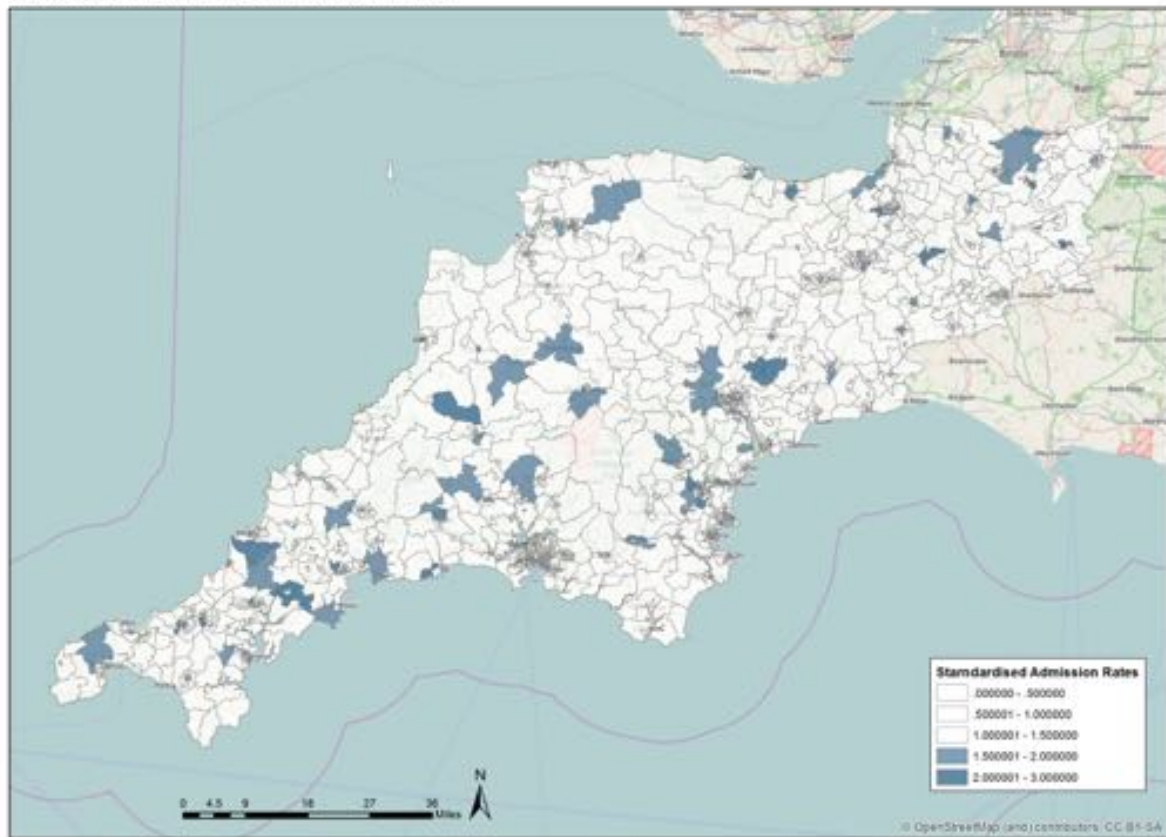
For the purposes of this mapping exercise we have considered areas with standardised admission rates >1.5 (i.e. 50% higher than expected), to have significantly higher than expected admissions, after controlling for other potentially confounding variables.

This next map (map 11) is the same as Map 10, but with the LSOA with as expected or fewer than expected admissions not displayed. This highlights possible areas that require more detailed investigations.

As you can see, this map shows relatively few LSOA with a higher than expected rate of admissions. However, it is important to reiterate the earlier point of low numbers and random spatial variability. Some LSOAs that have less than 5 or no admission data, we cannot be certain that the map tells the whole picture.

Dementia Mapping Project
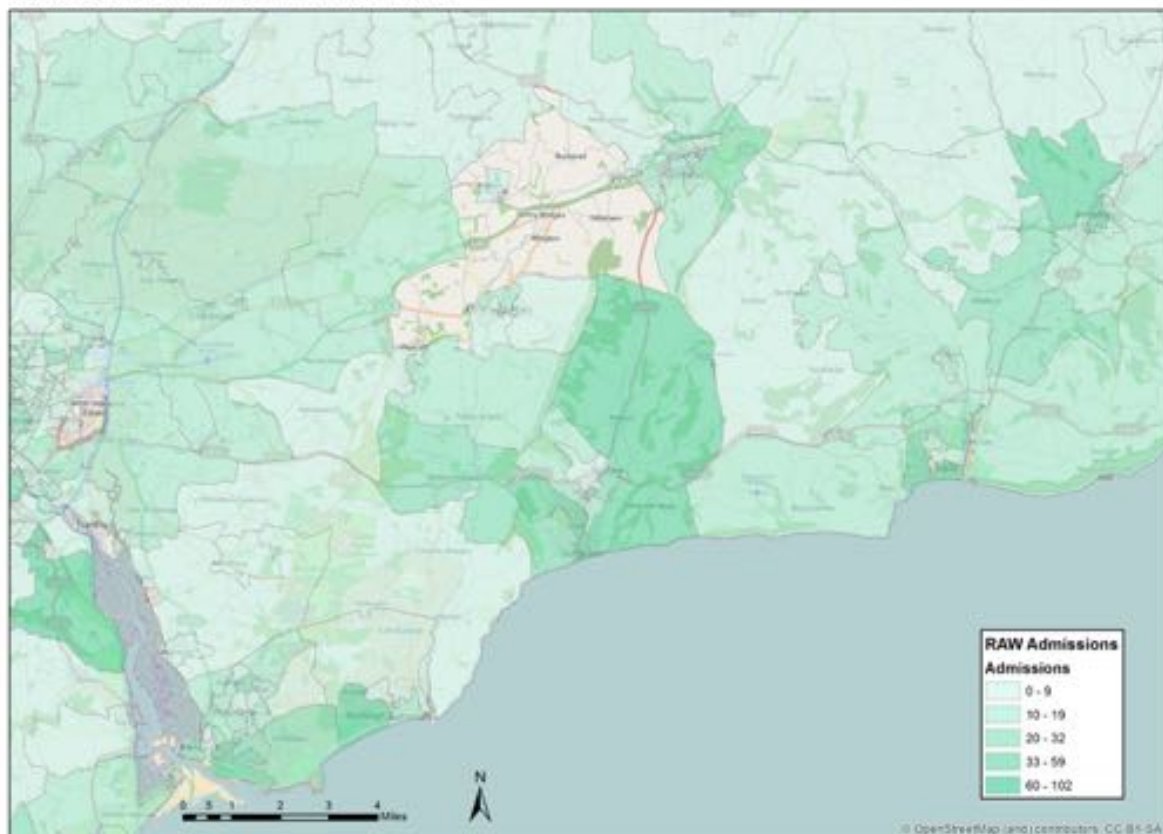Prof Chris Dickens, Tobit Emmens, Sarah Ross, Dr Sarah Robens

Map 11: Areas with a higher rate (more than 1.5 times the average) of admission than expected admission

To explore the data a little further, what is interesting here is that areas such Budleigh and Sidmouth have a high numbers of admissions (Map 12), but relatively low rate of admissions (Map 13). That is, when standardised, there are no more admissions than you would expect based on the underlying population. In lay terms we might say that the unstandardized data shows that there are a lot of admissions from areas where there are a lot of older people,. The standardised data, however, shows areas that have rates of admissions that are higher than would be expected for the age and deprivation of the population. In some cases, we observed fewer admission than you would expect. While we think this may be due to factors such as low levels of social fragmentation, deprivation and isolation, along with close proximity to a range of dementia services, we cannot be sure this is the case without more comprehensive and detailed analysis, disease risk mapping and better outcome data.
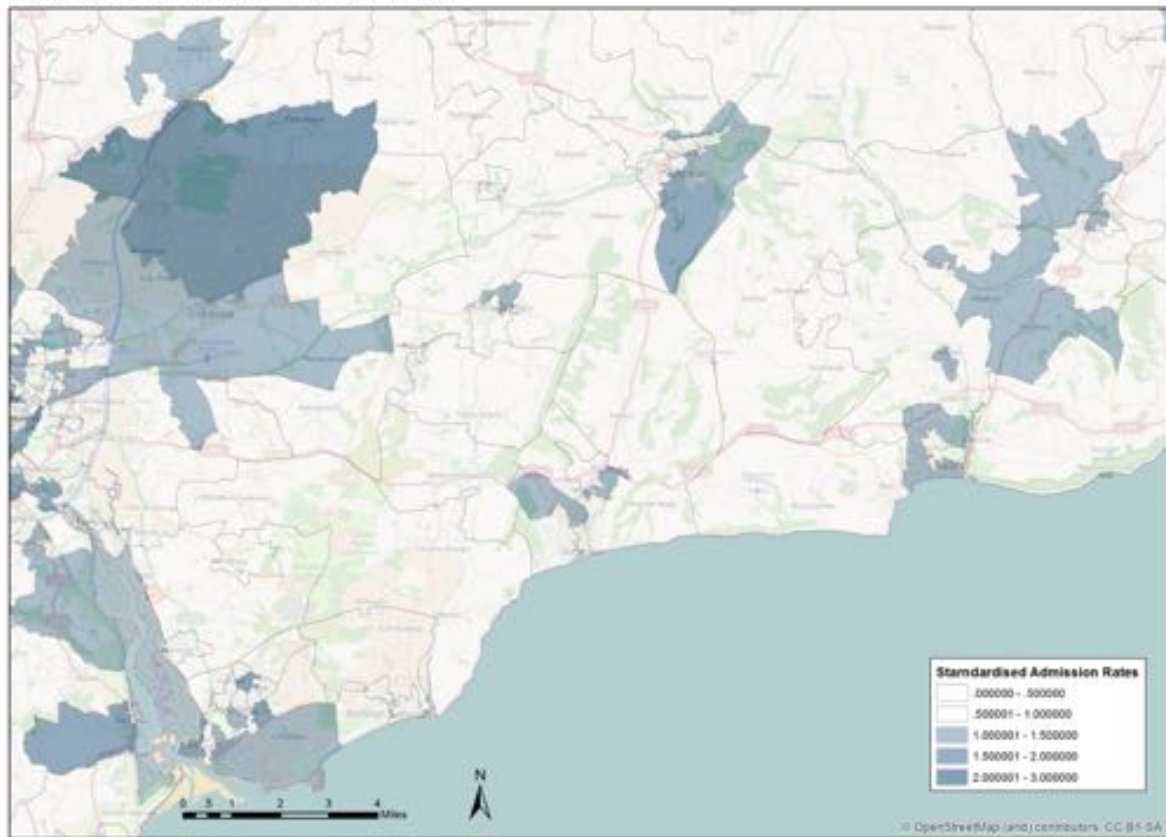

Map 12: Raw Admission Data for East Devon

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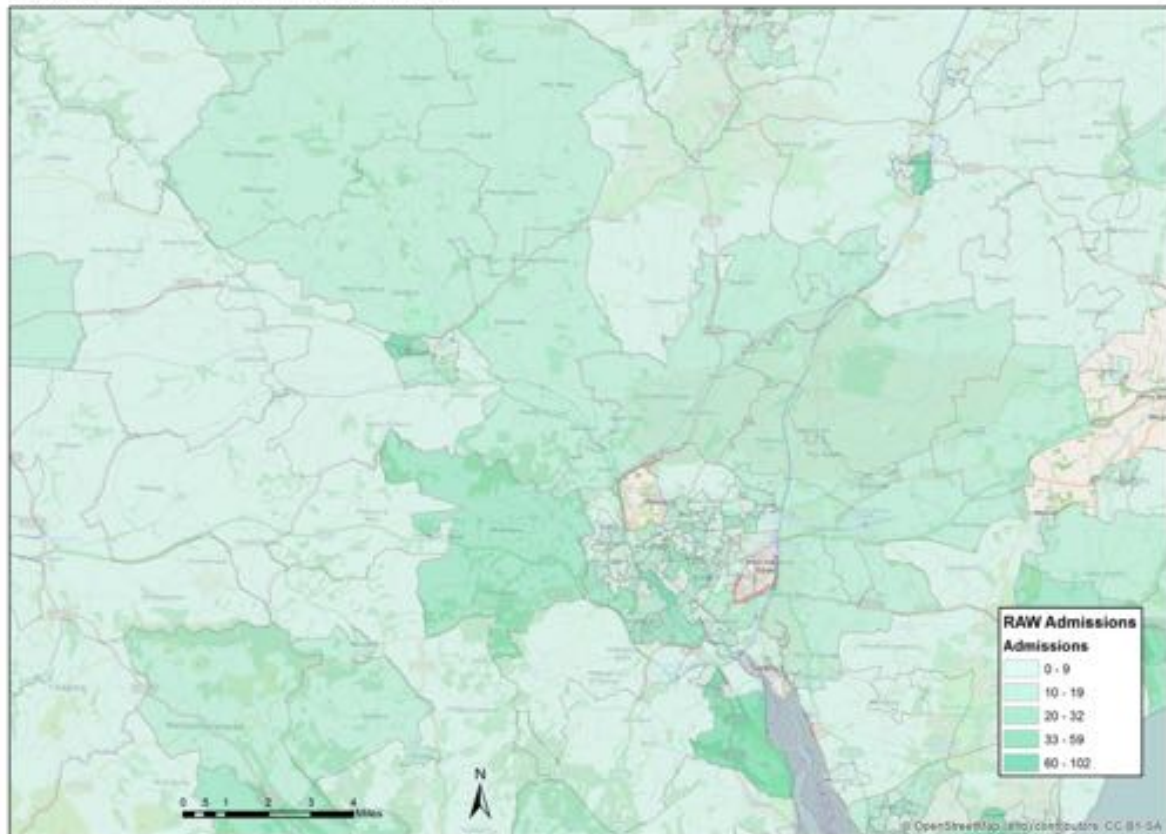Prof Chris Dickens, Tobit Emmens, Sarah Ross, Dr Sarah Robens

Map 13: Standardised Admission Data for East Devon

Maps 14 and 15 further illustrate what we observed on Maps 12 and 13. The light green areas on Map 14 shows areas that have low numbers of admissions, but when standardised measures are applied, there are actually more admissions than you would expect - i.e. fewer older people going to hospital more frequently. This is illustrated in the north mid and north east areas surrounding Exeter. These areas have broadly the same numbers of actual admissions per LSOA. However, when these admissions are standardised (Map 15) areas such as Broadclyst and Newton St Cyres have a higher than expected standardised rate of admission.

Map 14: Raw Admission Data for Mid Devon

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Map 15: Standardised Admission Data for Mid Devon

The Following maps illustrate areas with high standardised rates of admissions in relation to service provision
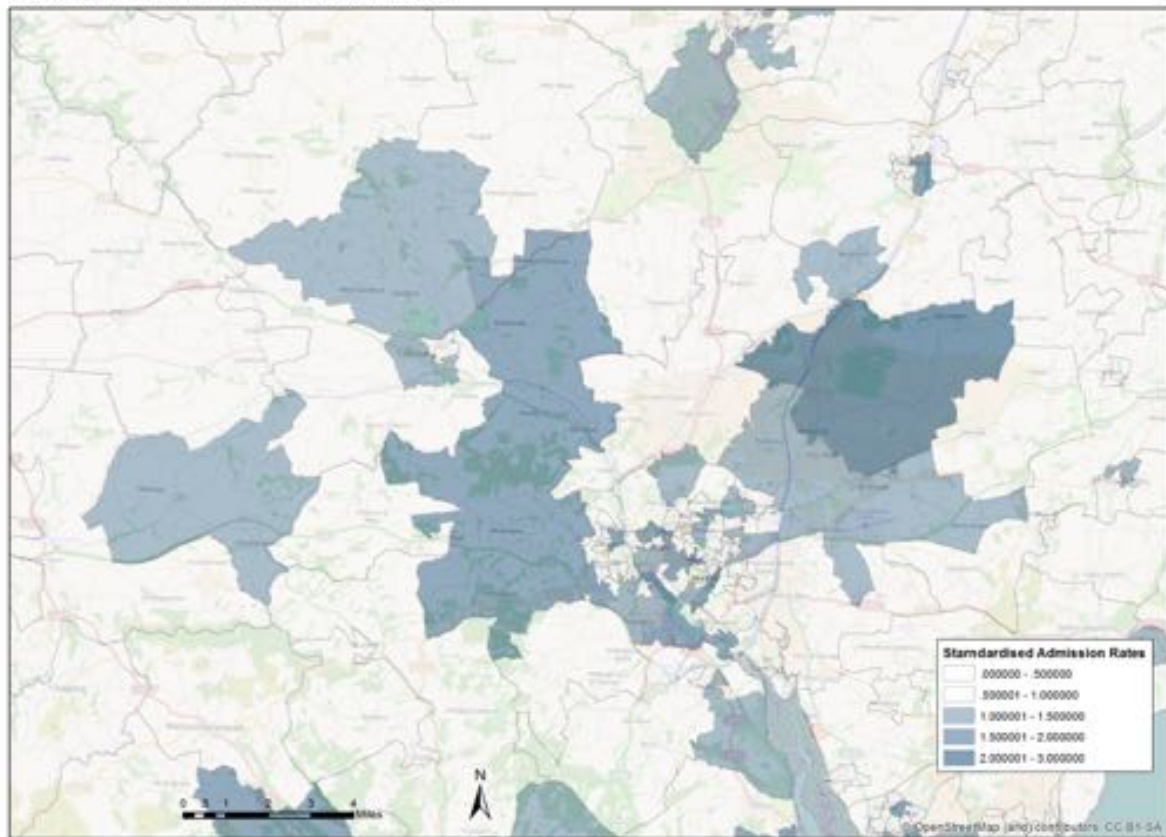

Map 16: The South West Peninsula

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Map 17: Cornwall

Map 18: Devon

Dementia Mapping Project
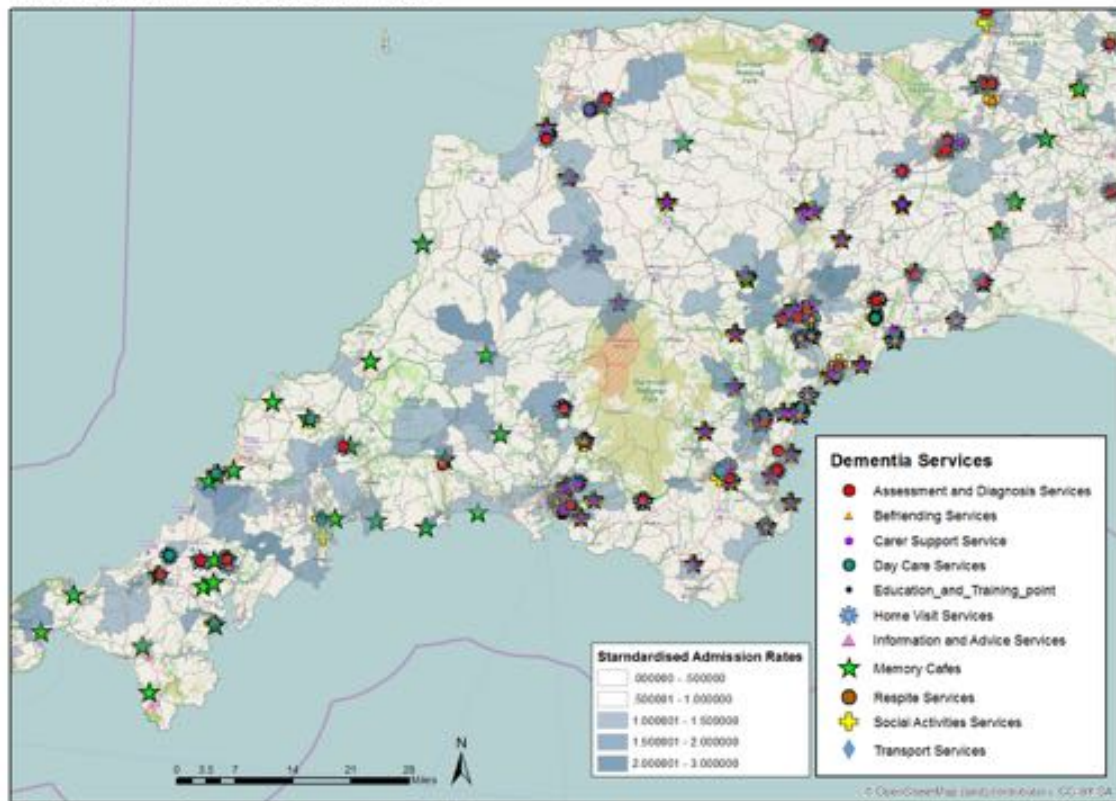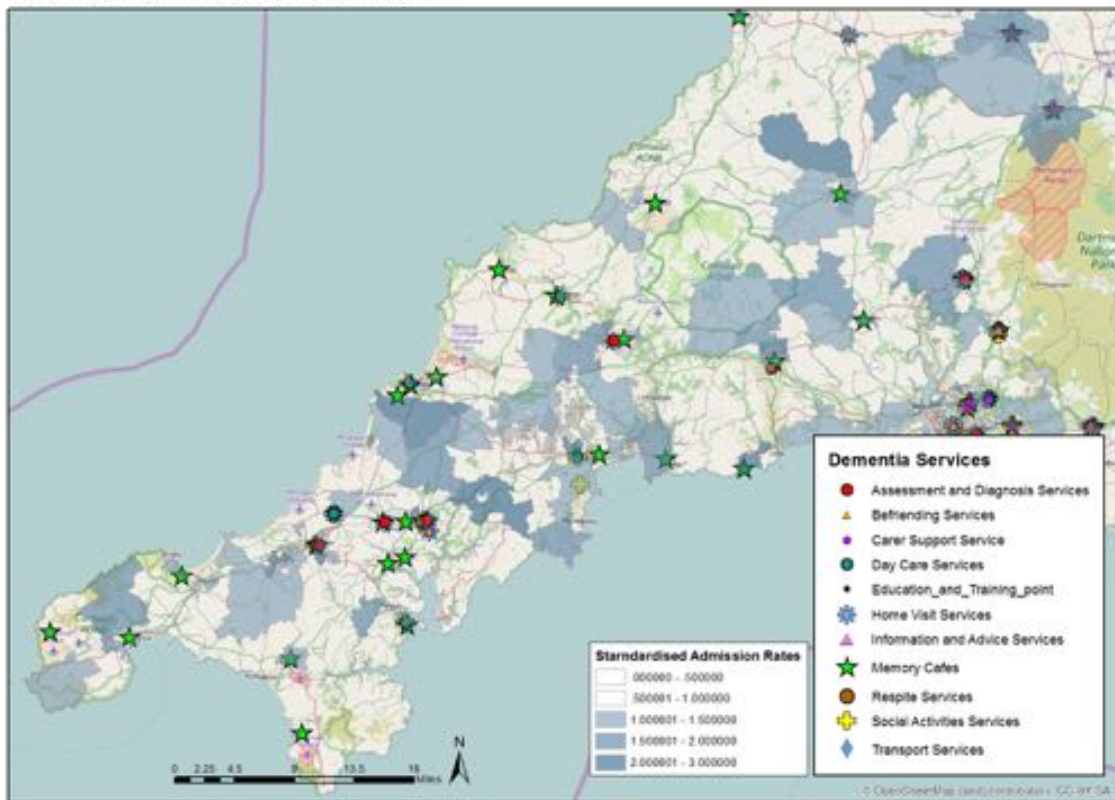Prof Chris Dickens, Tobit Emmens, Sarah Ross, Dr Sarah Robens

Map 19: Somerset

Dementia Mapping Project
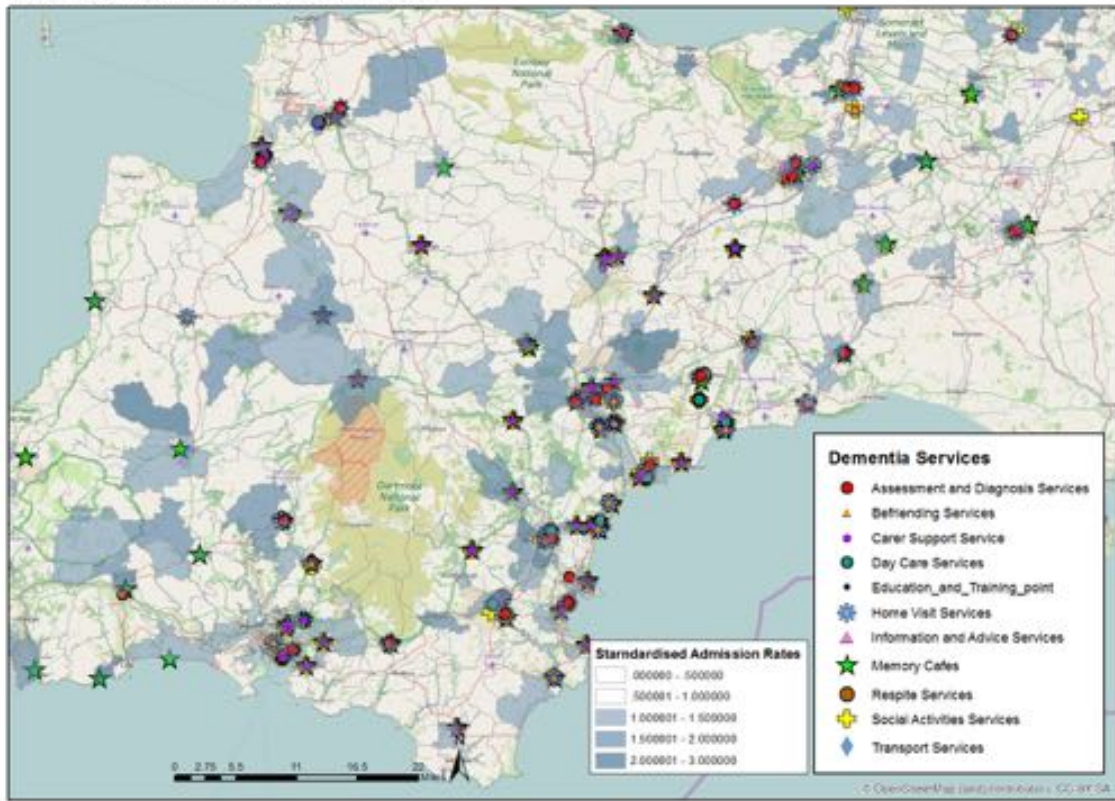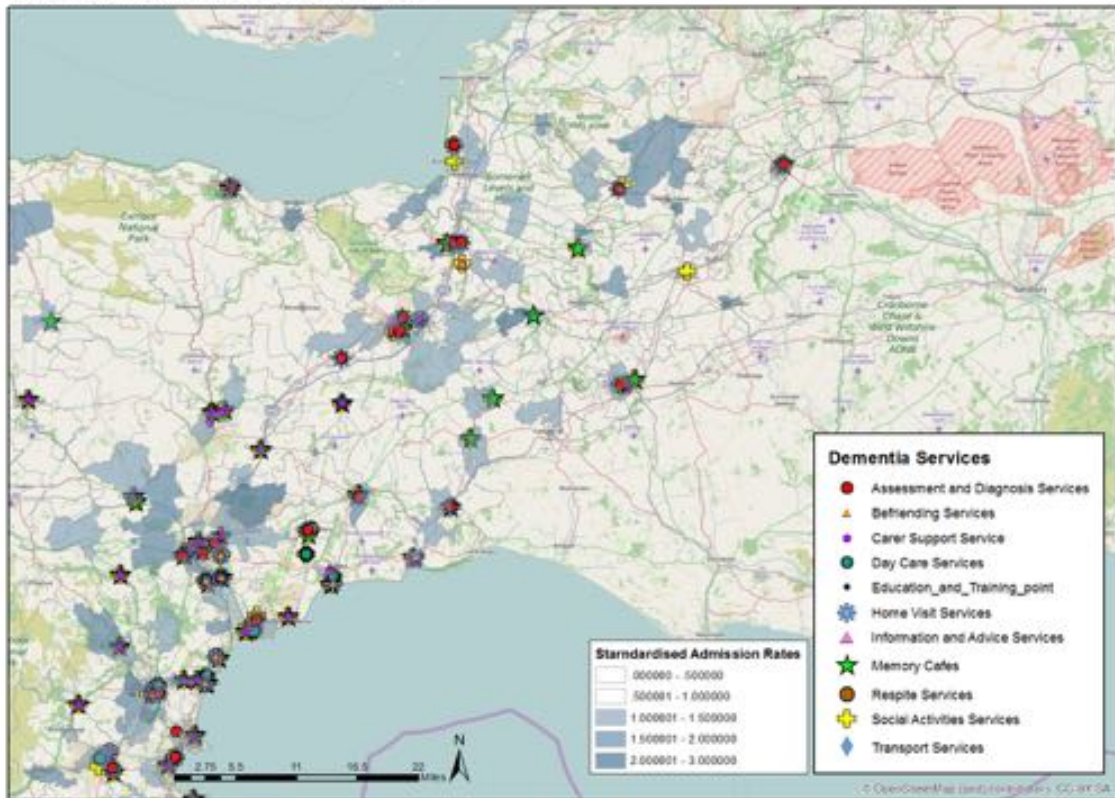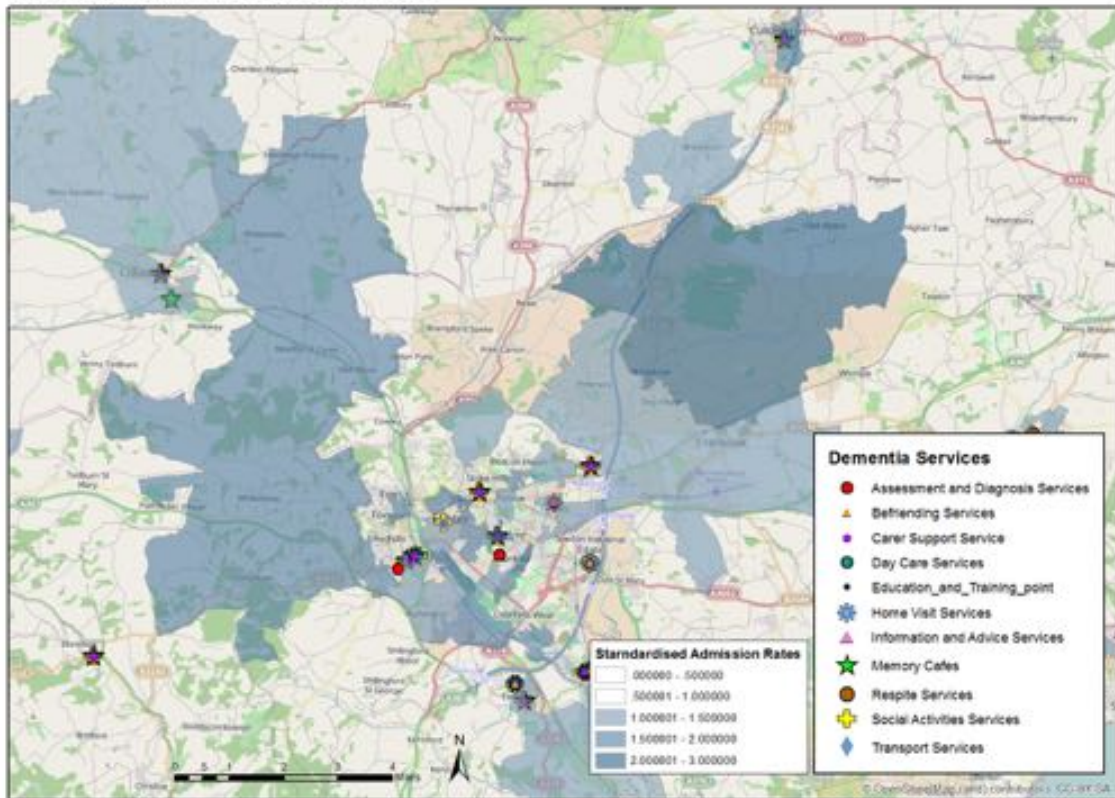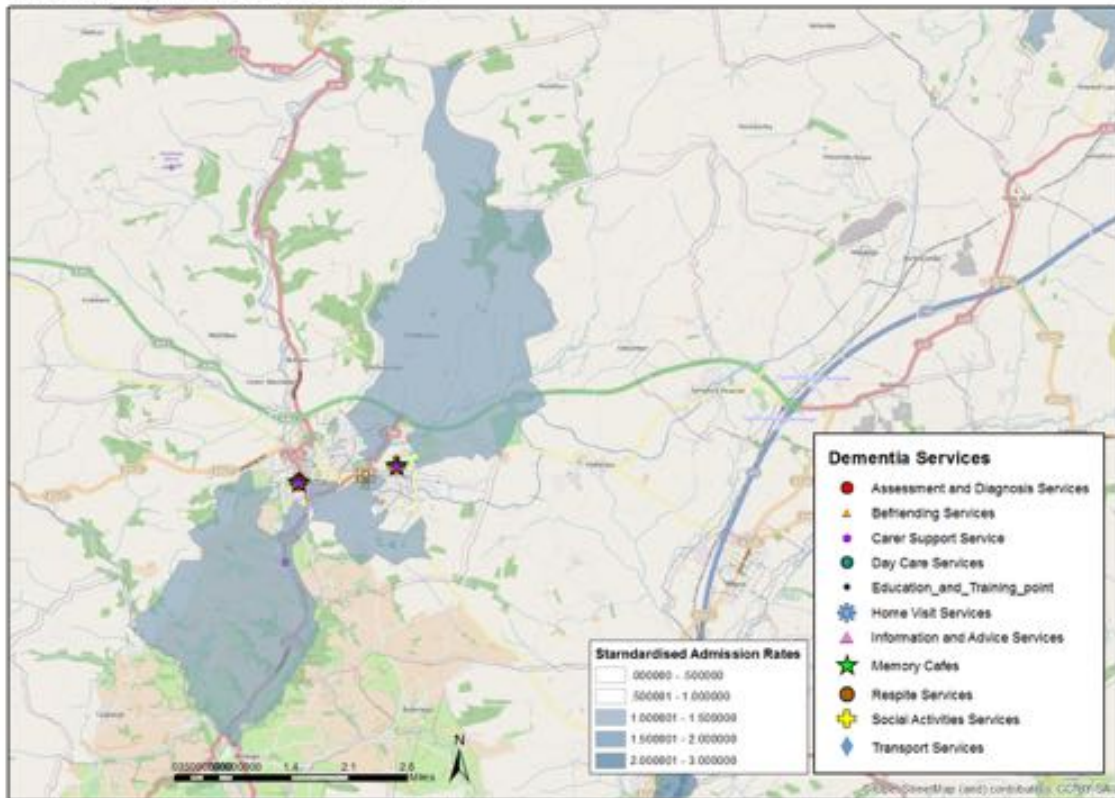Prof Chris Dickens, Tobit Emmens, Sarah Ross, Dr Sarah Robens

Map 20: Exeter

Map 21: Tiverton

Map 22: Taunton

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Map 23: East Devon

Map 24: Plymouth

6.3 Key observations

This preliminary analysis, and the limitations of the data available prompt further questions rather than provide answers.

We also observed high levels of random spatial variability when mapping hospital admission data. Our maps displaying the raw admission data may be misleading because of the low numbers and sparsely populated areas. However, we observed:

- Some places that have high number of admissions, actually have a low rate of admissions, after controlling for population density, age and gender.
- Some places that lave low numbers of admissions actually have a high rate of admissions after controlling for population density, age and gender.
- Higher rates of admissions appear to be found in and cluster around cities and large towns, i.e the nearer you are to a hospital, the more likely you are to use it.

Through the outcomes mapping process it became clear that conducting a comprehensive disease risk mapping would have aided this process, however, neither time or project scope permitted this. Comprehensive disease risk mapping is a type of spatial epidemiology. Spatial epidemiology comprises at least three types of focus. These are (i) disease mapping, (ii) disease clustering and (iii) geographical correlation. We were particularly interested in geographical correlation between disease risk, dementia services and other explanatory variables such as deprivation, isolation, and social fragmentation, and we recommend this line of enquiry for further work and set this out in Chapter 8.

7 Summary

7.1 Summary of Key Observations

Aim 1:   To develop a comprehensive map of service provision for people with dementia and their carers across the South West peninsula.

Method:

1.   A brief scoping review to identify existing service maps and directories.
2. Services were identified using online directories and through professional networks.
3. Telephone interview with the service coordinator took place.
4. Data managed using excel spreadsheet.
5. Raw data from stage II cleaned and prepared for Geographic Information System (GIS) mapping. Using ArcGIS software, data was related to other data sets. New GIS data files (shape files) were created to view and analyse the mapped data.

Results: 296 services were mapped across the region. More services were found to be provided in Devon than in Cornwall or Somerset (Devon 53%, Somerset 25%, Cornwall 22%) with the most common type of service being those providing information, advice and social support. Memory cafés are the most common service available to people with dementia and their carers, although there are a great deal more memory café's in Devon than in Cornwall, and more in both counties that in Somerset.   There are no standard funding sources for memory cafes, or standard models, with some providing space for informal social interaction whilst other have more structured sessions with speakers and activities. The memory cafes do not collect outcome data, so cannot easily report on outcomes, however, qualitative data can be collected from attendants as was done during this study. Across the areas, befriending and respite services are least common and not easily accessible and transport services are also limited.   Local Authority community directories are available across each county, but they are not kept up-to-date.

Aim 2: To better understand the processes and the nature of care provided to people with dementia and their carers.

Method:

1. Design interview proforma with collaboration from steering group.
2. Identify sample of service providers to be interviewed
3. Contact service providers and ask for suggestions of recipient stakeholders to be interviewed.
4. Carry out semi-structured interviews during memory café sessions.
5. Thematic analysis.

Results: 47 stakeholder interviews were carried out across 9 memory cafes. The qualitative work shows above all that there is a lack of commonality in the types of support accessed and how people find out and access support. The latter is closely linked to peoples' reports of little post-diagnosis support and limited signposting. People

create their own pathways to support, which is easier for those who have strong carer support than those who don't.   Overall, people are bewildered by the different organisations providing support and are looking for continuity of care. Memory cafes provide a good place for people to share experiences and find out what is available as well as for carers to share the burden of caring, but they are sometimes difficult to access for people who have no transport.   Transport is very much needed to enable people to access support.   Other frustrations reported by carers are around the complexity of organisational systems, paperwork and contacting people, and real concerns about what happens to their loved one when they themselves are ill.

Aim 3: To investigate potential to develop a map of dementia outcomes in the South West

Method:

1) Classify outcome data collected from services according to type
2) Negotiate access to and gather general dementia outcome data from the region
3) Map outcome data to the region
4) Identify gaps in data
5) Look for evidence that could be used to fill those gaps

Results:

Our analysis was limited by data availability, and as such has raised a number of further questions rather than provide answers.

We observed high levels of random spatial variability when mapping hospital admission data. Our maps displaying the raw admission data may be misleading because of the low numbers and sparsely populated areas. However, we observed:

- Some places that have high number of admissions, actually have a low rate of admissions
- Some places that lave low numbers of admissions actually have a high rate of admissions
- Higher rates of admissions appear to be found in and cluster around cities and large towns

Through the outcomes mapping process it became clear that conducting a comprehensive disease risk mapping would have aided this process, however, neither time or project scope permitted this.

7.2 Discussion

The numbers of individuals and families affected by dementia are forecast to increase over coming years. Pressures on dementia services are likely to be particularly marked in the South West peninsula of England due to the higher average age of the population compared to other areas in the UK.

Ensuring that care for people with dementia and their families is of high quality and well-organised is a priority for providers and commissioners of care across the South West Peninsula. As a first necessary step to improving the availability, accessibility, equitability and coordination of care for people with dementia in the South West Peninsula, we have:

    i)   Identified and described current service provision for people with dementia and their carers.

    ii)   Gained understanding of the processes and experiences of dementia care from people who use the existing services

    iii)   Developed a map of dementia outcomes across the South West to identify areas of service need to inform future service planning and provision.

Our methods have a number of strengths and some limitations that merit discussion. We collated information from disparate existing databases, from collaborators amongst service commissioners and providers, from the NHS and voluntary sector. We focused on identifying services provided specifically for people with dementia and their carers. The characteristics of these dementia specific services and support provided were verified via direct contact with each services identified. As a result of these methods we are confident that our current service map provides the most up-to-date and comprehensive list of dementia specific services available in the South West.

We used a "snow-balling" method to identify additional generic sources of care and support for people with dementia and their carers. To identify these dementia-relevant, generic services for people with dementia and their carers, our plan had been to continue the snow-balling activity until saturation point was reached. Due to the limited time available for this project and the number of additional, generic services identified through snow-balling, we were not able to reach saturation and we were not able to verify characteristics of all such services. Since service identification started in East Devon, we are most confident about identification and verification of dementia-relevant generic services in that region, where we consider saturation was reached. We are less confident that we achieved saturation in other regions. This means that some of the disparity in dementia relevant generic service provision across the Peninsula could be attributable to more limited data collection in areas outside East Devon.

General practitioners provide many essential services for people with dementia. Such services provided by GPs are likely to be particularly important in areas of limited dementia specific service provision, of which there are many in the South West due to areas of low population density. During the course of this project it became apparent that, in addition to generic support for people with dementia, some GP practices provide high quality dementia specific healthcare for their patients. For example, we are aware of a GP practice in Cornwall that obtained additional funding to provide a nurse specifically to coordinate care for people with dementia with the aim of improving care quality and reducing dementia admissions. Regrettably, we were not able to include details of such dementia specific services provided via primary care and general

practices due to problems with gaining access to email addresses for GP surgeries within the timeframe of this project. We acknowledge this limitation in the report and would recommend that future mapping exercises negotiate appropriate information from GP practice managers

We conducted detailed interviews with service users with dementia and their carers to find out about their experiences of healthcare. Our interviews were focused in East Devon region and provided useful insight into the benefits and challenges of current healthcare provision for people with dementia in that area. We recognise that we did not / could not focus equal attention to other regions across the South West due to limitation in resources available for this project. Consequently, we cannot be sure that the same perceived benefit and challenges would have been reported in other areas outside East Devon. Future research into healthcare processes for people with dementia in the South West should consider sampling experiences of service users and their carers from a broader range of regions.

We were able to map health outcomes by plotting urgent hospital admission for people with dementia diagnosis across the region. By controlling for population density along with the age and gender mix of population, we generated and mapped standardised admission rates and thereby we were able to identify areas with particularly high rates of urgent hospital admission. We also compared these regions with high urgent admission rates with existing service provision. Whilst no causal inferences can be drawn from these maps (i.e. about causal links between high rates of urgent admissions and existing levels of service provision) we intend that this information will inform the localisation and organisation of future service development.

We recognise that urgent hospital rates do not provide a sensitive measure of health outcomes for people with dementia however, and this measure does not include any perspective from the users of dementia services of their carers. Consequently such urgent hospital admission rates provide an extremely crude measure of health outcomes and miss many / most of the subtleties that service users and carers might consider important in determining health outcome, such as ability to live independently, presence of challenging behaviours psychological distress or overall quality of life. Apart from mortality however (an even more crude measure of health outcome), urgent hospital admissions represent the only measure of health outcomes currently routinely collected for people with dementia. Commissioners and providers of care for people with dementia should consider organising widespread regular collection of standardised outcomes measures for people with dementia

Our findings demonstrate varying levels and types of service provision across the South West Peninsula, as might be expected. This pattern of service provision has clearly evolved over time in response to needs of patients, opportunities and resources available via the NHS and the voluntary sector. Our map provides an important resource, that is currently up-to-date, and which could be of great use to users, providers and commissioners of care to help navigate, coordinate and plan services.

During the collection of service data, it became clear that services open and close with considerable frequency, meaning that our map represents a snap-shot of current service provision that will rapidly go out-of-date. Providers and commissioners of services should consider developing a strategy to maintain the accuracy of the service map.

Whilst it is understandable that the variation in the development of services across the South West has been influenced by different factors, this leads to a lack of standardisation of care provision and service inequity across the Peninsula. Service users report confusion around what services are available and how to access them, with little evidence of a clear pathway or signposting after diagnosis. This is evidenced by the lack of any commonality in the experiences of care even among populations even from a limited geographic area, such as east Devon. Access to services is not driven by the needs of the service user or their carers, but is more likely to be determined by chance.

It seems unlikely that complete standardisation of care provision across the Peninsula would be possible or even desirable, though it is clear from interviews that there is a serious need for sign-posting to services. Whilst some of this variability might reflect differences in patients needs, what people are telling us is that they do not know what they need, what is available and how they access it. There needs to be a plan to sign-post people to appropriate services and providers of care should consider local arrangements for such signposting. Even when accessed, services are complex and service users reported a need for greater continuity of care from the services that are available

Carer burden was also very evident, with stories of how crises can easily be escalated if the carer is unwell. In terms of what to do in these crises, carers were unclear as to how they should find help and tended to rely on friends and family where available. There is no crisis planning people should be supported to plan for crisis as part of post diagnostic care.

Memory cafes are highly valued by service users and their carers. Currently they represent the most widely accessible dementia specific service and they are used informally to connect people with information and services. However, the geographic spread of memory cafes in the South West and a lack of transport mean that access can be challenging for some people.

Furthermore, memory cafes are all very different in what they provide, because there is no standard specifications for these services. Currently they are used informally to connect people with information and services. With a small amount of additional financial support from NHS commissioners or charities, memory cafes could fill some of the gaps identified in services, by:

   i)   training staff to provide high quality, locality based, post diagnostic signposting to dementia services
   ii)   to collect standardised outcomes measures on the people attending the cafes that could be used to monitor health outcomes.

Commissioners of services should consider entering into partnerships with local charities and memory cafes to provide standardised signposting services and assessments of outcomes.

Transport, respite care and befriending services appear to be lacking across the SW peninsula. This finding was triangulated with data gathered during the qualitative research phase.

8 Recommendations for health service commissioners and providers

1. We have developed an accurate and detailed map of existing dementia services, which is intended to be useful to:
    i)   service users (to identify local sources of care and to see what services are offered),
    ii) service providers (to assist in the coordination of care) and
    iii) service commissioners (to increase understanding on current levels of service provision, to identify areas of need and to inform future service developments).

    If the map is useful it needs to be maintained.

    We recommend that the CCG considers:
    i)   where the map should be hosted to be accessible to service users, providers and commissioners
    ii) how hosting of the map can be funded on a recurrent basis
    iii) investing in maintaining the accuracy of map by developing systems to collect information on service provision at least annually. This latter could be achieved by funding a repeat of this survey or by requiring services to return details of service provision, possibly as a condition of some licensing agreement. Future mapping exercises should consider including details of dementia specific services offered through GP practices and should consider sampling.
    iv) work with researcher from the University and the Devon Partnership Trust to develop the methods to increase understanding of drivers of poor outcomes among people with dementia.

2. People reported difficulty accessing care, due to the complexity and variability of care. As a result there was a lack of commonality and standardisation of the way patients access care and the care they receive. When care was accessed there were reports of poor continuity of care which increase frustration.

    We recommend that CCGs improve services for people with dementia and their carers in the period following diagnosis by:
    i)   Standardising and clarifying care pathways for people with dementia where ever possible, so it is clear which services are appropriate for patients in any given situation
    ii) Ensure continuity of care for existing services where ever possible
    iii) Developing local arrangements to ensure patients have access to appropriate signposting to clinical services
    iv) Support patients and their carers to plan for crisis, including illness in the carer

3. Service provision has evolved organically in the past, with the result that there are many variations in care across the Peninsula, that complicate the future planning of services for commissioners, the coordination of care for providers and the access of care for service users and their carers.

We recommend that CCGs use standardised outcomes data mapping to inform planning of future dementia services to minimise inequalities in healthcare provision across the Peninsula.

4. There is a lack of meaningful, routine standardised assessment among people with dementia, apart from that delivered as part of the diagnostic services. This has the result that there are only very crude means of assessing health outcomes among people with dementia and their services, the performance of services, or evaluating the impact of service changes / developments

   We recommend that CCGs:

   i) Work with local Universities and Devon Partnership Trust to identify appropriate standardised outcomes measures suitable for use by people with dementia
   ii) Develop systems to collect standardised outcomes metrics for patients with dementia and their carers on an annual basis at least. These metrics could be collected by GPs as part of an routine, incentivised annual assessment, and could be completed opportunistically when patients access dementia specific services, possibly in return for a small amount of funding, as a condition of licensing of service, or a combination of both of these.

5. Memory cafes are widely available but vary considerably in their provision of services. They provide an important source of information that is valued by people with dementia and their carers. We believe it would be possible to support and further develop an infrastructure, based on existing network of memory cafes, to provide the signposting services required by service users and their carers.

We recommend that CCGS work with charities:

   i) To develop a service specification for memory cafes, to increase the standardisation of care provided
   ii) To collect, maintain and disseminate information on service provision by memory cafes, to improve access for service users
   iii) Support development of staff in memory cafes, through training
   iv) Support the development of accurate and locally relevant information resources for dissemination via memory cafes for people with dementia and their carers
   v) To encourage staff to collect and return standardised outcomes measures for people with dementia, possibly in return for a small amount of funding, training of staff and support to develop information resources.

Appendix I

Dementia Mapping Project - Telephone Survey

Name of person interviewed:_____ Job

title:_____

Telephone number:_____ Date of

call:_____ Time:_____

1. Organisation details

1.1 Name of organisation providing the service:

_____

_____

1.2 Statutory or non-statutory (charity sector/   private

sector)?_____

1.3   How long has your service been running

for?_____

2. Service description

2.1 Name of

service:_____

2.2 Name of service coordinator and job title:

_____

Contact details? Tel:_____ Email:

_____

2.3 Brief description of what your service offers:

_____

___

_____

___

_____

___

_____

___

2.4 Service type? *(please circle)*
befriending   / memory café   / music group   / information and advice   / carer support / transport service / home visits / day care   / social activities   / respite / education/ assessment/ other

_____

___

2.5   Health or social care or both?

_____

2.6   Frequency of service (daily/   weekly/   fortnightly/
monthly)?_____

2.7   Which day(s) of week?

   _____

2.8 Hours of
   service?_____

3.   **Who is the service for?**

3.1 Please describe a typical client, why they contact the service and what they receive

_____

___

_____

___

_____

___

3.2 Eligibility criteria?

people with dementia only/   carers/   friends and families/   all

3.3 Any inclusion and exclusion criteria?

_____

___

_____

___

_____

___

3.4 Age range of people with dementia using the service?   30 – 100/   Over 55 / 55 – 100

_____

___

3.5 Does the building have disabled access?   Yes   /   No   /   N/A

4.   Geographical area covered

4.1 Address and postcode?

_____

___

_____

___

_____

___

4.2 What geographic region do you cover?

_____

4.2 Any links with other regional or national groups?

_____

___

_____

___

_____

___

5.   Referral route

5.1 How can someone access your service?

_____

___

_____

___

_____

___

5.2 Is there a cost?   Yes /   No

_____

5.3 How many clients attend each session on
average?_____

5.4 What is your capacity _____ and is there a waiting list? Yes / No / Not presently

5.5 Do you keep a register of clients that attend each session?   Yes / No / Sometimes / N/A

5.6 Do you signpost people to other organisations? If yes, which ones?_____

_____

_____

_____

and do other organisations recommend or signpost people to your service?

_____

_____

_____

5.7 How do you advertise your service (online directory/ website/ social media)?

_____

____

_____

____

6.   Operational information

6.1 Does your service work with or share information with any other organisations?

_____

____

_____

____

_____

____

6.2 Do you know of any other organisations that provide dementia services in your area?

_____

____

_____

____

_____

____

6.3 Do you have any paid staff, if so, how many?

Full time _____ and part time_____

6.4 How many volunteers? _____

6.5 How many people have accessed the service within the last financial year 2013-14?

_____

____

6.6 How is your service funded?_____

6.7 Would you mind telling us the annual budget of your service?

_____

7. Outcome data

7.1 Do you routinely collect outcome data from people who use your service? *(examples below)*

Yes / No / Sometimes

7.2 What sorts of outcome data do you collect (service evaluation/ user experience/ relative & carer feedback/ assessment measures/ other)?_____

_____

_____

_____

7.3 Would you be prepared to share this data with us in the future? Yes / No / N/A

8. Close interview

8.1 We might want to arrange a follow up visit later this year to speak to you in more depth about your service, would you be the best person to contact about this?

Yes/ No / N/A

Name:_____

____

Position:_____

____

Telephone:_____

____

Email:_____
___

Thank you very much for taking the time to answer these questions

Appendix II

Dementia service mapping qualitative work

The next stage of the dementia service mapping project is to find out more about the views of those using and providing services about what is available, what is needed and how they are used.

This is a pragmatic and rapid piece of work, and as such, sampling will be equally pragmatic, but focused on particular areas of interest identified through the map. We will be interviewing 15 – 20 stakeholders across areas with:

- Low service density but high admissions
- High service density but low admissions
- High level of over 65s
- High service density
- Low service density.

The samples will be focused on memory cafes, but we would like also to talk to people who do not easily access services, and may do so through GP surgeries and memory services.

In the memory cafes, we will attend an open session and talk informally to those attending (people with dementia and their carers) as well as those running the session. Key areas of questioning will include:

- What support do you currently receive?

- Which of these work well for you, and which don't? What are the reasons for this?
- What additional services would be needed and helpful?
- If you have been through a particular crisis moment, what services/support did you use? Was it helpful?
- In a crisis, what services or support would be useful to you? Is such a thing currently available?

The interviews will be recorded using note-taking, and data will be analysed thematically but there will also be a number of case-study stories taken from the data.