

# Leicester, Leicestershire and Rutland Joint Dementia Commissioning Strategy 2011-2014



## Foreword

The aim of the National Dementia Strategy (NDS) is to ensure that significant improvements are made to dementia services across three key areas: improved awareness, earlier diagnosis and intervention, and a higher quality of care.

The NDS identified 17 key objectives that when implemented, largely at a local level, will result in significant improvements in the quality of services provided to people with dementia and should promote a greater understanding of the causes and consequences of dementia.

The Local Implementation Network (LIN) for Dementia started the development process, in conjunction with Care Services and Efficiency Agency (CSED) to host a series of workshops to map out the current delivery of services against the NDS. This work was then taken forward by the Directors of Adult Social Care for Leicester City, Leicestershire and Rutland Councils, and the Chief Executives for Leicester and Leicestershire NHS who commissioned the 3 year Joint Dementia Commissioning Strategy.

The strategy was developed by a group of lead commissioners across Health and Adult Social Care. Feedback was obtained from a series of workshops which included people living with dementia and their families/carers together with key stakeholders from across the health and social care community.

The delivery of the strategy is also underpinned by a broad set of commissioning principles, to support an integrated dementia care pathway across both health and social care services.

Key principles:

- Maximising a collaborative approach and bringing together joint arrangements for planning and commissioning, including a jointly owned process of strategic re-alignment of resources and/or investment planning.
- Developing joint commissioning in those priority areas where partnership will “add value” in terms of improved outcomes and promote greater efficiencies, and
- Employing a flexible approach to how organisations deliver on priorities, as one size certainly does not fit all.

The strategy identifies a number of local strategic actions, which link to the National Dementia Strategy objectives. These are detailed throughout the document and are reflected as priorities for the implementation of the strategy.

## Executive Summary

There are currently 126,200 people over the age of 65 within Leicestershire County and Rutland, and 35,600 in Leicester City. This is predicted to rise to 224,800 by 2025, an increase of 39%. The increase in the elderly population is much greater in Leicestershire County and Rutland than it is in Leicester City. The following information details the number of estimated people diagnosed with dementia in 2011 and the numbers predicted for the future.

Area	2011	2025
Leicestershire	8,115	12,728
Rutland	563	959
Leicester City	2,559	3,272

Reference: <http://www.poppi.org.uk>

Nationally less than half of the people with dementia receive a proper diagnosis and the Quality Outcomes Framework (QOF) data significantly under reports the prevalence of the condition. In 2009 Leicestershire & Rutland County NHS Primary Care Trust commissioned a review of Health Care for Older People with Dementia, the report estimated that only 30% of possible cases were reported at GP practice level<sup>1</sup>.

Although the Dementia Registers and the Leicestershire, Leicester and Rutland (LLR) diagnosis figures show an increase in the prevalence of dementia over time, 60 % of people living with dementia in Leicestershire and Rutland and 50% in Leicester City remain undiagnosed.

The direct cost to LLR health and social care services for people over 65 years of age with mental health problems (predominantly with dementia) equates to about £67 million per year which tends to be on the more complex care needs. In addition informal care costs of £104 million are borne by families/carers (this is a notional or opportunity cost, and represents the value of lost wages or time families/carers would forgo). It could also be interpreted as the cost the state would incur to replace families/carers if they were not undertaking their caring role. £116 million of care home costs are also shared between families (30 per cent) and public funding (70 per cent).

The Department of Health (DoH) has confirmed local health and social care communities will be held to account and will be expected to publish plans detailing how they will work together to deliver high quality care for people living with dementia. This draft strategy and the subsequent implementation plans will evidence progress against the nationally identified dementia care requirements.

The delivery of the strategy is also underpinned by a broad set of commissioning principles, to support an integrated dementia care pathway across both health and social care services, and was developed by a group of lead commissioners across Health and Adult Social Care.

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<sup>1</sup> Report prepared for Leicestershire & Rutland County NHS Primary Care Trust Review of Health Care for Older People with Dementia Analysis of current pattern of commissioning and scope for efficiency and transportation, January 2009.

- Maximising a collaborative approach and bringing together joint arrangements for planning and commissioning, including a jointly owned process of strategic re-alignment of resources and/or investment planning.
- Developing joint commissioning in those priority areas where partnership will “add value” in terms of improved outcomes and promote greater efficiencies, and:
- Employing a flexible approach to how organisations deliver on priorities, as one size certainly does not fit all.

The strategic direction of this strategy is:

- to improve early diagnosis and access to treatment for people living with dementia,
- to ensure that they and their carers have access to a co ordinated health and social care pathway.

Early diagnosis is essential to ensure that any identified care and support plan is based on individual need and can facilitate choice and control. However, often people are unknown to health or social care with services only being provided in response to a crisis.

The priorities are:

1. NHS Leicestershire County and Rutland (LCR) and Leicester City and Leicestershire Partnership NHS Trust (LPT) will lead on ***the early diagnosis and access to care and support services work stream***
2. NHS LCR/Leicester City and University Hospital Leicester (UHL) will lead on the ***improved experience of hospital care work stream***
3. Leicestershire County Council will lead on ***the Improved quality of care in residential/care homes work stream***
4. Leicester City Council will lead on the implementation of ***personalisation of care and living well with dementia in the community work stream***

The action and implementation plans will be mapped against the National Institute for Clinical Excellence (NICE) Quality Standards for dementia care and the social care outcomes framework and Care Quality Commission (CQC) quality standards. A full Equality Impact Assessment will be completed for each work-stream.

The delivery of the NDS is also reflected in:

- NHS White Paper (July 2010)
- NICE guidance (Donepezil, galantamine, rivastigmine and memantine for the treatment of Alzheimers disease (review) March 2011
- Dementia Quality standards, June 2010
- Dementia NICE Guideline March 2011)
- the NHS Operating Framework (2011/12)
- The Social Care Bill (2011)
- Localism Bill (2010),
- National Carers Strategy and
- End of Life Strategy

The issues raised within the All Parliamentary Group on Dementia report entitled '£20 billion question: An inquiry of the APPG on Dementia into improving lives through cost effective dementia services' are addressed within this document.

The strategy provides an overview of the current provision for health and adult social care services, the direction of travel to deliver improved services across Leicester, Leicestershire and Rutland for people eligible for local authority funding and self funders.

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# Chapter 1: National Context

'Living Well With Dementia: A National Dementia Strategy' (NDS) defines dementia as:

*'a syndrome which may be caused by a number of illnesses in which there is progressive decline in multiple areas of function, including decline in memory, reasoning, communication skills and the ability to carry out daily activities. Alongside this decline, individuals may develop behavioural and psychological symptoms such as depression, psychosis, aggression and wandering, which cause problems in themselves, which complicate care, and which can occur at any stage of the illness.'*

The NDS estimated that the prevalence of dementia across the UK was over 700,000 although only one third of people with dementia receive any form of formal diagnosis at any point in their care or during the progression of the condition.

The UK is in the bottom third of countries in Europe for diagnosis and treatment of people with dementia<sup>1</sup>. For older people, it is vitally important to diagnose dementia early so that any identified care plan is more holistic of individual need and can facilitate choice and control. Evidence suggests that early diagnosis and treatment can improve the quality of life for people with dementia and increase their independence as the condition progresses. Statistics indicate that nationally two thirds of people with dementia never receive a diagnosis.

The NDS estimated that dementia costs the UK economy approximately £17 billion a year. This cost is expected to rise as the prevalence of the condition increases due to an increasingly ageing population. It is estimated that the prevalence of dementia will increase to 1.4 million over the next 30 years; this is a 100% increase, with associated costs rising to an estimated £50 billion per year.

The National Institute for Clinical Excellence (NICE) has published the Quality Outcomes Statements (QOS) for Dementia Care. These standards are a set of statements that act as markers for high-quality, cost effective patient care, a benchmark for care providers, service users and commissioners for the services delivered in their health and social care economy. The statements are listed in appendix 1. In addition, NICE has published further guidance for the prescribing of dementia drugs, which is expected to radically change the medication available for people with dementia.

The Social Care Operating Framework (2011) also sets out a number of statements relating to improved care for people with dementia as well as the need for support for their carers and families. These are set out in appendix 2.

The DoH has confirmed local health and social care communities will be held to account, and expected to publish plans detailing how they will work together to deliver high quality care for people living with dementia.

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<sup>1</sup>National Audit Office - Improving services and support for people with dementia on 4 July 2007 <http://www.nao.org.uk/news/0607/0607604.aspx>



This strategy sets out how health and social care partners will deliver against 22 local strategic actions and the national priorities of the NDS across Leicester, Leicestershire and Rutland (LLR).

# Chapter 2: Local Context

## Leicester, Leicestershire and Rutland's Dementia Profile

There are currently 126,200 people over the age of 65 within Leicestershire County and Rutland, and 35,600 in Leicester City. This is predicted to rise to 224, 800 by 2025, an increase of 39%. The increase in the elderly population is much greater in Leicestershire County and Rutland than it is in Leicester City. The following information details the number of estimated people diagnosed with dementia in 2011 and the numbers predicted for the future.

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Although the Dementia Registers and the Leicestershire, Leicester and Rutland (LLR) diagnosis figures show an increase in the prevalence of dementia over time, 60 % of people living with dementia in Leicestershire and Rutland and 50% in Leicester City remain undiagnosed.

While it is relatively easy to identify investment in services specifically targeted at supporting people living with dementia, or those in receipt of older people's mental health services, it is not reflective of the wider investment into services that people with dementia use. As the above QOF rates indicate, the majority of people are unknown to adult primary care and/or social care services, and therefore care is often sub-optimal as it is unplanned, frequently resulting in a crisis intervention.

Other evidence of sub-optimal care resulting from under diagnosis and consequent lack of proactive planning of care packages:

- The National Audit Office report, 'Ensuring the effective discharge of older patients from NHS acute hospitals in 2003', highlighted that older patients were more likely to experience delayed discharge from hospital and that lack of joint working and care home capacity were key factors.

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<sup>1</sup> Report prepared for Leicestershire & Rutland County NHS Primary Care Trust Review of Health Care for Older People with Dementia Analysis of current pattern of commissioning and scope for efficiency and transportation, January 2009.

- A cross-sectional study of the prevalence of co-morbid physical illnesses in people with Alzheimer's disease found that 61% had three or more co-morbid illnesses and that medical co-morbidity increased with medical severity (Improving Services and Support for People with Dementia, National Audit Office, 2007).
- People with dementia over 65 years of age are currently using up to one quarter of hospital beds at any one time (Counting the Cost of Caring for People with Dementia on Hospital Wards, Alzheimer's Society, 2009).

## **Current Investment in Dementia Services**

### **Health Investment**

The direct cost to LLR health and social care services for people over the age of 65 with mental health problems (predominantly with dementia) equates to approximately £67 million per year, which tends to be spent on people with more complex care needs. In addition, informal care costs of £104 million are borne by families or carers (this is a notional or opportunity cost, and represents the value of lost wages or time families/carers would forgo). It could also be interpreted as the cost the state would incur to replace families/carers if they were not undertaking their caring role. £116 million of care home costs are also shared between families (30 per cent) and public funding (70 per cent).

Also older people are more likely to experience delayed discharge from hospitals and lack of 'joined up services' to expedite their return home. Where delayed discharge is a problem, around half of those affected are people with dementia. The DoH estimates that delayed discharges from all causes costs the local NHS for LLR £3 million a year and accounts for 34,000 lost bed days annually<sup>2</sup>.

It is currently not possible to fully determine the true LLR costs of acute and community physical healthcare for people living with dementia as diagnosis is not consistently recorded within a general hospital and physical healthcare community setting.

All Local Authorities and Primary Care Trusts undertake mental health finance mapping and the costs listed in this document are taken from the 2009/10 finance mapping process.

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<sup>2</sup> C&AG's Report, *Ensuring the effective discharge of older patients from NHS acute hospitals* (HC 392, Session 2002–03) para 1.5; Qq 28–30; Ev 19–20 (Q 28)

**Table 1: Current (2010/11) investment in older person’s mental health services across health and social care within LLR**

<b>Leicestershire and Rutland</b>	<b>Leicester City</b>
Older Peoples Mental Health Spend	Older Peoples Mental Health Spend
Health and Social Care commissioned services	Health and Social Care commissioned services
Approx. £42 million	Approx. £27 million

(Source Leicester, Leicestershire & Rutland Council’s & PCT’s finance departments)

Spend on voluntary sector specialist dementia services is not included, but is primarily related to a small spend on advocacy and advice. Spend on specific dementia related carers services are also not included.

Therefore, even with the limitations of the data collection, the greatest area of spend is for people with complex care needs and there is a relatively small spend on prevention and low level support. It is difficult to quantify what organisations spend as people with dementia often do not have a formal diagnosis and therefore the true spend is not clear at this time.

As a consequence, increasing the capacity of primary and secondary care to offer support for people in both the early and late stages of dementia is required. so that people with dementia can continue living in the community

# Chapter 3: Current Provision

## Primary Care: GP Services

Table 2 below reproduced from the 2007 report 'Dementia UK' shows that the estimated number of people with dementia in Leicester was 2606. In Leicestershire and Rutland the estimated number was 7194. In both areas, as with most of the country, there was a shortfall in numbers with dementia on GP registers; indicating perhaps a reluctance to diagnose, record and register a person as having dementia.

The report found that of the estimated 2606 people with dementia in Leicester only 1100 were on GP registers (42.2% of the estimated total). For Leicestershire County and Rutland the number registered with dementia totalled 2575 of the estimated total of 7194 (35.8% of the estimated total).

**Table 2. Numbers of people with dementia in Leicester, Leicestershire and Rutland, projections and proportions on the dementia register (Source, Dementia UK (2007) <sup>3</sup>**

Primary Care Trust Area	Estimated number of people with dementia in 2007	Estimated number of people with dementia in 2021	% Projected increase in number of people with dementia by 2021	Numbers of people on a GP register April 2007-March 2008	% of the numbers of people with dementia currently on the register
Leicester City	2606	3023	16.0	1100	42.2
Leicestershire County and Rutland	7194	11114	54.5	2575	35.8

Table 3 shows figures from the Quality Management and Analysis System (QMAS) database from the end of January 2011. Column 1 is the estimated number of people with dementia, based on an average annual increase from the *Dementia UK* estimations for 2007 and 2021.

**Table 3: Numbers of people with dementia in Leicester, Leicestershire and Rutland, projections and proportions on the dementia register (Source, QMAS Data Jan 2011)**

Primary Care Trust Area	Estimated number of people with dementia in 2010	Numbers of people on a GP register Jan 2011	% of the numbers of people with dementia on the register
Leicester City	2696	1380	51.2
Leicestershire County and Rutland	8034	3167	39.4

Figures from the Dementia UK report imply that there will be an increase in the number of cases of dementia in Leicester of 38 per year and of 280 per year in Leicestershire County and Rutland. This suggested that by the end of 2010 there would have been approximately 2696 cases of dementia in the city and 8034 cases

<sup>3</sup> Alzheimer's Society 2007 Dementia UK Report. London, LSE; Kings College; Alzheimer's Society

in the counties. The QMAS data show that 1380 cases were registered in Leicester (51.2% of the estimated dementia population) and 3167 cases in Leicestershire County and Rutland (39.4% of the estimated dementia population). Both areas have an increase in the proportion of the registered number of people with dementia.

In addition, QMAS data also records the number of people with dementia whose care had been reviewed in the previous 15 months. This data shows that 821 of the 1380 people registered with dementia in Leicester (59.5%) had had their care reviewed in that time period, and 1915 of 3167 (60.5%) registered patients in the counties had had a similar review.

**Table 4: Numbers of people registered with dementia in Leicester, Leicestershire and Rutland who have had a review in the last 15 months (Source, QMAS Data Jan 2011)**

<b>Primary Care Trust Area</b>	<b>Numbers of people on a GP register Jan 2011</b>	<b>Numbers of people on a GP register reviewed in previous 15 months</b>	<b>% patients diagnosed with dementia whose care has been reviewed in the previous 15 months</b>
Leicester City	1380	821	59.5
Leicestershire County and Rutland	3167	1915	60.5

### **What is the issue locally?**

The following factors are considered to have an impact on the numbers of people on the GP dementia registers:

NICE has recently recommended to the NHS in England and Wales, that the drugs donepezil (Aricept) rivastigmine (Exelon) and galantamine (Reminyl) should be made available to people with mild to moderate Alzheimer's Disease (AD). Previously, NICE recommended such treatment for people with more developed dementia. This previous limitation on access to drug treatment, would probably impact on the number of people referred to specialist mental health services for treatment.

GP's report that many patients do not want the stigma of a label of dementia and so in the early stages of the disease more vague symptomatic terms are used such as 'mild memory problems'. This is not a diagnostic code for the QOF dementia registers. As a consequence, GPs may be more aware of increased numbers of people with dementia than the formal QOF registers indicate.

However, there is a discrepancy between the numbers of people we would expect to have dementia locally and the numbers of people we know have dementia, this means people may not be getting the support they need. This does reflect the national picture.

At present anti-dementia drugs available to support some people diagnosed with dementia, can only be prescribed by psychiatrists within the Older Peoples Mental Health Community Teams (CMHT's) and memory clinics. As a result, stable patients cannot be discharged back to their GP's in primary care for ongoing support, as they are unable to access their medication. The development of a shared care protocol

for diagnosis and the prescription of donepezil (Aricept) rivastigmine (Exelon) and galantamine (Reminyl) is required.

## **What are we going to do about it?**

**Strategic Priority 1:** To increase early diagnosis and access to interventions for people with dementia (links to NDS key objective 2).

## **Community Care Provision**

At present the information collected around these services is limited and a key action for the strategy during 2011/12 is to embed robust data collection across all local partners delivering these services to inform future commissioning decisions.

### Community Mental Health Teams for Older People

*This service is provided by Leicestershire Partnership Trust (LPT) and Leicester City, Leicestershire County and Rutland Councils)*

The Community Mental Health Teams (CMHT's) offer a multi-disciplinary assessment and treatment service for older people with complex mental health needs. The service also offers support to older people living with a mental health condition other than dementia such as depression. The teams include health and social care staff who work together to support people in the community to promote independence and reduce the need for an admission to hospital and recovery following admission. The service also aims to reduce admission into residential and nursing care.

There are 9 CMHT's for older people covering LLR, with each team looking after patients referred from a given catchment area i.e. group of GP practices - 2 CMHT's covering the City and 7 covering the counties.

### Memory Assessment Service

*(This service is provided by LPT and commissioned by NHS Leicester City and Leicestershire County and Rutland)*

There are specialist memory clinics covering the whole of LLR for people experiencing some memory loss or showing early signs of dementia. The service is delivered from community clinics, within each of the nine CMHT's localities. The service has psychiatrists, junior doctors, community psychiatric nurses, occupational therapists, support workers, psychologists and other appropriate health professionals. They offer diagnostic and therapeutic assessments, drug treatments, activity schedules, group and psychological support, and treatment monitoring, as well as practical help and support to people with memory problems living in the community.

It is acknowledged that this service has evolved historically through demand and clinical expertise but that going forward the service needs to be specifically commissioned in order to be more closely aligned to need.

At present anti-dementia drugs available to support some people diagnosed with dementia can only be prescribed by the specialist teams within secondary care. As

a result stable patients cannot be discharged back to their GP's in primary care for on-going support as they are unable to access their medication. This has consequently led to capacity issues within the memory assessment service and serves to fragment the pathway of care.

A review of anti-psychotic medication prescribing locally is also now required to ensure it aligns with new DH guidance.

People living with dementia and their carers have stated that it is not clear how to contact services for help, particularly after they have been discharged from a service. They are aware that services are available but do not know how to access them.

**Strategic Priority 2:** To commission a single point of contact for people living with dementia at each step of the care pathway, so as to improve access to advice and services.

**Strategic Priority 3:** To strategically review the pathway for memory assessment and commission a service that is integrated into a health and social care pathway (links to NDS key objective 3).

**Strategic Priority 4:** Improved management of causes of behavioural and psychological symptoms in dementia via LLR wide implementation of prescribing guidelines for managing behaviour problems for people with dementia.

**Strategic Priority 5:** To commission a shared model of care allowing prescribing in both primary and secondary care, to benefit those living with dementia and allow the services to become more efficient (links to NDS key objectives 3 & 4).

#### Intensive Clinical Assessment and Treatment Service (ICATS).

*(This service is provided by LPT and commissioned by NHS Leicester City and Leicestershire County and Rutland)*

ICATS offers intensive support for people in the community and focuses on the intensive assessment and treatment for people with both functional and organic mental health problems. It also links with the locality Community Mental Health Teams and performs a number of roles including assessment, therapy, treatment and support after discharge from hospital, monitoring patients, facilitating groups and services to carers.

At present there are no support services that provide specialist mental health care at times of crisis for people with dementia and their carers out of normal operating hours. As a result if a problem arises outside the operating hours for these services, it can lead to unnecessary admission to hospital to support the patient and family or carers.

**Strategic Priority 6:** To review the existing ICATS model of delivery and develop a service focused on preventing admission to the older person's mental health inpatient wards, and facilitate timely discharge from the inpatient services (links to NDS key objective 6).



**Strategic Priority 7:** To review options for commissioning a joint health and social care crisis response service, to support both users and their families/carers (links to NDS key objective 7).

#### Intermediate Care

*(These NHS services are provided by Community Health Services and commissioned by NHS Leicester City and Leicestershire County and Rutland)*

Intermediate care services aim to support people on discharge from hospital and also to avoid hospital admissions. Intermediate care can be defined as a short term intervention limited to 6 weeks.

Work across the LLR area is in progress to develop integrated health and social care reablement and intermediate care service/s.

A pilot study in Market Harborough is being used to develop the integrated model for services. The integration of intermediate care services and social care reablement is planned to improve the overall effectiveness of both services by reducing hospital admissions and lengths of stay as well as reducing the need for long term social care packages. This service uses nursing and therapeutic resources of intermediate care with packages of social care reablement support within the first 6 weeks of an identified need.

Access to Intermediate Care support is for people living at home and in residential care. There are limitations in access to people living with dementia as all teams do not benefit from the support of a Community Psychiatric Nurse (CPN) and this is an area of inconsistency across Leicestershire and Rutland.

**Strategic Priority 8:** To commission an integrated intermediate care model across health and social care, that is able to support GP's look after physical health care needs of people with early and late stage of dementia in the community (links to NDS key objective 9).

#### Intermediate Care Beds

*(These services are provided by Community Health Services and Leicester City Council, commissioned by NHS Leicester City and Leicestershire County and Rutland)*

There are a number of inpatient facilities available to people requiring support following discharge from general hospital services.

In Leicester City there are two facilities available to older people needing short-term support, including those with dementia. This is delivered from Brookside Court and Elizabeth House. Brookside Court offers 12 reablement beds and 9 intermediate care beds. Elizabeth House offers a residential care assessment centre service for up to 6 weeks, to help determine an individual's long-term care needs. The ultimate aim of this service is to support people to regain their independence, to avoid hospital admission and long-term residential placements where possible.

Not all intermediate care services are able to meet the complex needs of people living with dementia, particularly where people are in the later stages of the disease, and access to Leicestershire and Rutland community hospital beds is inconsistent, and limited.

## Reablement

*(These services are provided by the local authorities and commissioned by the Local authorities)*

Leicester City and Leicestershire County Council both have established reablement services with health and social care input. The service provides intensive free care and support for 4 to 6 weeks, to enable a person to regain and maintain their independence. The aim is to reduce the need for long-term social care and support packages.

Leicester City Council is in the process of re-designing its reablement service to create a fully integrated health and adult social care pathway including a crisis response team to prevent people going into hospital, and enabling those being discharged from hospital care support for approximately 4 weeks. This also includes specific services for people with dementia. The service will also support those living in the community that need a short period of reablement. The service re-design will be underpinned by joint commissioning arrangements, joint working arrangements and a joint investment plan.

Leicestershire County Council has re-designed their Dementia Home Assessment and Reablement Care Service to enable service users with dementia and complex needs to have access to its specialist service. Support provided by this service is for a limited period providing assessment and reablement, to ensure there is a detailed care plan and phased transition to any ongoing service.

Rutland County Council operates a 'REACH' team, which offers up to 6 weeks of free reablement. The service is focussed on supporting people to regain skill, to maintain their independence which is often related to dementia or memory impairment.

Although there are intermediate care and reablement services across LLR for health and adult social care the care pathways are not joined up which can result in pressures being placed on adult social care services especially when dealing with hospital discharges. This situation is often compounded as services are not specifically focussed to support people with dementia or their families and carers.

**Strategic Priority 9:** To commission integrated reablement services that reflect the specialist needs of people with dementia, and to deliver a care pathway that avoids hospital admissions and reduces delayed discharges (links to NDS key objective 6).

## **Hospital Care**

### Mental Health In-patient Facilities

*(These services are provided by Leicestershire Partnership Trust and commissioned by NHS Leicestershire and Rutland and NHS Leicester City).*

NHS across LLR currently commissions 80 in-patient assessment and treatment bed, located at the Evington Centre, which is part of the Leicestershire Partnership Trust (LPT). These beds are for patients over 65 years with organic mental health problems and these will predominantly be people with dementia. In 2009/10 there were approximately 315 admissions to these beds with an average length of stay of 68 days. The primary reason for admissions related to family or carer breakdown which contributed to 42% of the total number of admissions. Family or carer

breakdown often occurs as a result of an exacerbation in the behaviour displayed by the person with dementia. A review of the admissions data for 2009/10 indicated that:

- the average length of stay was approximately 68 days
- 29% of patients stay over 12 weeks
- 48% were discharged to a care home
- 25% were discharge to a general hospital
- 20% were discharged home
- Of those patients that had a length of stay of less than 6 weeks, 49% were discharged to an acute general hospital

Discharges are subject to further analysis under the new payment by results tariff in mental health services. This information should provide a greater level of understanding as to the appropriateness of discharge to care homes and the alternatives that could be considered/developed in the future spanning both health and social care options.

**Strategic Priority 10:** To develop an integrated health and social care community based care pathway that reduced the length of stay and reduces the need for admissions, and is able to meet the mental and physical health care needs of people living with dementia (links to NDS key objectives 5 & 16).

As people living with dementia experience both mental and physical health problems, it is important that the development of this pathway is intrinsically linked to the development of intermediate care services and the frailty work programme.

### General Hospital Care

*(These services are provided by University Hospitals of Leicester (UHL) at the Leicester Royal Infirmary, Leicester General Hospital and Glenfield Hospital)*

University Hospitals of Leicester (UHL) have recently carried out a review of the care they give to support people living with dementia. The data show a lack of a standardised approach to the assessment and recording of the mental health status of older people admitted to local acute hospitals. Often these people do not present with a confirmed diagnosis of dementia and without a systematic approach to assessment and recording there will continue to be under reporting of the numbers of people living with dementia accessing general hospital care. Therefore it is difficult to quantify the impact an individual's dementia status has on the care received, for example, how long a person living with dementia stays within the general hospital setting compared to their peers who do not have dementia.

The review also highlighted the need to improve access to liaison psychiatric support for older people experiencing mental health problems. This is in line with national findings and recommendations.

The baseline review also demonstrated that considerable effort is needed to ensure that the core principles of caring for someone living with dementia are embedded across the hospital trust. Improving the care for people living with dementia has been acknowledged by UHL, which reflects the focus of the Lord Mayor's project (see below).

**Strategic Priority 11:** To ensure consistent detection of cognitive impairment within the general hospital setting and the development of appropriate care pathways (links to NDS key objectives 8 & 12).

The key areas to be addressed are:

- the adaptation of a number of wards to become 'dementia friendly'
- the development of a sensory garden at the Leicester General Hospital (the Lord Mayor's project)
- the provision of enhanced training to support specific staff groups in caring for someone living with dementia, including end of life

## **Carer's Support**

The contribution of carers in supporting vulnerable people has been acknowledged in the National Carers Strategy. In monetary terms, if family carers did not care for their loved ones, it would cost the Government a further £104 million a year. Therefore, it is important to acknowledge the valuable role families and carers play in supporting people with dementia and to ensure that they themselves have adequate support to continue to undertake their caring role.

LLR Local Authorities currently offer a number of services to support people caring for someone with dementia including advice, information, advocacy services and Carers Support Grants. These can be paid as a personal budget to enable a carer to buy support services to assist with their caring role, such as respite care on an ad hoc basis to give carer's a break from their caring role. This might include short stays in residential accommodation, 'respite at-home', short-stay sitting services, day care services, befriending services and dementia cafes.

As carer assessment and support is mainly initiated once a person living with dementia comes into contact with services, people caring for someone with dementia who have not accessed services are often missed. This means that they remain unaware of how to access early stage advice and information about support and that an individual presents to services at a time of crisis when a carer cannot cope.

Feedback from local stakeholders including users and carers has been consistent with the national findings and the work to produce the strategy has involved a series of engagement events with stakeholders some of which were facilitated by CSED.

**Strategic Priority 12:** To ensure all families/carers have access to dementia support services as early as possible, and to ensure that a Carer's Assessment is completed as part of an integrated care pathway across health and social care (links to NDS key objectives 7 & 15).

**Strategic Priority 13:** To commission a range of respite services, to support carers in their caring role (links to NDS key objectives 7 & 15).

## **Other support services to facilitate people living with dementia in the community**

In cases where people require ongoing support there are a number of services available depending on the level of assessed need of the individual.

Wherever appropriate, services are aimed at supporting an individual to live as independently as possible for as long as possible and there are a number of care options available to support this.

### Personalisation

Personalisation is a new way of delivering social care services: personalisation means thinking about care and support services in an entirely different way. This means starting with the person as an individual with strengths, preferences and aspirations and putting them at the centre of the process of identifying their needs and making choices about how and when they are supported to live their lives. It has meant there has been a significant change to the way adult social care services are provided.

There are four areas on which councils and their partners have focussed on to help make sure services become more personalised and to get the right results for people.

1. **Universal services** – providing general support and services available to everyone locally including things like transport, leisure, education, health, housing, community safety and access to information and advice.
2. **Early Intervention and Prevention** - support available to assist people who need a little more help, at an early stage to stay independent for as long as possible  
e.g. assistive technology, reablement etc.
3. **Choice and Control** - is about giving people the freedom to choose the services that suit them best, and to control how and when they receive those services.
4. **Social Capital** - is about how society works to make sure everyone has the opportunity to be part of a community and experience the friendships and care that can come from families, friends and neighbours.

Personal budgets were introduced as part of the National Personalisation Agenda in adult social care, which aims to give people much greater choice and control in the services arranged to meet their needs for care and support. The aim is to ensure that individuals eligible for social care services are allocated an amount of money to help arrange their support, based on their assessed need and to deliver agreed outcomes. The budget may be taken as a direct cash payment or as managed services.

Recent changes to direct payment rules have enabled more people living with dementia and a nominated suitable person to access direct payments, where issues of mental capacity may have prevented them from participating in the scheme in the past.

The national drive is that by 2013 all individuals accessing support from social care should be offered direct payments to meet their identified needs. This underpins the transformation and future direction of travel for adult social care, allowing more

individualised support and enabling people to live quality lives independently for as long as possible.

All three local authorities have implemented self-directed support, with all new service users accessing personal budgets and existing users transferring following a review.

**Strategic Priority 14:** To ensure that people diagnosed with dementia are given a personal budget, if eligible for support and that self funders are given appropriate advice and information as to the services available to them (links to NDS key objectives 6 & 15).

### Day Care

*(Local authority responsibility)*

Day Care is currently provided by the LLR Local Authorities for a range of vulnerable people including those with dementia. However, as part of the personalisation agenda and greater demand for community based opportunities, both Leicester City and Leicestershire County Council are currently reviewing their approach to delivering day care services for older people. The aim is to ensure that people have choice and control over services they receive and that services are flexible enough to meet people's individual needs. This could also include the development of specialist community based dementia service, which are more likely to be provided by the voluntary/independent sector who have the skills in this field..

Rutland County Council offers specialist day opportunities in residential care homes as well as personal budgets to enable 1:1 tailored support in service users' own homes.

**Strategic Priority 15:** For commissioners to work with the voluntary/independent sector to develop community based dementia services, to enable people to use their personal budgets to buy appropriate services (links to NDS key objective 6).

### Homecare and Personal Care

*(Local authority responsibility)*

These services offer support to allow people to continue living in their own homes whilst being able to access support to meet their identified personal needs. Both Leicestershire County and Leicester City Councils are currently reviewing their services ensuring that clear specifications and robust contract management are in place to ensure that the services meet the needs of the people they care for.

**Strategic Priority 16:** Increased specialist dementia home care to reflect improved quality, and choice and control for the individual (links to NDS key objective 6).

### Assistive Technology

*(Local authority responsibility)*

Assistive Technology (AT) is the generic term for Telecare and Telehealth. It is an effective way of supporting people with a wide range of conditions in their own home, reducing and/or delaying admissions to hospital, residential or nursing care. It is any product or service designed to enable independence for disabled and older people

and can also support carers, for example technological equipment that provides solutions ranging from:-

- Community alarms (life-lines) linked to an emergency response service
- Add-on equipment - sensors that monitor and support daily living
- Electronic motion monitoring equipment, and
- Remote monitoring of key diagnostic symptoms for people with long-term health conditions

It is recognised that the use of AT is one of the key preventative tools that can enable people to remain independent and is a cost effective method of meeting the social care and health needs of a growing population of older and disabled people.

Leicester City and Leicestershire County Councils both have an AT Strategy and there are staff specially trained to assess and install assistive technology equipment.

However, due to the lack of integrated health and social care pathways the use of AT is not fully embedded or exploited especially in relation to reducing the number of people needing long term health or social care support, including those with dementia or in supporting the reablement programme.

**Strategic Priority 17:** To ensure that, where needed, the use of assistive technology is commissioned and embedded into the care pathways across health and social care for people with dementia (links to NDS key objectives 6 & 10).

### Extra Care Housing

*(Local authority responsibility)*

The provision of Extra Care is a response to enduring demographic change that allows people in need of care and support to remain independent or remain in one place without having to move in particular to residential care or nursing homes.

Extra Care Housing offers purpose built accommodation to allow for a flexible and adaptive approach to the care of older people. Based on individuals' needs, this can increase or diminish according to circumstances. Personal care and housing support is available on site throughout a 24 hour period, 7 days a week. This model includes self contained accommodation and access to shared facilities.

Leicestershire County Council's Housing Related Support Strategy 2010-15 recognises the need for specialist care such as dementia. The ability to support an individual with dementia is greatly increased by an early move into a scheme whilst they still have some understanding and the capacity to develop relationships and adapt to new surroundings. However, Extra Care may not be appropriate for people who are in the advanced stages of dementia.

There are currently five schemes categorised as Extra Care Housing schemes in Leicestershire and two in Leicester City, managed by Registered Social Landlord (RSL's) housing providers. The schemes are also able to support people with low to moderate levels of dementia. One RSL in Rutland is in the early stages of developing a scheme offering both extra care and nursing care.

However, due to the affordability of Extra Care Housing schemes and with changes in the funding/grant arrangements from the Homes & Communities Agency (HCA), it is unlikely that many traditional Extra Care schemes will be built in the future. There is, however, the opportunity to develop 'life time' homes. These can include the conversion of some existing accommodation and the development of new build properties (on a smaller scale), which include separate flats, with wheel chair access, wet rooms and assistive technology. Some communal facilities are also included, such as a hoisted bathroom and a space for support workers. This type of model means that people can remain independent in the community with flexible support that is provided at a point in time when it is required, including to people with dementia.

**Strategic Priority 18:** To ensure that local housing strategies include the commissioning of life time accommodation that can support older people, and those with dementia within the community. This links to the strategic action to reduce the number of people with dementia moving from hospital into residential care (links to NDS key objective 10).



## Deprivation of Liberty Service

*(Local authority responsibility)*

Deprivation of Liberty Safeguards (DOLS), established by the Mental Capacity Act 2005, provides legal protection for vulnerable people who lack capacity to consent to the arrangements for their care or who receive care that deprives them of their liberty,

LLR health and social care services jointly established a local implementation network to set up and oversee a DOLS service. The service raises awareness and provides training on DOLS issues, encouraging all providers to ensure that their service and environments maximise choice and minimize restrictions. It is establishing consistent local procedures to implement the safeguards. A jointly funded team manages all DOLS assessments across LLR. Independent representatives can be appointed for individuals without an appropriate personal representative who are at risk of being deprived of their liberty.

Access is also commissioned to a service providing independent advocacy for vulnerable people facing decisions around serious medical treatment and change of residence.

## Advice and Information

LLR Local Authorities all commission advocacy services to provide independent advice and support for people with dementia and their families or carers. In addition, information and advice services specifically for people with dementia are commissioned as well as carers' support services. Leicestershire County Council commission Dementia Support Worker posts in partnership with the Alzheimer's Society for this purpose.

Leicestershire County Council are developing an Adults & Communities Information and Advice Strategy which will include analysis of the advice & information needs of people with dementia.

Leicester City Council has restructured its care management services to include eight locality based Dementia Care Advisor posts to provide advice and support to people at the time of diagnosis.

Leicestershire County Council commissions a service with Age Concern Leicestershire and Rutland to provide advice and support at the point of diagnosis and are due to begin a pilot project in partnership with NHS LCR and the Alzheimer's Society for a Dementia Advisor post based in the primary care setting.

Although individual authorities have commissioned some specialist advice services, these are limited and they need to be incorporated into an integrated care pathway across health and social care services. To be effective, advice and information needs to be provided at specific points as part of the care pathway for people with dementia and their families/carers.

**Strategic Priority 19:** For all people diagnosed with dementia, ensure that advice and information is effectively deployed as part of an integrated care pathway across health and social care (links to NDS key objectives 1 & 3).

### Residential and Nursing Care

In cases where residential care is required, this may be in either a residential or nursing home setting, depending on the level of need. At present there are over 120 residential or nursing homes registered to support people with dementia. Work is ongoing by both Primary Care Trusts and the Local Authorities across LLR to ensure that services meet stringent quality standards and individual outcomes by establishing appropriate contracts and specifications. However, this approach does not include the development of joint standards, which would enable the effective monitoring of care ultimately leading to improved joint safeguarding responses.

Alongside care home staff, it is acknowledged that GP's are central to the care of people living with dementia in care homes. It is important to ensure that care homes and GP's are equipped to manage the needs of people with dementia in order to maximise the care home's ability to manage the needs of people with dementia. In this way they are able to enjoy the stability of living in one care home without the need to be moved into to another care home or hospital.

A pilot project to reduce the prescribing of anti psychotic medication for people with dementia in care homes, via access to 'in reach specialist dementia support', will be undertaken. It is intended that this pilot project will offer support to both the care home staff and GP's in the management of behavioural and psychological symptoms in dementia. The evaluation of this project will inform future commissioning decisions.

It is also necessary to work with the independent providers to ensure their workforce is competent to deliver improved standards of care, and specialist dementia training.

**Strategic Priority 20:** To ensure that commissioned services include a range of quality standards to reflect the NICE and Care Quality Commission (CQC) standards (links NDS key objectives 11 &15).

**Strategic Priority 21:** LLR wide implementation of prescribing guidelines for managing behaviour problems for people with dementia

**Strategic priority 22:** review access to specialist support and other in reach for people living in care homes (links to NDS Key objective 11).

### Workforce Planning

Workforce planning is essential in ensuring that we secure and maintain a talented workforce to deliver the Dementia Strategy across Leicester, Leicestershire and Rutland.

There is a Dementia Workforce Planning Group (DWPG) in place to progress and oversee the development of the Dementia Workforce Strategy, which is supported by the Education Sub Group (ESG). This work is being taken forward as a fifth work stream of the Dementia Strategy.

Through engagement events, service users and carers have identified the workforce issues as:

- culturally appropriate services
- a representative workforce
- dementia training for all – not just the specialists
- more partnership working – really working together
- respect individual diversity
- person centred care
- staff with the right attitude

People with dementia are not being diagnosed early enough and this issue is being addressed by the NHS. In respect of the LLR Local Authorities, dementia training and awareness raising are available, but this is often ad hoc and needs to be delivered in a more co-ordinated way as part of the care pathway for dementia.

**Overarching Strategic Priority 23:** To ensure that workforce is commissioned to deliver services to support the care pathway for dementia (links to NDS key objectives 1 & 13).

The DWPG will develop and oversee the workforce strategy action plan. The ESG is developing a programme of tiered dementia training (categories A, B and C) which provides a competency based approach.

# Chapter 4: Local Progress in Delivering the National Dementia Strategy

In order to implement the National Dementia Strategy (NDS) a Local Implementation Network (LIN) was established in LLR made up of stakeholders from across the health and social care community. The purpose of the group was to allow the sharing of best practice and key developments in line with the NDS.

The LIN 2009 worked with the DoH in the East Midlands supported by the Care Services Efficiency and Delivery Agency (CSED) to host a series of workshops to map out current performance against the NDS objectives. The workshops brought together people living with dementia, their families and carers and other stakeholders to review service delivery against the NDS.

The series of workshops explored the 'as is' pathway, in terms of what was good about the pathway and what hadn't worked so well. In particular the workshops looked at individuals' experiences, to draw out the factors that resulted in them 'tipping' into needing a higher level of care and support.

The workshops highlighted the key 'tipping factors' that often result in people requiring higher levels of support, and were around breakdown in times of crisis. The families and carers present at the workshops highlighted that when things went wrong, they felt powerless and unsure about what to do.

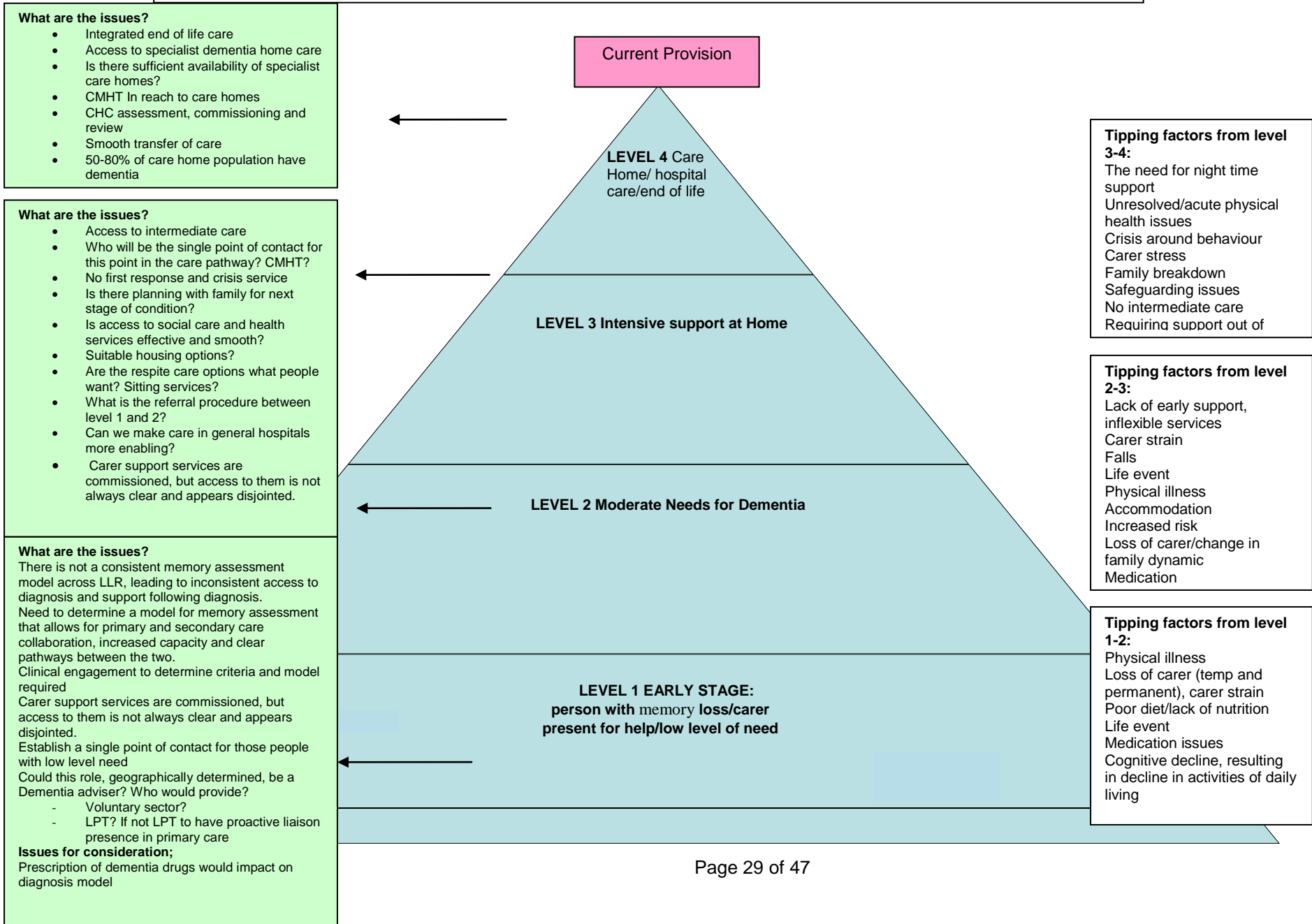
A summary of the issues relating to the current dementia pathway are detailed in diagram 1.

The outcome of the workshops was the identification of 22 strategic actions for the development and re-design of the dementia pathway.

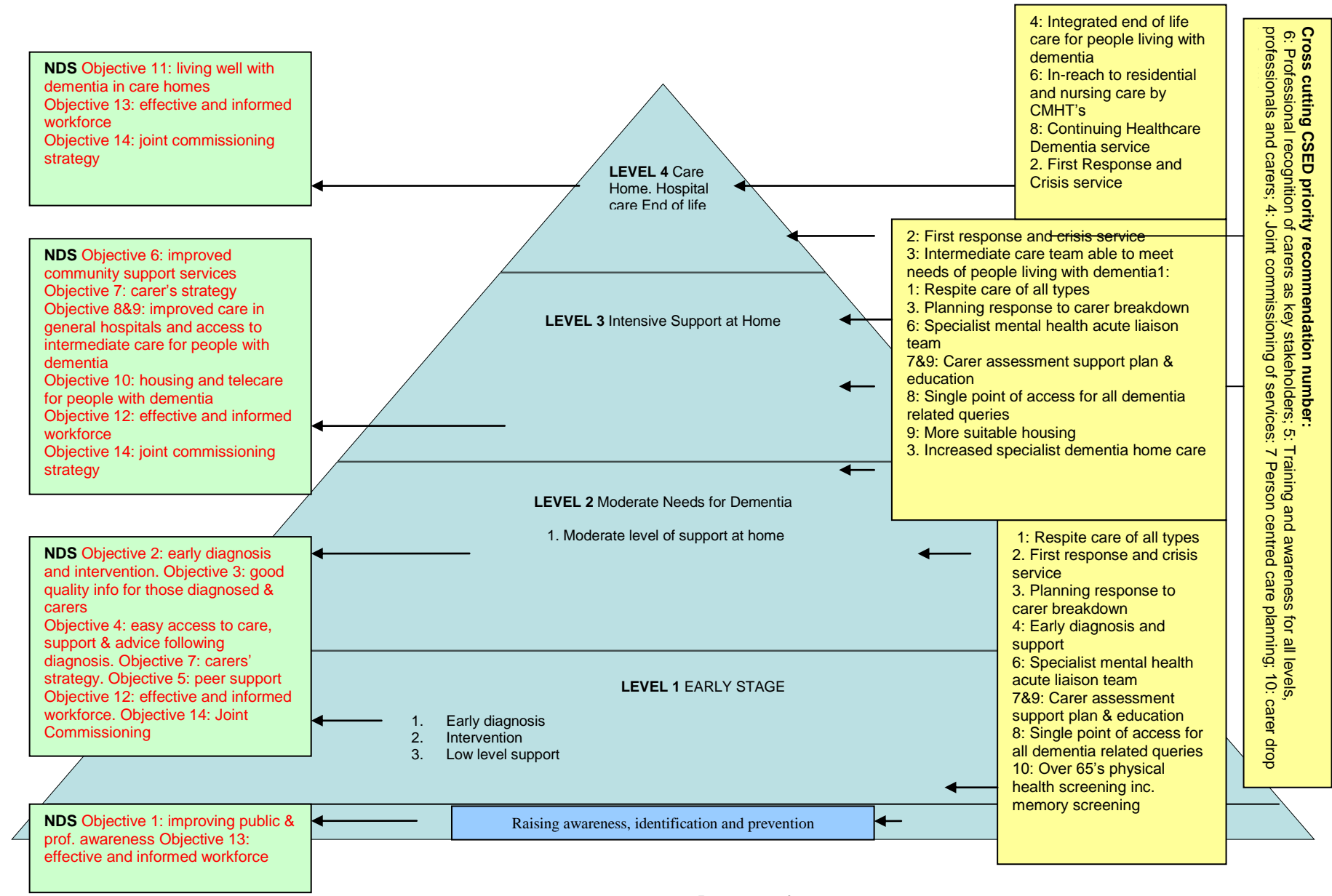
These are illustrated in diagram 2, where they are aligned to the key objectives of the NDS and reflect the national care pathway model. This analysis has underpinned the development of the LLR Joint Dementia Strategy and delivery plan (links to NDS key objective 14).

**Diagram 1. Current Care Pathway and Gap Analysis**  
**- Leicester, Leicestershire and Rutland (LLR) Integrated Dementia Care pathway with reference to local priority recommendations from the Care Services Efficiencies Delivery Programme (CSED) stakeholder workshops.**

End of life care



**Diagram 2. Future Care Pathway**  
**Leicester, Leicestershire and Rutland (LLR) Integrated Dementia Care pathway with reference to the National Dementia Strategy (NDS) and local strategic actions**



# Chapter 5: Local Priorities

The local strategic actions, identified as part of the engagement process, and the 17 key objectives of the NDS have been grouped into four strategic themes. These reflect the overarching national NDS objective and stakeholder work shop recommendations:

1. early diagnosis and access to care and support services
2. improved experience of general hospital care and the management of physical health needs of people living with dementia
3. improved quality of care in residential/care homes
4. personalisation of care and living well with dementia in the community

These themes have been translated into four delivery work streams, as a means to developing integrated pathways across health and social care services. Continued engagement with all stakeholders is crucial to the pathway development and the establishment of core stakeholder groups will ensure people with dementia and their families/carers are central to all developments in service delivery. A fifth work stream has been added to cover the overarching theme of workforce planning, education and training.

The local strategic themes and priority actions have been developed into a governance structure that will oversee the implementation. Each of the above 5 strategic themes will be translated into an action and implementation plan:

1. NHS LCR/Leicester City and LPT will lead on the early diagnosis and access to care and support services work stream
2. NHS LCR/Leicester City and UHL will lead on the Improved experience of general hospital care work stream
3. Leicestershire County Council will lead on the Improved quality of care in residential/care homes work stream
4. Leicester City Council will lead on the implementation of Personalisation of care and living well with dementia in the community work stream
5. LLR Workforce Development Team will lead on workforce planning, education and training

The key outcomes of success will be measured against the National Institute for Clinical Excellence (NICE) Quality Outcomes Statements (QOS) for Dementia Care and the Social Care Operating Framework (2011). There is also an overarching workforce development strategic action.

**Work stream 1: Increased awareness, early diagnosis and access to care and support services.**

**Strategic Priority 1:** To increase and improve early diagnoses and access to interventions for people with dementia (links to NDS key objective 2).

**Strategic Priority 2:** To commission a single point of contact for people living with dementia at each step of the care pathway, so as to improve access to advice and services.

**Strategic Priority 3:** To strategically review the pathway for memory assessment, and commission a service that is integrated into a health and social care pathway (links to NDS key objective 3).

**Strategic Priority 4:** Improved management of causes of behavioural and psychological symptoms in dementia via LLR wide implementation of prescribing guidelines for managing behaviour problems for people with dementia.

**Strategic Priority 5:** To commission a shared model of care allowing prescribing in both primary and secondary care to benefit those living with dementia and allow the services to become more efficient (links to NDS key objectives 3 & 4).

**Strategic Priority 12:** To ensure all families/carers have access to dementia support services as early as possible, and to ensure that a Carer's Assessment is completed as part of an integrated care pathway across health and social care (links to NDS key objectives 7 & 15).

**Strategic Priority 13:** To commission a range of respite services, to support carers in their caring role (links to NDS key objectives 7 & 15).

**Strategic Priority 15:** For commissioners to work with the voluntary/independent sector to develop community based dementia services, to enable people to use their personal budgets to buy appropriate services (links to NDS key objective 6).

**Strategic Priority 17:** To ensure that, where needed, the use of assistive technology is commissioned and embedded into the care pathways across health and social care for people with dementia (links to NDS key objectives 6 & 10).

**Strategic Priority 19:** For all people diagnosed with dementia, ensure that advice and information is effectively deployed as part of an integrated care pathway across health and social care (links to NDS key objective 1 & 3).

**Overarching Strategic Priority 23:** To ensure that workforce is commissioned to deliver services to support the care pathway for dementia (links to NDS key objectives 1 & 13).

### **Who will lead delivery?**

This will be led by Primary Care Trusts Dementia Commissioners, LPT and Mental Health Primary Care Champions who will engage with prescribing leads. The implementation of anti psychotic prescribing guidelines across LLR will be led by Cluster and Consortia Medicines Management Team and Commissioners, with LPT clinical and pharmaceutical expertise.



## **How will achievement be measured?**

- There will be services commissioned to offer support, information and advice for people and their carers within primary and secondary care.
- Service specifications to include quality standards as required. Outcomes and data will be measured within contract monitoring process.
- Increase in the proportion of people with dementia having a formal diagnosis compared with the local estimated prevalence.
- Increase in the number of patients and carers who have a positive service experience

## **Work stream 2: Improved experience of general hospital care and the management of physical health needs of people living with dementia**

**Strategic Priority 3:** To strategically review the pathway for memory assessment, and commission a service that is integrated into a health and social care pathway (links to NDS key objective 3).

**Strategic Priority 4:** Improved management of causes of behavioural and psychological symptoms in dementia via LLR wide implementation of prescribing guidelines for managing behaviour problems for people with dementia.

**Strategic Priority 8:** To commission an integrated intermediate care model across health and social care, that is able to support GP's look after physical health care needs of people with early and late stage of dementia in the community (links to NDS key objective 9).

**Strategic Priority 9:** To commission integrated reablement services that reflect the specialist needs of people with dementia, and to deliver a care pathway that avoids hospital admissions and reduces delayed discharges (links to NDS key objective 6).

**Strategic Priority 10:** To develop an integrated health and social care community based care pathway that reduced the length of stay and reduces the need for admissions, and is able to meet the mental and physical health care needs of people living with dementia (links to NDS key objectives 5 & 16).

**Strategic Priority 11:** To ensure consistent detection of cognitive impairment within the general hospital setting and the development of an appropriate care pathway (links to NDS key objectives 8 & 12).

**Strategic Priority 12:** To ensure all families/carers have access to dementia support services as early as possible, and to ensure that a Carer's Assessment is completed as part of an integrated care pathway across health and social care (links to NDS key objectives 7 & 15).

**Strategic Priority 14:** To ensure that people diagnosed with dementia are given a personal budget, if eligible for support, and those who are not are given appropriate advice and information (links to NDS key objectives 6 & 15).

**Strategic Priority 15:** For commissioners to work with the voluntary/independent sector to develop community based dementia services, to enable people to use their personal budgets to buy appropriate services (links to NDS key objective 6).

**Strategic Priority 19:** For all people diagnosed with dementia, ensure that advice and information is effectively deployed as part of an integrated care pathway across health and social care (links to NDS key objective 1 & 3).

**Overarching Strategic Priority 23:** To ensure that workforce is commissioned to deliver services to support the care pathway for dementia (links to NDS key objectives 1 & 13).

### **Who will lead delivery?**

Local delivery will be led by the main acute general hospital in partnership with other key stakeholders, via UHL using the Cluster Acute Contracting Team and quality directorate. This work stream should be intrinsically linked to the LLR frailty agenda

### **How will we measure success?**

- The development of general hospital care pathway including the journey into accessing intermediate care services and End of Life Care
- Development of consistent standardised mental health screening status for older people displaying cognitive and mental health problems, including delirium and depression within general hospital settings
- All community care pathways will be made available to people eligible for local authority funding and self-funders

### **Work Stream 3: Improved quality of care in residential/care homes**

**Strategic Priority 4:** Improved management of causes of behavioural and psychological symptoms in dementia via LLR wide implementation of prescribing guidelines for managing behaviour problems for people with dementia.

**Strategic Priority 7:** The review options for commissioning a joint health and social care crisis response service, to support both users and their families/carers (links to NDS key objective 7).

**Strategic Priority 20:** To ensure that commissioned services include a range of quality standards to reflect the NICE and Care Quality Commission (CQC) standards (links NDS key objectives 11 &15).

**Strategic Priority 21:** LLR wide implementation of prescribing guidelines for managing behaviour problems for people with dementia.

**Strategic priority 22:** Review access to specialist support and other in reach for people living in care homes (links to NDS Key objective 11)

**Overarching Strategic Priority 23:** To ensure that workforce is commissioned to deliver services to support the care pathway for dementia (Links to NDS key objectives 1 & 13).

### **Who will lead delivery?**

Implementation of the national contract will be lead by Local Authority and Primary Care Trust Care Homes contracting leads.

The review of service delivery will be led by PCT and LA contract leads, PCT quality directorate and Continuing Healthcare Team.

Leicester Partnership Trust will deliver the care home/anti psychotic reduction pilot project, with PCT medicines management and commissioning involvement.

The implementation of anti psychotic prescribing guidelines across LLR will be led by PCT Medicines Management Team and Commissioners, with LPT clinical and pharmaceutical expertise.

### **How will achievements be measured?**

- There will be a greater strategic understanding of all partners locally of capacity versus demand of care home places and how quality impacts on capacity.
- A model of how to facilitate access to specialist dementia support to people living with dementia in care homes will be developed. This will inform future commissioning decisions and content of service specifications. This will be centred on the NICE quality standards 7 and 9.
- There will be a baseline figure on anti psychotic prescribing in care homes and consequential completion and implementation of an action plan to facilitate reduction in prescribing rates
- Contracts will include NICE quality standards for dementia and a reduction in anti psychotic prescribing for people living with dementia

### **Work stream 4: Personalisation of care and living well with dementia in the community**

**Strategic Priority 2:** To commission a single point of contact for people living with dementia at each step of the care pathway, so as to improve access to advice and services.

**Strategic Priority 4:** Improved management of causes of behavioural and psychological symptoms in dementia via LLR wide implementation of prescribing guidelines for managing behaviour problems for people with dementia.

**Strategic Priority 6:** To review the existing ICATS (Intensive Community Assessment and Treatment Services) model of delivery, to develop a service focused on prevent admission to the older person's mental health inpatient wards,

and facilitate timely discharge from the inpatient services (links to NDS key objective 6).

**Strategic Priority 7:** The review options for commissioning a joint health and social care crisis response service, to support both users and their families/carers (links to NDS key objective 7).

**Strategic Priority 8:** To commission an integrated intermediate care model across health and social care, that is able to support GP's look after physical health care needs of people with early and late stage of dementia in the community (links to NDS key objective 9).

**Strategic Priority 9:** To commission integrated services that reflect the specialist needs of people with dementia, and to deliver a care pathway that avoids hospital admissions and reduces delayed discharges (links to NDS key objective 6).

**Strategic Priority 10:** To develop an integrated health and social care community based care pathway that reduces the length of stay and reduces the need for admissions, and is able to meet the mental and physical health care needs of people living with dementia (links to NDS key objectives 5 & 16).

**Strategic Priority 12:** To ensure all families/carers have access to dementia support services as early as possible, and to ensure that a Carer's Assessment is completed as part of an integrated care pathway across health and social care (links to NDS key objectives 7 & 15 and the Carers Strategy).

**Strategic Priority 13:** To commission a range of respite services, to support carers in their caring role (links to NDS key objectives 7 & 15).

**Strategic Priority 14:** To ensure that people diagnosed with dementia are given a personal budget, if eligible for support and those who are not, are given appropriate advice and information (links to NDS key objectives 6 & 15).

**Strategic Priority 15:** For commissioners to work with the voluntary/independent sector to develop community based dementia services, to enable people to use their personal budgets to buy appropriate services (links to NDS key objective 6).

**Strategic Priority 16:** Increased specialist dementia home care to reflect improved quality, and choice and control for the individual (links to NDS key objective 6).

**Strategic Priority 17:** To ensure that, where needed, the use of assistive technology is commissioned and embedded into the care pathways across health and social care for people with dementia (links to NDS key objectives 6 & 10).

**Strategic Priority 18:** To ensure that local Housing Strategies include the commissioning of life time accommodation that can support older people, and those with dementia within the community. This links to the strategic action to reduce the number of people with dementia moving from hospital into residential care (links to NDS key objective 10).

**Overarching Strategic Priority 23:** To ensure that workforce is commissioned to deliver services to support the care pathway for dementia (links to NDS key objectives 1 & 13).

**Who will lead delivery?**

Local authority commissioning leads, with LPT collaboration.

**How will we measure success?**

- An agreed pathway from the mental health hospital setting to the community, with particular reference to how people and their carers' needs will be met in a crisis.
- Future service specifications will include the above quality standards and will be measured within the contract monitoring process.
- All carers of people with dementia will be offered a Carers Assessment.
- The community care pathway will be made accessible to people eligible for local authority funding and self funders.
- As people living with dementia experience both mental and physical health problems, it is important that the development of a community mental health care pathway is intrinsically linked to the development of intermediate care services.

**Work stream 5:** To ensure that workforce is commissioned to deliver services to support the care pathway for dementia (links to NDS key objectives 1 & 13).

- To develop a sub-regional dementia workforce strategy
- Complete a cross organisational training needs analysis against the LLR dementia training framework
- Pilot the Basic Awareness session with INSPIRE
- Develop an e-learning version of the Basic Awareness session
- Develop an evaluation toolkit for assessing outcomes in line with the strategy
- Develop the resources for the enhanced and specialist training

**Who will lead delivery?**

All LLR partners

**How will we measure success?**

- A LLR wide strategy will be in place which will see a range of training and education opportunities

## Chapter 6: Local Delivery

There are many people and organisations involved in the delivery of care for people living with dementia, and the efficient and effective use of services is dependant on the development of agreed inter agency care pathways. The development of this joint strategy aims to create a governance structure that will allow for the co - ordination and development of such inter agency pathways.

### Governance Structure

As all commissioning organisations (Leicester City Council, Leicestershire County Council, Rutland County Council, NHS Leicester City and Leicestershire County and Rutland) are members of the Dementia Joint Commissioning Group (DJCG), the DJCG will oversee progress of the delivery plan and report to their respective organisational boards.

The DJCG will ensure that it is able to accurately review progress by ensuring that it has formal and regular communication channels with work streams within the delivery plan. NHS, LCR and Leicester City Members will ensure that they are able to state progress within all NHS stakeholder organisations, and LA Members able to state progress with social care work streams.

A governance structure diagram can be found in appendix 3.

The following work streams and lead organisations will develop an implementation and action plan, which will outline wider stakeholder collaboration and timelines for completion.

1. NHS LCR and Leicester City and LPT will lead on the early diagnosis and access to care and support services work stream
2. NHS LCR/Leicester City and UHL will lead on the Improved experience of general hospital care work stream
3. Leicestershire County Council will lead on the Improved quality of care in residential/care homes work stream
4. Leicester City Council will lead on the implementation of Personalisation of care and living well with dementia in the community work stream
5. LLR Workforce Development Team will lead on workforce planning, training and education

The action and implementation plans will be mapped against the NICE quality Standards for dementia care (Appendix 1) and the social care outcomes framework and CQC quality standards (appendix 2).

## Appendix 1: NICE Quality Standards for Dementia Care

People with dementia receive care from staff appropriately trained in dementia care.

1. People with suspected dementia are referred to a memory assessment service specialising in the diagnosis and initial management of dementia.
2. People newly diagnosed with dementia and/or their carers receive written and verbal information about their condition, treatment and the support options in their local area.
3. People with dementia have an assessment and an ongoing personalised care plan, agreed across health and social care that identifies a named care coordinator and addresses their individual needs.
4. People with dementia, while they have capacity, have the opportunity to discuss and make decisions, together with their carer/s, about the use of: advance statements, advance decisions to refuse treatment, Lasting Power of Attorney, Preferred Priorities of Care.
5. Carers of people with dementia are offered an assessment of emotional, psychological and social needs and, if accepted, receive tailored interventions identified by a care plan to address those needs.
6. People with dementia who develop non-cognitive symptoms that cause them significant distress, or who develop behaviour that challenges, are offered an assessment at an early opportunity to establish generating and aggravating factors. Interventions to improve such behaviour or distress should be recorded in their care plan.
7. People with suspected or known dementia using acute and general hospital inpatient services or emergency departments, have access to a liaison service that specialises in the diagnosis and management of dementia and older people's mental health.
8. People in the later stages of dementia are assessed by primary care teams to identify and plan their palliative care needs.
9. Carers of people with dementia have access to a comprehensive range of respite/short-break services that meet the needs of both the carer and the person with dementia.

## Appendix 2: Adult Social Care Operating Framework (2011)

1A	Social care-related quality of life (High is good)
1B	The proportion of people who use services who have control over their daily life (High is good)
1C/NI130	Proportion of people using social care who receive self-directed support, and those receiving direct payments (Higher is good)
1D	Care-reported quality of life – not required until 2012/13
1H	Proportion of adults in contact with secondary mental health services living independently; with or without support (Higher is good)
2A	Permanent admissions to residential and nursing care homes, per 1,000 population (Lower is better)
NI 125	Achieving independence for older people through rehabilitation/intermediate care (Higher is good)
2B	Proportion of older people (65 and over) who are still at home 91 days after discharge from hospital into reablement/rehabilitation services.
2C/NI131	Delayed Transfers of Care (Lower is good)
2C	Sub measures number of delays from above that are attributable to adult social care
3A	Overall satisfaction of people who use service with their care and support (High is good)
3B	Overall satisfaction of carers with social services – not required until 2012/13 (High is good)
3C	The proportion of carers who report that they have been included or consulted in discussion about the person they care for – not required until 2012/13 (High is good)
3D	The proportion of people who use services and carers who find it easy to find information about services – (2011/12 relates to ASC user survey) (High is good)
4A	The proportion of people who use services who feel safe (High is good)
4B	The proportion of people who use services who say that those services have made them feel safe and secure (High is good)
NI132	Timelines of social care assessments – (Higher is good)
NI133	Timelines of social care packages following assessment (Higher is good)
NI135	Carers receiving assessment or review and a specific carer's service or advice and information (Higher is good)
PAF D40	Clients receiving a review



## **Care Quality Standards (2010/11)**

### **Involvement and information**

- Outcome 1: Respecting and involving people who use services
- Outcome 2: Consent to care and treatment
- Outcome 3: Fees

### **Personalised care, treatment and support**

- Outcome 4: Care and welfare of people who use services
- Outcome 5: Meeting nutritional needs
- Outcome 6: Cooperating with other providers

### **Safeguarding and safety**

- Outcome 7: Safeguarding people who use services from abuse
- Outcome 8: Cleanliness and infection control
- Outcome 9: Management of medicines
- Outcome 10: Safety and suitability of premises
- Outcome 11: Safety, availability and suitability of equipment

### **Suitability of staffing**

- Outcome 12: Requirements relating to workers
- Outcome 13: Staffing
- Outcome 14: Supporting workers

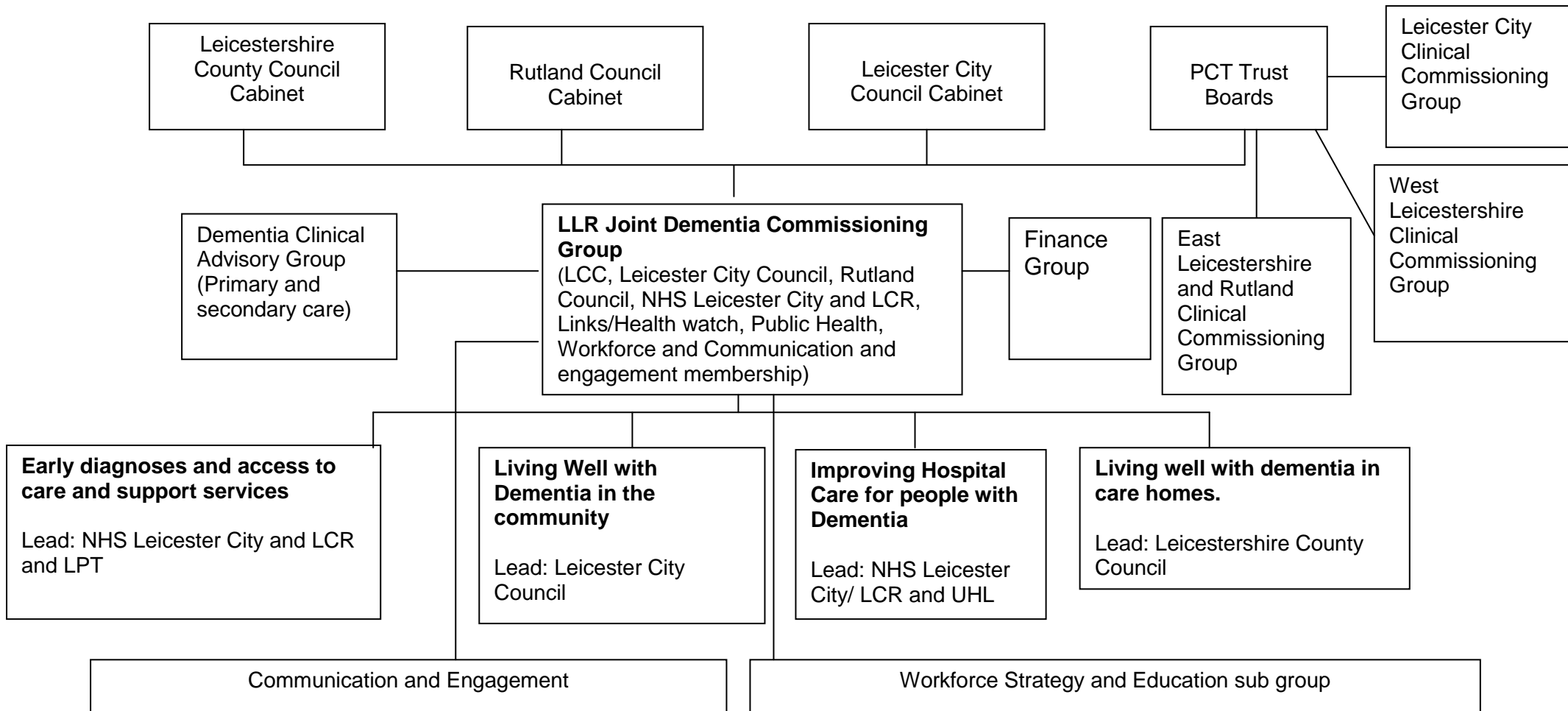
### **Quality and management**

- Outcome 15: Statement of purpose
- Outcome 16: Assessing and monitoring the quality of service provision
- Outcome 17: Complaints
- Outcome 18: Notification of death of a person who uses services
- Outcome 19: Notification of death or unauthorised absence of a person who is detained or liable to be detained under the Mental Health Act 1983
- Outcome 20: Notification of other incidents
- Outcome 21: Records

### **Suitability of management**

- Outcome 22: Requirements where the service provider is an individual or partnership
- Outcome 23: Requirement where the service provider is a body other than a partnership
- Outcome 24: Requirements relating to registered managers
- Outcome 25: Registered person: training
- Outcome 26: Financial position
- Outcome 27: Notifications – notice of absence
- Outcome 28: Notifications – notice of changes

### Appendix 3: Leicester, Leicestershire and Rutland Governance Structures



## Summary of Stakeholder Engagement

<b>Date</b>	<b>Title</b>	<b>Attendees</b>
November 2009 to January 2010	DH's Care Services and Efficiency Delivery (CSED) Programme hosted a series of workshops to map out the current delivery of services against the NDS. These workshops made a number of recommendations for dementia care in LLR.	These workshops were attended by a range (attendance of approximately 70 people) of stakeholders including service users and carers
6 <sup>th</sup> July 2011	Dementia carers event	Carers and service users
11 <sup>th</sup> July 2011	Dementia strategy launch LIN stakeholder event	Stakeholders from various organisations across LLR, such as LPT, UHL, Voluntary Sector organisations
12 <sup>th</sup> July 2011	East Leicestershire Clinical Care Group	GP's
25 <sup>th</sup> July 2011	Links workshop (LLR)	LLR wide representative
9 <sup>th</sup> August 2011	UHL Executive Board	Senior Management Team Consultants Nursing Representation
9 <sup>th</sup> August 2011	West Leicestershire Clinical Care Group	GP's
August date TBC	Leicester City Clinical Care Group	GP's
7 <sup>th</sup> September 2011	LPT strategic programme board	Senior Management

## **EQUALITY STATEMENT**

NHS Leicester City, NHS Leicestershire and Rutland, Leicestershire County Council, Leicester City Council and Rutland County Council aim to design and implement services, policies and measures that meet the diverse needs of our service, population and workforce, ensuring that none are placed at a disadvantage over others. It takes into account the Equality Act (2010) including the Human Rights Act 1998 and promotes equal opportunities for all.

An equality impact screening assessment has been undertaken to ensure that no one receives less favourable treatment on the protected characteristics of their age, disability, sex (gender), gender reassignment, sexual orientation, marriage and civil partnership, race, religion or belief, pregnancy and maternity.

As a consequence, it is recognised that a further full equality impact assessment will be undertaken for the four priority work streams as it is recognised that there are some issues to consider. The National Dementia strategy describes these as:

### **Ethnicity**

People from all ethnic groups are affected by dementia. The number of people with dementia in minority ethnic groups is estimated to be around 15,000 in England (approximately 3% of the estimated overall number of people with dementia) and there may be a lower degree of knowledge of dementia amongst some ethnic groups. This compares with the proportion of minority ethnic groups in the population in England as a whole of 9%. (2001 NHS census), but it should be noted that the number of people from ethnic minorities with dementia, and their proportion of the population as a whole, is set to rise sharply with the aging of ethnic minority populations. Public information campaigns to support the Dementia Strategy will need to be targeted at all ethnic population groups to raise awareness of dementia. There is also an issue as to whether current services for people with dementia and their family carers adequately take account of cultural differences. The Dementia UK report noted that ethnicity can be a significant factor in the extent to which dementia understood or acknowledged, or in people's willingness to seek help.

### **Disability**

Surveys show that dementia is one of the major causes of disability in the elderly, affecting personal care, everyday cognitive activities, and social behaviour. Early diagnosis and better quality of care can therefore make a major contribution to the postponement of disability in old age. People with dementia also have other disabling conditions unconnected with the dementia itself, which will complicate the nature of the care they require. This is particularly true of people with learning disabilities. The Strategy acknowledges this and emphasises that the needs of people with disabilities may require specifically-tailored approaches to care. It also points to the fact that training should enable an understanding of the differing needs of people with dementia, including those with different disabilities.

### **Gender**

There are differences in the incidence of dementia according to gender with a higher proportion of men in the ages 65-74 years and a higher proportion of women aged over 75 having dementia. There will also be differences in the nature of care required according to the gender of individuals, and in the approach of caregivers to the

provision of care. Male and female caregivers can respond differently to their care giving role in terms of depression, burden, stress, and substance abuse – support for carers is covered by the recently published Carer’s Strategy. There is a need for these factors to be taken into account in the care provided for people with dementia, and training provided for professionals should reflect this.

### **Age**

One of the misapprehensions of both the public and professionals alike is that dementia is a normal part of the aging process, and simply a consequence of getting old. The incidence of dementia undoubtedly increases with age, but dementia is far from being inevitable and is certainly not a natural consequence of the aging process.

Although dementia is primarily an illness associated with older people, there are also a significant number of people, currently around 15,000 (nationally), who develop dementia earlier in life and services for dementia should reflect this fact. Training for providers of dementia services should take account of the particular needs of younger people with dementia and their family carers, which might include issues around childcare, employment and peer support.

### **Religion or belief**

Religion is closely associated with the cultural and ethnic differences described in the section on Ethnicity above and care provided for people with dementia should respect religious and other beliefs. Although there is no obvious religious dimension to dementia, feedback from the consultation told us that religion might play an important part in the lives of people with dementia and religious organisations may be able to provide a link between individuals and health and social care services. In recognition of this, we have suggested in the Strategy that information campaigns targeted at public facing organisations include religious groups and that NHS and local authorities may want to provide some training or information sessions about dementia for religious and community organisations.

### **Sexual orientation**

Studies on the experience of lesbian, gay, bisexual and trans-gender AHPs have not been identified in relation to dementia. However, lesbian women and gay men are likely to face particular challenges in caring for partners or friends with dementia, challenges which are not faced by others in Society. No robust data is available on carers by sexual orientation, and indeed this is a generally under researched topic where more information is required. At present it is impossible to make an evidence-based assessment of impact, and it is not clear from the way they are specified whether the proposed new measures in the Carer’s Strategy, relating to information about carers would be capable of addressing this issue. The Department of Health (DH) commissioned Stonewall to undertake a project to explore why lesbian, gay, bisexual and trans-gender individuals may not report discrimination and homophobia in the NHS, social care or DH and this report, ‘Being the Gay One’, was published in 2007. There is no place for any form of discrimination in health and social care. The Department recognises the seriousness of the findings of this report and work is underway to meet the recommendations outlined in the report through the Better Employment work stream of the Department’s Sexual Orientation and Gender

Identity Advisory Group and through its broader equality and human rights work programme.

We will address these with the completion of a full equality impact assessment for the four LLR priority work streams.

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