

Leicester
City Council

MEETING OF THE ADULT SOCIAL CARE SCRUTINY COMMISSION

DATE: THURSDAY, 5 DECEMBER 2013
TIME: 6:00 pm
**PLACE: THE OAK ROOM - GROUND FLOOR, TOWN HALL,
TOWN HALL SQUARE, LEICESTER**

Members of the Committee

Councillor Dr Moore (Chair)
Councillor Chaplin (Vice-Chair)

Councillors Alfonso, Fonseca, Joshi, Wann and Willmott

Standing Invitee (Non-voting)

Chair of Healthwatch Leicester

Members of the Commission are invited to attend the above meeting to consider the items of business listed overleaf.

Elaine Baker

for the Monitoring Officer

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PUBLIC SESSION

AGENDA

1. APOLOGIES FOR ABSENCE

2. DECLARATIONS OF INTEREST

Members are asked to declare any interests they may have in the business to be discussed.

3. MINUTES OF PREVIOUS MEETING

Appendix A

The minutes of the meeting of the Adult Social Care Commission held on 7 November 2013 are attached and the Commission is to confirm them as a correct record.

4. PETITIONS

The Monitoring Officer to report on any petitions received.

5. QUESTIONS, REPRESENTATIONS AND STATEMENTS OF CASE

The Monitoring Officer to report on any questions, representations or statements of case received.

6. MENTAL HEALTH CARE

Appendix B

Councillor Cooke, Chair of the Health and Wellbeing Scrutiny Commission, has been invited to this meeting to present an overview of that Commission's review of the mental health of working age adults in Leicester and progress with its recommendations. A copy of the report of that review is attached at **Appendix B1** for information.

The Commission is recommended to receive this update and consider what further work this Commission needs to do following the review, including any work considered desirable on the care of those with dementia.

The "Leicester, Leicestershire and Rutland Joint Dementia Commissioning Strategy 2011-2014" and the "Joint Specific Needs Assessment: Dementia In Leicester" are attached at **Appendices B2** and **B3** respectively as background information.

7. REPRESENTATIONS ON THE HOUSING SUPPORT SERVICES CONSULTATION

Representations will be made to the Commission regarding the recent

consultation on proposed changes to housing related support services and how people would be affected if those changes happened. The Commission is recommended to receive these representations.

8. DOMICILIARY CARE REVIEW **Appendix C**

The Scoping Document for the review of Domiciliary Care is attached. The Commission is recommended to approve the Scoping Document and agree how the review should be progressed.

Background information on the tendering process is attached in the exempt part of the agenda for Members only.

9. OUTLINE TIMETABLE FOR THE FUTURE OF THE COUNCIL'S ELDERLY PERSONS' HOMES **Appendix D**

The Director for Care Services and Commissioning (Adult Social Care) submits a report setting out an indicative timetable for the actions needed to support existing residents living in the Council's Elderly Persons Homes that are due to be closed. The Commission is recommended to note the report and comment as appropriate.

10. PROPOSAL FOR THE FUTURE OF MOBILE MEALS PROVISION **Appendix E**

The Director for Care Services and Commissioning (Adult Social Care) submits a report setting out the results of a statutory consultation on a proposal to stop the Council's current mobile meals service and helping people to prepare or obtain meals in alternative and more flexible ways. The Commission is recommended to note the report and comment as appropriate.

11. WORK PROGRAMME

The current work programme for the Commission is attached. The Commission is asked to consider this and make comments and/or amendments as it considers necessary.

12. ANY OTHER URGENT BUSINESS

13. PRIVATE SESSION

AGENDA

MEMBERS OF THE PUBLIC TO NOTE

Under the law, the Commission is entitled to consider certain items in private. Members of the public will be asked to leave the meeting when such items are discussed.

The Commission is recommended to consider the following report in private, on

the grounds that it contains 'exempt' information as defined by the Local Government (Access to Information) Act 1985, as amended and consequently that the Commission makes the following resolution:-

"that the press and public be excluded during consideration of the following reports in accordance with the provisions of Section 100A(4) of the Local Government Act 1972, as amended, because it involves the likely disclosure of 'exempt' information, as defined in the Paragraph detailed below of Part 1 of Schedule 12A of the Act and taking all the circumstances into account, it is considered that the public interest in maintaining the information as exempt outweighs the public interest in disclosing the information

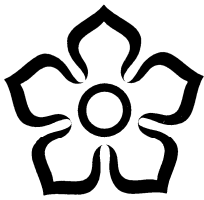
Paragraph 3

Information relating to the financial or business affairs of any particular person (including the authority holding that information)"

14. DOMICILIARY CARE REVIEW - ADDITIONAL INFORMATION

Appendix F

Attached is background information regarding the proposed review of Domiciliary Care. The Commission is recommended to note this information.



Leicester
City Council

Minutes of the Meeting of the
ADULT SOCIAL CARE SCRUTINY COMMISSION

Held: THURSDAY, 7 NOVEMBER 2013 at 5.30 pm

P R E S E N T :

Councillor Dr Moore – Chair
Councillor Chaplin – Vice Chair

Councillor Alfonso
Councillor Fonseca

Councillor Joshi
Councillor Willmott

* * * * *

50. APOLOGIES FOR ABSENCE

Apologies for absence were received from Councillor R Patel, Assistant Mayor (Adult Social Care) as, although not a member of the Commission, she normally attended its meetings.

51. DECLARATIONS OF INTEREST

Councillor Joshi disclosed an Other Disclosable Interest in relation to the general business of the meeting in that his wife worked in the Reablement Team within Adult Social Care.

In accordance with the Council's Code of Conduct, this interest was not considered so significant that it was likely to prejudice Councillor Joshi's judgement of the public interest. He was not, therefore, required to withdraw from the meeting.

52. MINUTES OF PREVIOUS MEETING

RESOLVED:

That the minutes of the meeting of the Adult Social Care Scrutiny Commission held on 10 October 2013 be approved as a correct record.

53. PETITIONS

The Monitoring Officer reported that no petitions had been received.

54. QUESTIONS, REPRESENTATIONS AND STATEMENTS OF CASE

The Monitoring Officer reported that no questions, representations or statements of case had been received.

55. ELDERLY PERSONS' HOMES - VERBAL UPDATE

a) Elderly Persons' Homes

The Director for Care Services and Commissioning (Adult Social Care) advised the Commission that:-

- A programme board had been established to look at the sale of the homes and asset disposal once they were sold, as well as the “moving on” of residents from the three homes that would be closed;
- There would be dedicated “moving on” staff, who would be trained on 14 November 2013;
- Following staff training, community care assessments would be started in line with legal requirements;
- Customers without mental capacity to make decisions about moving would be appropriately represented at all stages in the moving plan process;
- The stages in the “my moving plan” process were:
 - i) Deciding who needed to be involved in “my moving plan”
 - ii) A meeting to look at what was most important to the service user about moving and the development of an outline moving plan
 - iii) A reassessment of the service user’s needs
 - iv) A review of the service user’s plan after their assessment and deciding who would support them in choosing a home
 - v) Planning the move in detail
 - vi) What needs to happen on the day of the move
 - vii) After the move, putting in place the checks the service user had asked for in the first few weeks, following up with a formal review at 4 weeks and 6 months; and
- The timescales for this could only be known once the reassessments were completed.

The Chair reminded Members that the Commission had been resolute that it wanted to see a recognised carer designated for each resident who was moving. The Director for Care Services and Commissioning (Adult Social Care) confirmed that the member of staff identified for each resident would accompany that resident to viewings at other homes. Efforts would be made to try and enable the member of staff to be a daily presence in the resident’s new home, including releasing the member of staff from other work. However, any arrangements would be based on the individual’s needs and the family’s

wishes.

The following comments were made in discussion:-

- Before the decision was taken, officers wrote to families and spoke to residents who had the capacity to discuss the matter. Some individuals were anxious about changing home, but extra help would be provided where needed. Where residents did not have capacity, communication was via the residents' representatives;
- Updates were required on the position of each resident at each stage of the process, so that the Commission could reassure that residents' anxiety was being minimised;
- If relatives wanted to address the Commission at any time they could do so. Arrangements could be made for this to be done in private if preferred; and
- It was hoped that all residents of elderly persons' homes would have moved by the end of the current financial year, but individuals' circumstances could result in some residents remaining in homes scheduled for closure after then. If this happened, the support outlined above would continue.

RESOLVED:

That anonymised updates be made on the position of each resident at each stage of the process of moving them from their current Elderly Persons' Home to new ones.

b) Intermediate Care

The Director of Adult Social Care and Safeguarding reminded the Commission that the decision on the closure of Elderly Peoples' Homes included the development of a 60-bed Intermediate Care facility. Work was underway to establish how this could be done, which took in to account the previously agreed requirements to make the facilities homely and to develop them around small households. When this was finalised, the proposals would be submitted for approval.

The Director of Adult Social Care and Safeguarding further advised that:-

- A robust approach to procurement would be taken, so that the Council could control finance and service delivery;
- An outline business case was being developed, which would be brought to the Commission for scrutiny before it was submitted for approval; and
- The final configuration of the service had not been agreed yet and all options would be considered, (for example, having two smaller units of 30 beds each, or one larger unit of 60 beds).

c) Elderly Persons' Commission

The Director of Adult Social Care and Safeguarding reminded the Commission that the decision on the closure of Elderly Peoples' Homes included the creation of an Elderly Persons' Commission. Discussions on the structure of that Commission, and how it would operate, would be held with the Assistant Mayor (Adult Social Care). The Adult Social Care commission would be kept advised of how the Elderly Persons' Commission was developing.

Members expressed concern that some elements of the decision on Elderly Persons' Homes appeared to have not been recorded clearly and asked that greater care be taken in the future to record decisions accurately, so that all detail was included.

RESOLVED:

- 1) That the Director of Delivery, Communications and Political Governance be asked to request that the Executive ensure that care is taken to record decisions accurately; and
- 2) That the Chair of this Commission raise this Commission's concerns about the recording of the decision on Elderly Persons' Homes at Overview Select Committee.

56. DOUGLAS BADER DAY CENTRE

Janet McKenna, Social Care and Health Convenor for the Leicester City Council branch of Unison, made the following representation to the Commission under the consultation on the proposal to stop running the Douglas Bader Day Service:-

- The rationale given for the proposed closure of the Douglas Bader Day Centre was a reduction in numbers. However, the Centre had 60 people on its books and 35 attended daily. These were good numbers;
- The personalisation agenda could lead to a reduction in numbers attending, but the Council did not help the situation, for example by recently not referring people there. The Council's 2011 budget included a planned strategy to manage referrals to prevent placement at this Centre, but it was not known if this had become a Council policy;
- An advantage of closing the Centre had been stated to be the flexibility offered to service users by personal assistants. However, no consideration had been given to whether current staff could provide this service. This was more than a traditional Day Centre and it had forged good links with the community;
- Unison was disappointed that other options for buildings had not been considered, (for example, whether they could be available for community use), particularly as staff at the Centre were willing to work flexibly, (for

example, in the evenings);

- Not all of the Centre's clients would benefit from the work of the Inclusion team, as some were highly dependent;
- A lot of services had closed, but there were other alternatives. Public services should be provided by the public sector, to keep accountability; and
- If the cost of the service was not the main driver in the proposal to close the Day Centre, the Council was asked to consider the suggestions made by staff for how to keep the Centre operating.

On behalf of the Commission, the Chair thanked Janet McKenna for attending the meeting.

The Commission made the following points in discussion:-

- The principle of closing this provision was wrong, as individual budgets and direct payments were not right for everyone;
- Closing the Centre would leave no "safety net" for those needing a higher level of support and help to organise their social contact;
- When this type of facility closed it was very hard to replace it;
- The Council had a role in providing services needed by residents and this was the only centre operated by the Council for those with physical disabilities and mental health issues;
- Offering no alternative options in a consultation meant that residents were not being offered a true choice, as their preferences could not be established;
- It appeared that staff had not been consulted on how flexible they could be, (for example, whether they were willing to provide services during evenings or weekends). However, the nature of adult social services care was that it was needed at all times, not just in office hours. It would be a concern if staff could not adapt to that;
- It would be disappointing if the main impetus for the proposed changes was problems with the building being used, as the focus should be on how a service could be delivered in a different way; and
- A full discussion of these issues should be held, based on all the evidence available, (for example, attendance figures, the cost of maintaining the building, salary costs), and identifying the alternatives available, (for example, keeping the service, but moving it to another building, such as a community centre).

In reply to a question about whether the Day Centre staff would be willing to continue working with Centre users, but in another building, Janet McKenna explained that it was recognised that the current Day Centre was a large building that needed upgrading. For this reason, it currently was not possible to work in small groups, so all activities had to be either building-based, or one-to-one. It was hoped that this could be explored further with Centre staff and users during the consultation. However, for a consultation to be carried out on the assumption that the Centre would close would mean that any staff consultation would be about redundancies.

RESOLVED:

- 1) That the Adult Social Care Scrutiny Commission endorses the views of unison recorded above; and
- 2) That the representations by Unison recorded above be considered as part of the Council's consultation on the proposal to stop running the Douglas Bader Day service.

57. DRAFT ADULT SOCIAL CARE LOCAL ACCOUNT 2012-13

The Director for Care Services and Commissioning (Adult Social Care) submitted the draft Adult Social Care Account for 2012-13. The tables for inclusion on pages 16 and 17 of the Account were tabled at the meeting and are attached at the end of these minutes for information.

The Commission identified several grammatical errors in the Account, which officers undertook to correct.

The Commission welcomed the report, but expressed some concern that the drop in some of the percentages shown on page 16 was quite high. Despite this, it was stated on page 15 of the report that the number of users whose overall satisfaction with their care and support had increased. The Director of Adult Social Care and Safeguarding undertook to clarify whether this meant that, although there had been an increase in satisfaction, the service had not reached the level of satisfaction it aimed for.

The Single Point of Contact was a vital, and well run, part of the service. However, more work was needed to inform the public about how to access services, especially if a crisis occurred outside of standard office hours. The Director of Adult Social Care and Safeguarding explained that a key strand of the service's work was the dissemination of information, but the need for further work on information, advice and guidance had been identified. Consequently, an officer had been seconded to work on this for the coming 18 months.

The following points also were made during discussion on the Account:-

- It would be useful to receive information on how much it cost to communicate the Account to interested parties. Wider communication was needed than just to staff and the media. This could include ward community meetings and community groups;

- Were people able to give feedback on the Account?;
- It could be useful to amend the wording in the introduction from the Assistant Mayor, (especially in the seventh paragraph), to take account of public concern caused by some recent decisions, such as that to close Elderly Persons' Homes; and
- More information should be provided on the areas shown in the tables on pages 16 and 17 of the Account in which the Council was performing less well. For example, actual numbers should be included, not just percentages.

58. DOMICILIARY CARE REVIEW

Members were reminded that the Director for Care Services and Commissioning (Adult Social Care) had circulated a report before the meeting providing a response to a number of questions previously raised by the Commission in relation to the procurement of Adult Social Care Domiciliary Care services.

During discussion on this report, the Commission expressed concern that Members needed to understand what the implications of the responses were, but this was difficult when information on the key issues was not available, (for example, the number of contractual hours, core times, the specification for the service, how this was responded to, which organisations responded and which organisations the successful tenders were from). In reply, the Head of Contracts and Assurance explained that these details were available through hyper-links in the report, but offered to circulate it to Members.

In response to questions from the Commission, it was noted that:-

- Six new contractors had been awarded contracts for Generic Domiciliary Support Services;
- In order to maintain controlled management of providers, a reserve list of providers had been compiled. Therefore, if one of the main providers was unable to provide the package of work awarded, one of the providers on the reserve list could be used;
- The percentage scores from each mandatory section of the tender document were totalled for each bidder. Quality was then weighted at 80%. A test also was completed by each bidder;
- There would be a new provider of Extra Care Services at Danbury Gardens, (for example, housing, landlord services, or domiciliary care). Staff employed by the current provider of these services, (Direct Care), would transfer to the new provider (Care UK) under the Transfer of Undertakings (Protection of Employment) Regulations. As with other services, a reserve provider had been identified;

- The Commission had concerns that the Extra Care Services at Danbury Gardens had been identified as a centre of excellence, but the current provider had lost the contract. However, it was noted that the staff who provided the service to users would transfer to the new provider;
- More information was needed on why the providers selected were chosen and how close other bidders had come to being awarded contracts;
- New service providers would be willing to come to a Commission meeting to answer questions if Members wished;
- The minimum time to be allocated to each visit was now 30 minutes, but many service users would have much longer visits. The change from a minimum 15 minute visit was endorsed by the Commission;
- It was recognised that carers were delivering sensitive and intimate personal care, but it was suggested that it would be beneficial for the Chair of this Commission to accompany a carer for a day, if possible. This would enable her to observe their activities and/or the time taken on visits and travelling, and to obtain feedback from the carer on their work;
- Some service users received direct payments, so could choose whether to use Council provided services or private care providers; and
- Service specifications were compiled based on the requirements of the Regulator and of the Council.

RESOLVED:

- 1) That the scoping document for the review of Domiciliary Care be included in the agenda for the next meeting of this Commission;
- 2) That an anonymised score matrix of tenders for each Domiciliary Care service type be presented to the next meeting of this Commission;
- 3) That an anonymised example of a care plan be presented to the next meeting of this Commission, showing the kind of activities that can take place during a visit and the number of carers involved;
- 4) That enquiries be made to determine whether it will be feasible for the Chair of the Commission to accompany a carer for a day; and
- 5) That details of the number of service users using Council-provided care and the number purchasing care from private providers be presented to the next meeting of this Commission.

59. WORK PROGRAMME

NOTED:

That the final meeting of the Elderly Persons' as Carers Task Group would be held at 5.30 pm on Friday 13 December 2013 and would be attended by Liz Kendall MP.

RESOLVED:

- 1) That a report on the Joint Commission Review of the Winter Care Plan be made on 5 December 2013;
- 2) That a further meeting be held for the Commission's review of Domiciliary Care; and
- 3) That information be provided for Members about the service changes occurring in Housing.

60. ANY OTHER URGENT BUSINESS

a) Representation of Healthwatch at Adult Scrutiny Care Commission

This item was taken as matter of urgent business with the agreement of the Chair, as issues relating to mental health were scheduled to be considered at the Commission's next meeting and an urgent review of winter care planning would be continuing over the next few weeks in conjunction with the Health and Wellbeing Scrutiny Commission. This item therefore needed to be considered at this meeting, rather than be deferred to the Commission's next meeting, on 5 December 2013.

The Chair reported verbally that the Commission had been approached by Healthwatch Leicester with a request that it be a standing invitee to meetings of this Commission.

RESOLVED:

That the Chair of Healthwatch Leicester be a standing invitee to meetings of the Adult Social Care Commission.

b) Potential Call-In of Executive Decision relating to Evesham House

This item was taken as matter of urgent business with the agreement of the Chair, because if the decision referred to was called-in, the meeting at which the Call-In would be considered would be held before the next meeting of this Commission. This item therefore needed to be considered at this meeting.

The Chair reported verbally that it was possible that the decision by the Assistant Mayor (Housing) to close Evesham House could be called in, due to concerns that there was not a clearly-enough defined programme of support for users of the facility once it has been closed.

The Chair of the Housing Scrutiny Commission had indicated that, if the decision was called-in, it could be considered at the Housing Scrutiny Commission's meeting at 5.30 pm on Tuesday 12 November 2013. If this was done, members of this Commission would be invited to attend that meeting.

NOTED:

- 1) That that the decision by the Assistant Mayor (Housing) to close Evesham House may be called in; and
- 2) The arrangements for considering the decision referred to in 1) above if it is called-in.






61. CLOSE OF MEETING


















The meeting closed at 7.31 pm























Minute Item 57

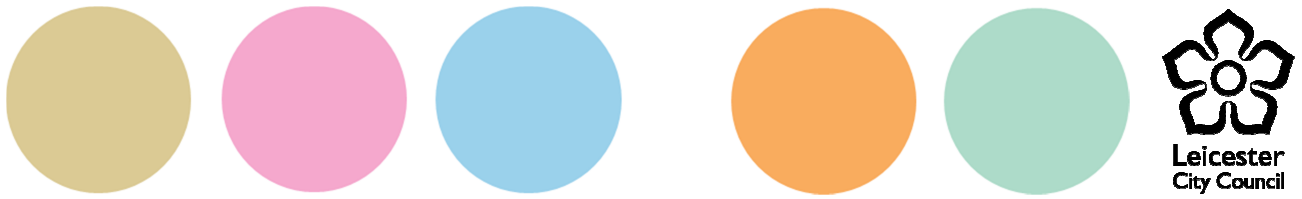
Adult Social Care Outcomes Framework 2012-13: Leicester compared to England as a whole

This table shows you how our performance for 2012-13 compares with the previous year, and how our performance compares with other councils that are in our 'family' group. Our family group is a list of 15 other councils who are similar to us in terms of the needs of the population they support.

Key	Change from 2011-12	Key	Comparison with Family Group
	Better than 2011-12		In top quarter
N/A	Data not collected in 2011/12		In 2 nd or 3 rd quarter
	Not as good as 2011-12		In 4 th quarter

National measure	Leicester 2012-13	Change from 2011-12	Family average	Family Comparison
Social care-related quality of life.	18.3		18.9	
Proportion of people who use services who have control over their daily life.	70.2%		75.3%	
Proportion of people using social care who receive self-directed support, and those receiving direct payments.	64.2%		61.4%	
Proportion of people using social care who receive a direct payment either through a personal budget or other means.	25.8%		18.5%	
Carer reported quality of life.	7.1	N/A	7.9	
Proportion of adults with a learning disability in paid employment.	8.8%		5.8%	
Proportion of adults in contact with secondary mental health services in paid employment.	2.9%		4.6%	
Proportion of adults with a learning disability who live in their own home or with their family.	71.8%		77.0%	
Proportion of adults in contact with secondary mental health services who live independently, with or without support.	32.2%		51.1%	

National measure	Leicester 2012-13	Change from 2011-12	Family average	Family Comparison
Permanent admissions to residential or nursing care homes, per 100,000 population (low is good).	13.94		16.0	
Older people aged 65 or over admitted on a permanent basis in the year to residential or nursing care per 100,000 population (low is good).	735.27		787.9	
Proportion of older people (65 and over) who were still at home 91 days after discharge from hospital into reablement/rehabilitation services.	83.1%		81.8%	
Proportion of older people (65 and over) offered reablement services following discharge from hospital.	3.9%		3.0%	
Delayed transfers of care from hospital per 100,000 population.	11.4		9.8	
Delayed transfers of care from hospital attributable to adult social care and / or the NHS per 100,000 population.	4.1		2.9	
Overall satisfaction of people who use services with their care and support	67.1%		62.7%	
Overall satisfaction of carers with social services.	37.9%	N/A	42.2%	
Proportion of carers who report that they have been included or consulted in discussion about the person they care for.	63.5%	N/A	71.0%	
The proportion of service users who find it easy to find information about services.	64.6		73.0%	
The proportion of people who use services who feel safe.	61.1%		65.7%	
The proportion of people who use services who say that those services have made them feel safe and secure.	74.8%		76.8%	



Leicester City Council Scrutiny Review

Revisiting the 'Review of Mental Health Working Age Adults in Leicester'

A Report of the Health & Community Involvement Scrutiny Commission

April 2013

Health & Community Involvement Scrutiny Commission

Title of Scrutiny Review:

Revisiting the Mental Health Review of Working Age Adults in Leicester

Chair: Councillor Michael Cooke

Commission Members:

Councillor Sangster (Vice Chair)
Councillor Alfonso
Councillor Desai
Councillor Gugnani
Councillor Naylor
Councillor Singh
Councillor Westley

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Minutes from Health & Community Involvement Scrutiny Commission meetings

The minutes from the Health & Community Involvement Scrutiny Commission in relation to this review can be accessed on line at:

<http://www.cabinet.leicester.gov.uk:8071/ieDocHome.aspx?Categories=>

Chair's Foreword

On behalf of the Health & Community Involvement Scrutiny Commission, I would like to thank all the individuals and organisations that have contributed to this review.

In Leicester the estimated number of people with serious and enduring mental illnesses is about 3,400. The estimated number of people with anxiety and depression is about 30,000. Prescriptions for anti-depressant medications are increasing.

Mental health services support some of the most vulnerable people in our society. This review has shown that there needs to be a more effective holistic partnership approach to addressing mental health issues in order to improve people's lives, health and wellbeing.

Leicester City Council is facing funding challenges in delivering high quality social support services that are essential for service users and carers e.g. supported housing, drop-in facilities or various learning and educational activities. The role of the voluntary community sector and its relationship to Leicester City Council and lead commissioners is vital to providing these.

This report will be presented to the City Mayor, to local health and social care commissioners and providers of mental health services, for their consideration, in order to improve the mental health of working age adults in Leicester:



Councillor Michael Cooke
Chair, Health & Community Involvement Scrutiny Commission

Revisiting the Scrutiny Review of Mental Health Working Age Adults

1. Summary of findings

The commission found the following:

- 1.1 Effective interventions across the life course promote mental health and prevent mental illness; these include improving parental health, promoting healthy workplaces and emphasising the role of school and colleges in adult mental health and wellbeing.
- 1.2 There is a need for a cross departmental approach to adult mental health focusing on community cohesion, employment, education, leisure and environmental services as well as health and social care.
- 1.3 VCS organisations report limited engagement with health and social care commissioners about mental health issues.
- 1.4 VCS organisations report that difficulties in meeting the nationally set personalisation criteria means that people with mental ill health have restricted access to commissioned services.
- 1.5 Community support is important in developing resilience to mental ill health, and local VCS organisations are often best placed to deliver such services effectively.
- 1.6 Mental illness is a continuing concern for people in hard to reach groups and communities; for instance those from BME backgrounds and new communities; lesbian, gay, bisexual and transgender people; students; people in the criminal justice system and homeless people.
- 1.7 Mental health services, such as Improving Access to Psychological Therapy (IAPT), could be commissioned to allow opportunities for VCS Counselling Projects to deliver part of the service.

2. Conclusion and Recommendations

Conclusion

- 2.1 The Health and Community Involvement Commission concludes that broad, joined up action is necessary to improve and sustain mental health and wellbeing in Leicester. This can be achieved by effective cross departmental and cross sector collaboration. The evidence considered by the Commission suggests that the prevention and treatment of mental illness are complementary activities.
- 2.2 Mental wellbeing will be achieved by greater community cohesion and resilience. This requires the recognition that factors such as education, employment, transport, leisure and the environment all play a part in sustaining mental health. A cross cutting strategic approach to mental wellbeing could contribute to an improved quality of life and reduce the burden of mental illness in Leicester.

- 2.3 The Commission recognises the role played by the health, social care and voluntary sector organisations in supporting and treating people with mental illness. The Commission concludes that primary care and social care are well placed to develop an integrated approach to adult mental illness, in collaboration with all three sectors, based on the Joint Strategic Needs Assessment.
- 2.4 The Commission finds that in developing care and support for people with mental illness health and social care commissioners should focus on at least three areas of concern.
- a) Development of better care pathways and outcomes for people with mental illness, facilitating timely access to appropriate treatment to meet their needs and monitoring rates of recovery.
 - b) Addressing the physical health and social care needs of adults with mental illness; including clear links between Leicestershire Partnership Trust, University Hospitals Leicester and Leicester City Council.
 - c) Recognition that a strong voluntary sector is necessary to overcome the stigma associated with mental illness and to facilitate access to support for individuals in hard to reach groups.

Recommendations

- 2.5 The Health and Community Involvement Scrutiny Commission makes recommendations based on the findings of the review, which are summarised in Section 6 and the strategic approach set out in Section 4.
- 2.6 The City Mayor, local health and social care commissioners and providers should consider the following broad objectives in order to improve the mental health of working age adults in Leicester:
- 1. A joint health and social care approach to meet the mental health and wellbeing needs of working age adults in Leicester.**
 - 2. A focus on mental health and wellbeing which includes addressing the risk factors associated with mental ill health.**
 - 3. Improved planning and performance of mental health and social care services to ensure that people who need help obtain early diagnosis and prompt treatment.**
- 2.7 In order to meet these broad objectives the City Mayor and health and social care commissioners are further recommended to:
4. Develop a broad strategic approach to mental health and wellbeing which harnesses polices on a range of services and organisations available across the city; including schools, colleges and universities; debt management; employment and the workplace;

sport and leisure facilities; the environment, transport and tackling crime as well as health and social care (**Sections 4.6, 6.1, 6.2**).

5. Engage with voluntary sector organisations in order to improve services for hard to reach communities, and to tackle stigma and discrimination in mental health (**Sections 4.6, 4.13, 6.3, 6.4, 6.5**).
6. Recognise that childhood interventions to promote resilience to mental illness in adulthood should be implemented as early as possible, focusing on improved parental and family health and wellbeing (**Section 4.11**).
7. Deliver parity of esteem between mental and physical health and wellbeing, recognising the close links between mental and physical illnesses (**Sections 4.7, 4.9**).
8. Ensure that the mental health and social care needs of carers are assessed and acted upon (**Section 4.6, 4.12**).
9. Ensure that areas for health promotion activity, such as obesity, drug and alcohol misuse and smoking have a recognised mental health and wellbeing component (**Section 4.9**).
10. Engage local employers to improve access to work for adults with mental health problems (**Section 4.8**).
11. Promote mental health and wellbeing in the workplace, commissioning services to tackle stress and provide work environments which are conducive to mental wellbeing (**Section 4.8**).
12. Target support at those groups who are at high risk of adult mental illness, such as the socially excluded, looked-after children, substance misusers and people in touch with the criminal justice system (**Section 4.14**).
13. Enhance the role played by primary care in developing an integrated approach to adult mental health care (**Section 6.6**).
14. Encourage a range of service providers and models of service provision as a way of improving the quality and accessibility of services (**Section 4.6**).
15. Address the stigma and discrimination associated with mental ill-health which affects diagnosis and treatment and exacerbates the impact of some disorders (**Section 4.13**).
16. Reaffirm a commitment to the implementation of the Mental Health Charter (**Section 4.16**).

3. Report

- 3.1 A report of the Health Scrutiny Review on the Mental Health of Working Age Adults in Leicester was presented to Cabinet in April 2011. It was based on an examination, conducted in 2010, of mental health need in the city and the resources required to provide high quality mental health care.
- 3.2 That report set out short and long term aims and objectives to improve the care of working age adults with mental ill health in Leicester.
- 3.3 The purpose of this further report is to make recommendations to the City Mayor and local health care commissioners and providers, on the findings of the re-visited Health Scrutiny Review on the Mental Health of Working Age Adults held between February and May 2012.
- 3.4 The Commission examined the previous recommendations, identified progress and received an update on the changes in health and social care service provision. Evidence for this review was received from health and social care and the voluntary sector (VCS).

4. Background

- 4.1 In December 2010 the Health Scrutiny Committee completed an investigation into the delivery of Adult Mental Health Services. The report and its recommendations were endorsed by Cabinet on 11th April 2011.
- 4.2 In response the Strategic Director for Adults and Communities, Leicester City Council and NHS Leicester City acknowledged the need for a co-ordinated approach to the commissioning of health and social care to meet the mental health needs of working age adults in Leicester.
- 4.3 In October 2011, the new Health and Community Involvement Scrutiny Commission agreed to conduct a review of those recommendations and the actions which have since been taken to improve the service.

5. Introduction

- 5.1 Leicester City Council engages with a range of organisations to support independent living and to promote health and wellbeing for all. Mental health and resilience to mental illness is a core component of this engagement. In the context of an economic recession there is a risk of increased prevalence of mental illness, coupled with fewer opportunities to invest in services. Given these circumstances, and strategic changes to the statutory sector, the Commission sought assurance that there is effective planning and commissioning to meet mental health need in Leicester.
- 5.2 According to *No health without mental health: a cross-government mental health outcomes strategy for people of all ages* mental health is everyone's business. Individuals, families, employers, educators and communities should all play a part in creating resilience to mental illness. Furthermore, good mental health and resilience are fundamental to physical health, relationships, education, training and work.

5.3 The national strategy targets six areas, including:

- **More people of all ages and backgrounds will have better wellbeing and good mental health.**
- **More people with mental health problems will recover and have a good quality of life.** They will have the skills they need for living and working, improved chances in education and better employment.
- **More people with mental health problems will have good physical health.** Fewer people with mental health problems will die prematurely, and more people with physical ill health will have better mental health.
- **More people will have a positive experience of care and support.** They will have access to timely, evidence-based interventions and approaches that give people the greatest choice and control over their own lives.
- **Fewer people will suffer avoidable harm.**
- **Fewer people will experience stigma and discrimination.** The public's understanding of mental health will improve and, as a result, negative attitudes and behaviour to people with mental health problems will decrease.

5.4 The implementation framework for the strategy recommends evidence based actions for the NHS, other public services and employers. It details how success will be measured and how future work on outcomes indicators will be taken forward nationally.

5.5 Changes set out in the Health and Social Care Act set new parameters within which *No Health without Mental Health* will be implemented. Levers to help drive improvement include the mandate to the NHS Commissioning Board and the new NHS, public health and adult social care outcomes frameworks. The implementation framework has been endorsed by the NHS Commissioning Board and Public Health England. As with the original strategy, the implementation framework is wide ranging and makes recommendations for the NHS, schools, local government, social services and the criminal justice system.

5.6 The implementation framework recommends that mental health services focus on these areas:

- **Improving equality of access and outcomes.** This is related to Equality Act characteristics, and may be extended to other vulnerable groups known to experience particular mental health problems, such as homeless people and people from certain Black and Minority Ethnic (BME) communities.
- **Improving experience for service users and carers.** This may be facilitated by implementation of NICE quality standards on service user experience in adult mental health.
- **Better use of technology.** In providing self-care and peer support online.
- **Orientate services around recovery.** Services should provide support and access to appropriate advice on housing, benefits and debt issues and evidence-based employment support, training and education.
- **Other initiatives which support mental health.** Such as smoking cessation, weight management and tackling drug and alcohol misuse. Mental health providers may develop innovative practice aimed at improving the mental health of people with long-term physical conditions and medically unexplained symptoms.

- 5.7 Poor mental health is both a contributor to and a consequence of wider health inequalities. It is associated with increased health-risk behaviour and increased morbidity and mortality from physical ill health. Good mental health has multiple potential benefits. It can improve health outcomes, life expectancy, educational and economic outcomes and reduce violence and crime.
- 5.8 Poor mental health is associated with unemployment, lower educational attainment, lower income and adverse life events. Promoting the wellbeing of those who have become unemployed and helping their return to work can result in reduced depression. Workplace screening can reduce depression and sickness absence.
- 5.9 Poor mental health is associated with increased risk-taking behaviour for example, poor diet, less exercise, heavy smoking and drug and alcohol misuse. As a result mental illness is linked to premature mortality from cardiovascular, pulmonary and infectious diseases.
- 5.10 The scale of the problem of mental ill health is huge. One in six adults will be affected by mental distress in their life and more people are not in work due to mental health problems than any other issue. Mental Health represents 23% of the total burden of ill health in the UK and is the largest single cause of disability. Poor mental health adds considerably to the cost of education and criminal justice system and homeless services.
- 5.11 Much of lifetime mental illness starts before the age of 14 and continues to have a detrimental effect on an individual and their family for many years.
- 5.12 The mental health and wellbeing of carers is an important issue. Caring is recognised as potentially stressful for both the carer and the care recipient. The impact of caring is likely to be exacerbated the longer a person is in the caring role; for some carers this may be many decades. Most carers report a negative effect on their mental wellbeing (stress and depression).
- 5.13 Discrimination and stigma experienced by those people with mental health problems compounds inequality, reducing employment opportunities and weakening supportive networks.
- 5.14 Relative deprivation is associated with mental illness. Other groups who are at risk of mental health problems include children with parents who have mental health or substance misuse problems; young people excluded from school; teenage parents; offenders and ex-offenders; lesbian, gay, bisexual and transgender people; people from BME communities; asylum seekers and refugees and isolated older people.
- 5.15 Primary and community care are fundamental in providing support people with mental illness.
- 5.16 University Hospitals Leicester (UHL) often provides support to people with mental health problems who attend the Emergency Department. UHL also care for people with mental health problems which result from long term physical illness.

- 5.17 Specialist mental health support is provided by Leicestershire Partnership NHS Trust (LPT) for the population of Leicester, Leicestershire and Rutland. It has a budget in excess of £250 million and employs almost 6,000 staff.
- 5.18 Local mental health services reflect the national approach in offering a range of services from prevention to treatment and recovery; they are provided by primary and secondary care. They are characterised by partnership working between psychiatrists, social workers and nurses. Mental health care services bring together NHS, local authority, the voluntary and independent sectors, community groups, service users and carers.
- 5.19 The Joint Commissioning Strategy for Mental Health for Leicester focused on prevention and early intervention, transforming social care and supporting the mental health of older people. It is underpinned by
- Delivering Race Equality in Mainstream Services
 - Implementing the Mental Health Charter
 - Valuing User/Carer experience and using this to inform service design/redesign
 - Strengthening partnership working with all key stakeholders including VCS.

6. Review process

- 6.1 The Review was conducted between February and May 2012. Evidence was gathered by examination of key stakeholders in select committee style at 3 special Commission meetings. Additional material was gathered through presentations, written submissions and reports.
- 6.2 The themes of the 3 meetings were held to gather evidence, as follows:

1st stage inquiry on 7th February 2012: An examination of how Leicester City Council and NHS Leicester City jointly commission mental health services in the city.

The Commission heard evidence from:

- Tracie Rees, Director for Care Services and Commissioning (Adult Social Care) Leicester City Council;
- Yasmin Sidyot, Commissioning Manager of Mental Health Services, Leicester, NHS Leicester City / NHS Leicestershire County and Rutland;
- Yasmin Surti, Commissioning Manager, Leicester City Council;
- Mark Wheatley, Public Health Principal – Mental Health and Vulnerable Groups, NHS Leicester City.

2nd stage inquiry on 27th February 2012: An examination of the views and experiences of service users and VCS organisations.

The Commission heard evidence from:

- Viv Addey, Gabby Briner, Ushma Patel and Mary Woodley of Network for Change
- Kamn Bates of Genesis
- Denise Chaney of LAMP
- Rosie Leivas of Crossroads Care

3rd stage inquiry on 6th March 2012: An examination of mental health service provision by LPT in Leicester.

The commission heard evidence from:

- Carol Marsden, Head of Complex Care
- Paul Miller, Director of Adult Mental Health services
- Teresa Smith, Head of Access.

6.3 In addition to this the commission received written evidence from (attached in appendices):

- Yasmin Sidyot, NHS Leicester City Mental Health;
- Yasmin Surti, Leicester City Council;
- Mark Wheatley, NHS Leicester City Public Health
- Adhar Project; Network for Change Project;
- Akwaaba Ayeh Project
- Central Project;
- Foundation Housing Association;
- Genesis Project
- LAMP Project
- Recovery Project
- Voluntary Sector Partnership for Mental Health, Leicester, Leicestershire and Rutland
- Paul Miller, Leicestershire Partnership NHS Trust

7. Findings of the review

7.1 The voluntary sector has a role to play in building capacity and capability to support the development and delivery of mental health services, but their role or budgets have not been specifically defined.

The local authority and PCT commission a number of services which support people to remain within their community and provide care closer to home. The following is a list of the types of services commissioned from the statutory and voluntary sector:

- IAPT
- Home Based Carer support
- Supported living
- Outreach services
- Common Mental Health Teams
- Crisis
- Telephone helpline
- Advocacy
- Employment related support
- Peer support

The Commission heard evidence from VCS organisations which described the financial pressures faced by the voluntary sector. This evidence covered a number of areas.

- Many national and local policy documents suggest that partnership working is important in addressing mental health problems. The Commission noted that, in terms of VCS organisations, the Leicester Joint Commissioning Strategy for Mental Health states that:
 - There is wide recognition of the added value of VCS providers to mental health care
 - Scoping and developing commissioning priorities are part of the VCS review
 - Commissioners should liaise with providers to identify what works and could be done differently
 - Services will be developed through personal budgets.
- Evidence presented to the Commission by VCS organisations suggests that they are experiencing financial difficulties, and need better core funding to ensure their sustainability. A significant part of their income is derived from grants and charitable sources, but only 10% of such applications are successful. Furthermore it is difficult to get grants for core funding, as grants tended to be given for new projects.
- VCS representatives suggested that there was serious under investment in their organisations in 2011/2012 and they are concerned by media reports of potential further cuts to existing VCS contracts from April 2012.
- The VCS and service users and carers appreciate the impact of health and social care reforms and public sector cuts, but felt that more could have been done to involve VCS views and interests.

- VCS organisations suggested that funding for mental health should be ring-fenced so that it cannot be diverted to meeting physical health needs. A restating of the recommendation, made by the Scrutiny Committee, that a percentage target be set for investment in the mental health VCS would be very welcome. It would show that commissioners truly respected the added value provided by VCS.
- VCS representatives suggested that there are areas for potential investment. For instance there is an under-spend on community-based support services, whilst many of these services could be provided, with good value for money, by local VCS organisations
- More could be done to protect small organisations in competitive tendering processes, as they currently could not compete effectively.
- The move to personalised budgets presents difficulties for VCS organisations which could make it difficult to predict service user numbers. VCS organisations could lose funding if those service users used services provided elsewhere.
- Anecdotal evidence offered to the Commission suggested that services provided by Network for Change may prevent hospital admission and could therefore produce cost savings, although no figures were presented to the Commission.
- Representatives of LAMP explained that the organisation helps more than 200 people at any one time. LAMP also hosts the Genesis project, which is the voice of service users and carers. LAMP representatives explained that, although LAMP and the VCS in general, had been identified as producing good practice, the level of funding is being reduced. This reduction could result in the closure of some organisations.
- LAMP suggested that the funding of the Genesis project exemplifies the risk to VCS services. Genesis is an effective necessary service offering value for money; it has one paid worker but helps several hundred people. Losing funding for the service would have a negative effect, including greater risks to adult safeguarding
- Representatives of Akwaaba Ayeh Mental Health Project explained that last year they lost funds in the region of £30,000. They reported that larger voluntary sector organisations are better able to respond to the bidding process; however, those larger organisations are not necessarily well placed to meet the needs of hard to reach communities.
- Adhar Mental Health project has over achieved the targets set by the service level agreement with Leicester City Council. Adhar supports people with chronic mental health conditions, who would otherwise be seen in the statutory sector. Projects like Adhar have maximised individual ability to live in their homes and have therefore contributed to reduced rates of hospital re-admission and entry into institutional care.

With regard to VCS organisations in Leicester the local authority and PCT have jointly developed a number of commissioning objectives that will be achieved and delivered through:

- Ensuring that every person with eligible needs has choice and control of their support to help them lead independent lives, e.g. Customers (currently only in Adult Social Care, but likely to be extended to Health have personal budgets to meet their eligible needs, and options to spend this
- Maximising the use of universal services and promoting social inclusion/community cohesion e.g. helping people access other council services
- Developing local community based alternative services to support and sustain people in their own homes e.g. supporting the establishment of peer support, befriending services etc.
- Reducing the use of residential care in favour of supported housing
- Redefining the role of local voluntary organisations and focus the our investment on priority outcomes
- Developing Health and adult social care re-ablement services
- Developing a transparent and equitable charging policy for Adult Social Care
- Realigning assessment and care management with general practice and community health services
- Developing enablement services to support increased independence.

7.2 The commission heard evidence on progress made regarding payment by results on the LPT block contract, and ways in which VCS may compete for more contracts.

In April 2011 NHS Leicester City reported that the existing block contract will remain in place but will be subject to continued monitoring, with demands for improved data quality. Contract monitoring arrangements will change once the planned Payment by Results funding framework is implemented in 2013/14.

Mental Health Payment by Results (MHPbR) means that payment will only be made where LPT is performing at the required level. It is linked to improved quality of services, which is monitored by the Department of Health. MHPbR should provide opportunities for service re-design where appropriate. 21 care clusters have been developed and all service users will be assigned to a care cluster. The costs of these care clusters are being developed locally during 2012/13 by commissioners and providers working together.

The Commission received evidence that the current combined expenditure on VCS organisations by Leicester City Council and NHS Leicester City is £4,200,000, which includes service provision for:

- IAPT
- Supported Living
- Outreach work for people with Severe and Enduring Mental Illness
- Counselling Services
- Home based support for Carers
- Mental Health support for older people
- Money advice support for people with Mental Health problems
- Support for young carers
- Outreach work for homeless people

- Crisis helpline for people with mental health problems
- Carers' respite
- Carers' Information and training
- Welfare rights
- Employment Support
- Information and advice – early prevention work
- Independent mental health advocacy
- Social Groups
- Day services for older people with mental illness

The commission heard evidence from VCS organisations.

- VCS organisations suggested that service users feel that a block contract does not always result in the provision of appropriate services. Furthermore VCS organisations provide many good services which are not recognised by the current system of letting contracts.
- VCS pointed out that LPT has increased its range of services since April 2011, when it took on local community healthcare services under the Transforming Community Services agenda.
- VCS organisations suggested that resources are targeted on in-patient services, whilst investment in statutory community mental health services has been cut, placing an additional burden on shrinking VCS resources.
- As LPT has a great influence over service planning and design, they are well placed to help VCS organisations by championing the need for more investment from the commissioners. However, LPT has shown little interest to include VCS in delivering community-based provision.
- Commissioners suggested there has actually been an overall reduction in the value of the LPT contract and that most of the service areas which are affected by the block contract are not those in which there is VCS expertise. Furthermore, LPT has been a champion for local VCS organisations, as it works with local VCS organisations (such as Adhar, Akwaaba Ayeh and Network for Change) in the Open Minds service; with Aspiro to encourage employment of people with mental ill health, and with SUCRAN, the Service User Audit Network.
- SUCRAN is an important initiative, commissioned by the PCT Cluster, to enable service users and carer to audit MH services. The network is a partnership between Genesis and Peoples Forum. It has completed an audit of inpatients and community services to evaluate the quality of service provision and patient experience mapped against the LLR MH Charter. SUCRAN plans to undertake an audit of employment support provided to mental health service users and an audit of the quality of advocacy support provided to mental health service users.
- The PCT has been working closely with LPT to develop a recovery focussed approach within inpatient settings. This has led to the implementation of the STAR Recovery tool

within LPT. The effectiveness of this project is currently being audited as part of the Quality Schedule with LPT.

7.3 The Commission heard evidence concerning the progress made on the implementation of the Joint Commissioning Strategy for Mental Health

- The Commission heard evidence from lead officers for mental health commissioning and public health. A presentation outlining the following progress on the strategy was provided to the Commission:
- Mental Health has been identified as a joint commissioning work stream across health and social care. The priorities include:
 - To develop and implement a stepped care approach to ensure that all patients have timely access to appropriate services.
 - To continue to work in partnership to address the determinants of inequality and deprivation which are linked to mental illness
 - To increase support for the involvement of service users and carers in the planning, development and delivery of mental health services.
- The strategy was developed in consultation with service users, carers and providers from the statutory and VCS sectors. It builds on past achievements and provides a refreshed strategic direction, particularly in light of the Government's programme of action for mental health. It aims to strengthen the mental health and wellbeing of the population.
- Personalisation is central to the strategy. It aims to give people more choice and control over their lives in all social care settings, including those integrated with health. It aims to move away from the traditional service-led approach, which has often meant that people have not received the right help at the right time and have been unable to shape the kind of support they need.
- Health and social care services have a key responsibility to support people with mental ill health. They also have a role in improving health and wellbeing. Mental health services have evolved the last twenty years. Whilst this has led to many positive outcomes, people who experience mental health problems still encounter significant difficulties in their daily lives; they experience gaps in services and variation in the support available to them.
- While secondary care services have improved, the development of primary and out of hospital services has not proceeded at the same pace; there is a need to shift the focus and the balance of investment towards primary and out of hospital services.
- The strategic ambitions for mental health services are being delivered against a backdrop of change and a challenging financial landscape. In order to realise the strategic ambitions the Quality, Innovation, Productivity and Prevention (QIPP) Programme has been developed.

- The Joint Commissioning Strategy provides the framework for effective commissioning to improve care outcomes. It aims to develop strong leadership and innovative approaches and to address the links between inequalities, social exclusion and discrimination and mental ill health.
- New reporting structures have been developed to support the management, monitoring and implementation of the current strategy, and to scope strategic development for 2013 onwards.
- Improving access to psychological therapies (IAPT) has been rolled out across Leicester. This service is called Open Mind and is based on collaboration between LPT and local VCS.
- The review and redesign of the acute mental health care pathway was agreed as part of the 2011/12 contract with LPT as a Service Development Improvement Plan.
- A draft pathway for supported living has been developed and is part of the implementation plan.
- Transforming Social Care is part of the implementation Plan.
- The Joint Commissioning Strategy for Mental Health has been linked to the 2014 Vision for Adult Social Care work streams and has progressed in several areas. However, the on-going organisational review has had significant impact on the pace of delivery.
- Autism and Asperger Syndrome Services span health and social care and are represented both in the Mental Health and Learning Disabilities Joint Commissioning Strategies.
- With regard to long term residential care, the moving on team is looking at the needs of all client groups. This team is initially focusing on adults with mental illness, enabling them to be part of the wider community.
- In relation to increased up take of direct payments and personal budgets, bespoke workshops to all client groups have been commissioned from the voluntary sector. Personalisation also forms part of the carers training plan.
- A review of in-house day services is underway with a view to changing the way current services are currently offered towards an enablement model of support.
- Discussions with current providers have resulted in some offering a range of community based services for people who have a personal budget; this work is on-going with all providers.
- Work is taking place with supported employment providers to enhance the employability of current and future clients.

The Commission also heard evidence from VCS organisations about the Joint Commissioning Strategy, to which the Commissioners were able to respond:

- Although Commissioners suggested that groups such as Network for Change, LAMP and Adhar had been involved in the priority setting and had worked with commissioners to seek the views of service users, VCS organisations suggested that service users and carer groups did not feel involved in the planning and strategy of mental health services in the city.
- Consultation with local service users and carers suggests that their priorities are largely ignored in current commissioning priorities and actions. These priorities are stated as IAPT; crisis intervention; re-ablement, remodel residential care; supported living. The VCS organisations suggested that there have been cuts rather than new investment in these areas.
- Commissioners replied that there have been no cuts to the IAPT or crisis services in Leicester. Leicester City Clinical Commissioning Group are committed to expanding the IAPT programme to include support of people with long term conditions, serious mental illness and vulnerable groups (older people, the homeless, asylum seekers). IAPT will be receiving further investment. With regard to supporting people in crisis, there will be a project aimed at redesigning crisis services with transformational funding available to increase liaison psychiatry services in Emergency Departments.
- VCS responses also suggested that LPT has invested in day services at a hospital based 'Involvement Centre' which is not wanted by most service users. Although a tender for Early Intervention and Prevention may include some of the other day services type preferences of services users, no funds are likely to be available for these until 2013. Commissioners suggest that this is not the case.
- VCS organisations expressed concerns that multi-agency meetings which had been designed to lead on mental health had been disbanded with no successor bodies in place. These meetings were regular opportunities for engagement between health and social care commissioners, VCS and service user and carer representatives. Commissioners suggested that this was because of the structural changes in health and social care, and that work was currently underway to create a new forum which would work to the Health and Wellbeing Board.
- VCS groups suggested that people with mental illness have difficulty in accessing personal budgets. However, commissioners responded that re-organisation has meant there is extra capacity for people to receive timely assessments. However, the outcome of these assessments suggests that people with mental health needs may not necessarily require social care support, but may be signposted appropriately.
- VCS groups suggested that there are situations where clients are being told they do not qualify for social care payments, even though these clients had high mental health needs. These people may have to wait for the introduction of individual health budgets for support, which will not happen until 2014.

- From a VCS perspective there is a lack of clarity about who is eligible for social care packages and show the need for a better understanding of assessment criteria by those undertaking the assessments.
- VCS organisations suggested that there is a need for increased funding to be invested into non-personal budget funded VCS services to meet needs of vulnerable 'hard to reach' groups. For there are many people with severe and complex mental health issues who fall through the gap between primary and a reduced statutory/ secondary community care.

The Commission asked about the framework and objectives for the development of services through personal budgets.

- In terms of a transition period from day services to Personal Budgets one of the options being considered are framework agreements, however no decisions have yet been made as frameworks may actually work out to be more costly.

With regard to the commissioning of mental health services the Commission asked about the progress that has been made on the implementation of IAPT.

Yasmin Sidyot, NHS Leicester City said that:

- Implementation of the new service had started in 2010.
- IAPT is a primary care based service aimed at delivering evidence based talking therapies and counselling to people with common mental health problems, such as depression and anxiety. It is a national and local strategic priority. 1 in 4 people will suffer from some depression/anxiety at some point in their life. Most people will not require any additional support or access to therapy. However it is estimated that about 15-20% of people who suffer from depression/anxiety will require additional support and access to therapy.
- This service is currently delivered by LPT in Partnership with Network for Change and Adhar Project. The evaluation of the current service and its achievements are detailed in an evaluation report.
- The PCT is in the process of re-commissioning the service. 12 months' notice has been given by the PCT to the current providers.
- The new service will be redesigned and commissioned based on service user and public consultation. The service user and public consultation was underway at the time of the review by the Commission.

With regard to the acute care pathway

- This is about re-designing acute care for mental health service users at the point of crisis. Outcomes focussed in the inpatient setting which will improve patient experience. Supporting people at the time of crisis and when discharged from the inpatient setting. A

discussion document with a draft of proposed plans was disseminated and a service user and stakeholder event held to engage people's views. This will influence the revision of plans and the development of clear measurable outcomes that aim to improve patient experience.

- The expansion of the liaison psychiatry service was still a priority; it is unlikely that the Clinical Commissioning Group would discontinue this work. Dr Cross, who had been the GP lead for mental health in Leicester, has recently left the Clinical Commissioning Group and has been replaced by Dr Jawahar.

7.4 The commission had specific questions regarding mental health and vulnerable groups:

Commission Question – Can maternal health be affected by social and economic conditions?

- Response - from Mark Wheatley, NHS Public Health Principal - Women in the perinatal period are as vulnerable to mental ill health as the rest of the population. Perinatal maternal mental illness is particularly important, and may have a wide impact, because it occurs at a crucial time in the lives of mothers, their babies and families.

Commission Questions – a) What is the definition of Black and Minority Ethnic groups, b) What is the number of Black and Minority Ethnic people currently using working age adult mental health services compared to the number using these before the introduction of the Improving Access to Psychological Therapies services?

- Response - from Yasmin Surti NHS Leicester City – a) The term black and minority ethnic (BME) is used to refer to minority communities in the local population on the basis of their 'racial,' 'ethnic' or national origin. It includes established groups (e.g. African, Asian, African-Caribbean), new migrant communities (e.g. people from Eastern European countries), refugee and asylum seeker communities, transient communities (e.g. the Traveller community) and groups often referred to as 'invisible minorities' (e.g. the Irish community).
- With regard to structural disadvantage, research confirms that people from BME communities are more likely to reside in deprived areas, experience poverty, live in overcrowded and unsuitable accommodation, be unemployed and suffer ill health.
- For members of many minority ethnic communities, the stigma attached to any suggestion of mental illness influences their decision when deciding whether to acknowledge or conceal a problem and seek treatment. Currently approximately 40% of people in receipt of services or support are from a BME background. The PCT and the Local Authority also commission BME specific services in the voluntary and independent sector to offer culturally appropriate services and support to local communities.
- Response from Mark Wheatley, NHS Leicester City suggested that poor mental health disproportionately affects those experiencing greater deprivation. Evidence suggests that individual resilience to poor mental health is influenced by a range of factors in the

lifetime of an individual, including social position, education, housing, employment and exposure to violence; it is possible to suggest that relative deprivation is associated with an increased risk of mental illness. People with mental ill health are more likely to experience discrimination and stigma, the impact of which can reduce employment opportunities, weaken supportive social networks and contribute to further socio-economic inequality. So mental illness further exacerbates inequality as people with mental health problems are more likely to be unemployed, live in poverty, and in neighbourhoods with less social and environmental capital.

- Evidence also suggests that people from Black/Black British ethnic backgrounds are over-represented in having severe mental health illnesses, but those from South Asian backgrounds were under-represented. Efforts were therefore being made to encourage people of that background to take up services, such as those provided by Open Mind.
- The Commission felt that these responses were significant, considering the pressures on VCS funding. For instance, Adhar suggested that further pressures on funding could have a serious impact on the existing services for people from South Asian backgrounds.
- Akwaaba Ayeh Mental Health Project stated that the gaps in services have got much worse over the years, and that:
 - There is a continued over representation of people from Black African Caribbean backgrounds in the Mental Health System and Prison Service.
 - Continued lack of Access to Psychological Therapy. This is despite research showing that people from Black/Black British ethnic backgrounds are over represented in social care and psychiatric systems and yet are least likely to be offered psychological therapy.
 - Lack of access to services is affected by to lack of trust and understanding,
 - There is a risk of BME groups becoming more marginalised,
 - There is not enough Early Intervention and prevention support to prevent the high level of admission into the mental health system
- Commissioners' feedback suggested that the independent evaluation of the IAPT service showed that significant improvements had been made in BME communities accessing psychological therapy. In addition funding had been made available to Akwaaba Ayeh for a peer educator project, to promote early intervention and access to services.

The Commission welcomed this information, as the influence of ethnicity had not been identified in the previous review. The Commission stressed the importance of considering other services, (for example housing, environmental services, leisure activities and access to transport), when looking at this issue, as they were important in ensuring that help was targeted appropriately.

7.5 **The Commission heard evidence regarding progress made regarding clear leadership, accountability and better governance of commissioning of mental health services**

In April 2011, Leicester City Council reported that there is a clear leadership, accountability and commitment from both Leicester City Council and the NHS Leicester City to drive forward the Joint Commissioning Strategy for Mental Health. There is currently a Mental Health and Wellbeing Partnership Group, which is being re-configured to ensure the commissioning intentions outlined in the strategy are delivered. This group will feed into the new statutory Health and Wellbeing Partnership Board, which is currently being set up to develop joint strategies to improve outcomes for health and social care users across the City. Membership of the Board is likely to include the chair of the GP consortia, the Chief Executive for NHS Leicester and Leicester City Council, the chair of the Local Involvement Network (LINK soon to change to Health Watch), the Lead Cabinet Member for Adults and other key partners.

The Commission heard the following evidence:

- Over the last year a range of material has been emailed to contracted and non-contracted providers for their information and to share with users and carers. These detailed events, activities and about new approaches to working. There have also been many formal and informal discussions about how to develop future personalised services.
- The Mental Health Promotion Network plays a role raising the profile of mental health across the wider public domain.
- A Carers Pack is being commissioned from and developed by LAMP and Genesis who have been commissioned with this piece of work. Carer's awareness training, commissioned by health and social care through a joint contract, is also provided by Genesis.
- In the period October to December 2011, 62 complaints were raised about LPT and dealt with by staff through local resolution compared to 69 received in the previous quarter. Communication and staff attitude were the most frequent source of complaints.
- LPT has received 4 requests for files by the Parliamentary and Health Service Ombudsman from complainants who remain dissatisfied having exhausted the Trust complaints procedure. None of these are being considered further, suggesting that LPT has provided a sufficient response to the complainant at the time.
- A total of 772 compliments were received for the quarter, October through to December 2011.
- A total of 120 public enquiries were made to the Trust.
- LPT received three unannounced visits from the Care Quality Commission (CQC).
- As part of the CQC national patient survey programme, LPT was carrying out a survey to find out what mental health patients think about the care they receive. The Director of Adult Mental Health services, Paul Miller said to the Scrutiny Commission that :

“obtaining feedback from people who use our services and taking account of their views and priorities is vital for bringing about improvements in the quality of care. Results from the CQC survey, alongside our own internal surveys, our patient and carer listening events and other service user feedback provide us with valuable information and help us to find out how we are doing and how we can improve”.

- Paul Miller added that the views of patients, carers and relatives had been surveyed by LPT about proposed changes to the way its mental health services for adults are provided; such as on a single point of access, which could make it simpler and easier for GP's to refer patients, and enable them to receive immediate advice from qualified mental health staff through a dedicated telephone number.
- New Centre of Excellence Building for Mental Health Hospital Care – LPT building works of a £23 million phased refurbishment is well underway at the Bradgate Mental Health Unit (at the Glenfield Hospital site). The hospital unit has been developed into a new centre of excellence for inpatient care and will allow all acute adult wards to be co-located in a single improved facility and alongside other specialist mental health services. The improvements include rebuilt and refurbished wards to provide more single en-suite rooms and private garden areas, and changes to the way staff work to allow more time to be spent on direct patient care. Eventually the older, more out-dated Brandon Unit will close in spring 2013.

The Scrutiny Commission heard evidence about levers to improve the quality of mental health care to be provided by LPT:

- In order to ensure that mental health services that are commissioned are delivering high quality evidence based services the quality is monitored through the contract with the means of the quality schedule. This is attached to this paper in order to provide the commission with the outline of what this means and how quality is measured.
- In addition a series of CQUINs (Commissioning for Quality and Innovation) are also agreed. There are a number of national CQUINs and regional CQUINs that are mandated and a number of CQUINs that are locally agreed. These are based on where service gap or health need is identified. 5% of the total contract value is withheld from the provider and is paid once the CQUINs have been achieved.
- The 2012/13 CQUINs were being developed and agreed with LPT at the time of the Commission.

7.6 The Commission heard evidence about how the number of people with mental illness using supported living accommodation had changed since the last report

Evidence from services users included the following:

- One service user explained that she benefited from supported housing through Network for Change. She had previously lived in a third floor flat, but the Network had arranged for her to have a ground floor flat and had helped her to organise her finances. She was concerned about the future of the Network, as its funding has been reduced.

- One person had been waiting 5 months for her payments to arrive following an assessment.
- A service user had been assessed as having substantial needs only for a social worker to suggest on a further visit that she “did not look like she had substantial needs”.
- Some service users experienced unnecessarily prolonged stays in hospital, or other unsuitable accommodation, because of difficulties accessing housing. This could lead to them becoming institutionalised, but under the Supported Living programme they were able to live as independently as possible.

VCS organisations added:

- The Mental Health Opportunity Assessment shows that In Leicester the residential and nursing placements have remained fairly constant at just over 200 people over the last 4 years whilst there has been a 37% decrease in community based services during the same period.
- Leicester City Council has made reductions to housing related support services of 15% in 2011/12 and 7.5% in 2012/13 impacting on the existence of local specialist mental health housing providers.
- There needs to be an increase in housing related support to reduce residential care, otherwise the commissioning strategy priorities will not be met.

Yasmin Surti, Commissioning Manager at Leicester City Council, said that supporting people with mental health conditions to move from residential homes into independent housing and helping them people to continue to live in their own home is a priority of the Joint Commissioning Strategy.

The commissioning plan includes a Moving On Programme which aims to move a minimum of 50% of existing residents out of residential care over the next 3 years and, through the development of Supported Living options, reduce the number of future residential care placements. It is assumed that most, if not all, existing residents of working age will eventually move on to live in their own homes.

Various supported living schemes have been established aimed at addressing the barriers faced by some communities, including:

- Pathways for both accessing housing and accessing community support packages
- Development of new service specifications
- A broader range and type of accommodation based predominantly on individual tenancies/home ownership with possibly some limited buildings based “supported housing” schemes of a “sheltered” nature.
- A wider range of levels of support including floating support/low level support to more intensive outreach services (health & social care), both of which are gaps in current provision.

Financial pressures and organisational change means that this work has not progressed within the original time scales. However, a new Commissioning Framework for Supported Living is near completion. This area of work has been confirmed as a priority by the Senior Leadership Team, with the commitment of additional staff to progress it.

Evidence was given concerning the number of people with mental ill health who were accessing Leicester City Council Supported Living Provision. In the period 2009/10 there were 19 people, 16 from a White/White British ethnic background and 3 from Black/Black British ethnic backgrounds. By 2011/12 this number had increased to 42 people; 4 from Asian/Asian British ethnic backgrounds, 7 from Black/Black British ethnic backgrounds and 31 from White/White British ethnic backgrounds.

The existing adult social care provision was described. There are no existing voids at these properties

- Orchard House 13 self-contained flats - referrals managed by LPT Service Manager, maximum stay 3 years
- Glenfield Rd x 2 houses, total of 8 self-contained flats (1 flat used by onsite support provider)
- Hinckley Road 1 house, 4 self-contained flats with floating support

A summary of new developments included:

- New build of supported housing in 2011 achieved moves from hospital, residential care and other schemes;
- Wolsey Extra Care (mixed client group) age designated scheme of 63 flats currently has 8 tenants with Mental Health
- Manor Farm total of 11 flats with communal areas and a hobby room

Looking ahead:

- Allocations Policy and Choice Based lettings can meet the needs of majority of service users requiring 1 bed general needs accommodation with floating support
- A group of staff from LPT care management who will be transferring back to the Local Authority in April 2012 have been identified as a potential resource to achieve targeted moves for people currently in residential care or hospital.
- Potential to gain further units through reusing existing LCC Housing stock, current addresses being explored:
 - Former warden's house within a sheltered accommodation scheme would provide short stay accommodation for those with high support needs up to 2 years.
 - Welford Road property use of ground floor 5 units with onsite support
 - Cluster of 5 bungalows, Thurnby Lodge with floating support.

7.7 The Commission investigated the links between employment and mental health problems

- The relationship between unemployment and mental ill health is complex because an individual suffering the onset of mental illness is more likely to leave employment compared with other health conditions. People with mental health problems have the lowest employment rate of any disabled group. Mental illness is more prevalent in the most deprived areas. Currently 6.5% of people known to services are in some form of employment.
- People with mental health needs face stigma and perceptions about their needs and abilities in work. Many employers have the perception that people with mental health needs will have long periods of sickness and therefore costly to their business.
- One disincentive for people to come off Welfare Benefits is the perception that they will have to immediately work at least 16 hours a week and that they will be less financially stable, resulting in additional pressures and stress before a person has even started a job. This combined with a lack of self-esteem and low or even no confidence, all create further barriers to someone ever getting back in to employment.
- Evidence shows however, that employment has a key role to play in a person's recovery and sustained mental wellbeing. Creating the right support to enable someone to manage their condition and begin to enter the job market makes a positive difference to a person's self-belief and how they are viewed by others. Voluntary work, work experience, job trials and supported employment are some of the many ways that someone can begin to work again. People with mental ill health may benefit from structure and routine. Work may give people a purpose beyond coping with their own condition. Ultimately work may help people with mental illness to be seen in a positive light, as contributing towards society, and generate a genuine sense of self-worth.
- Leicester City Council and PCT have worked together to commission additional support for people with mental illness to get back into employment or to remain in employment. An example of this is the voluntary initiative Baby Gear which supports people with mental health problems to develop skills that support them to find employment. ASPIRO is another social enterprise that is supporting people with mental health needs and learning disability in to work and education.
- The Council has commissioned Case-Da an independent social enterprise to work with providers to support them to redesign services towards personalisation and personal budgets. Case-Da are able to assist with for example, development of business plans, employment advice, HR support etc. This service is free to all providers and has been widely publicised to enable providers to take advantage of the support offered on a one-to-one basis.

7.8 The Commission requested an update on deaths from suicide and undetermined injury in Leicester

- In Leicester there are about 32 deaths from suicide every year. Whilst there has been a downward trend in England since 1993, the rates in Leicester have fluctuated. Each case of suicide is a tragedy for individuals and their friends and families. Although there are a comparatively small number of deaths involved, the recent Community Mental Health Profile suggests that the indirectly standardised mortality ratio for death from suicide and undetermined injury is significantly higher in Leicester.
 - In addition to auditing deaths from suicide and undetermined injury, local suicide prevention work includes a suicide audit and prevention group for Leicester, Leicestershire and Rutland. This group is attended by key stakeholders such as local authorities, probation trust, HMP Leicester, voluntary sector organisations, local health commissioners and providers, local colleges and universities, people involved in safeguarding children and adults and the police.
 - The group receives the annual audits of suicide and undetermined injury and prepares the suicide prevention strategy. The group participated in the consultation for the new national suicide strategy in the autumn of 2011. The outcome from that consultation will be a new national suicide prevention strategy. The local group is awaiting the new national strategy to develop the new local strategy.
 - The directorate of Public Health and Health Improvement has commissioned local Suicide Awareness and Prevention Training (SAPT) from the Rural Communities Council. This training is validated by the University of Nottingham and has been used to target vulnerable areas in Leicester.
 - The core objectives of SAPT include:
 - Challenging attitudes about suicide
 - Raising awareness of risk factors and indicators of suicidal behaviour
 - Increasing confidence in individuals to help those in distress
- d) Evaluation pre and post training and 6 months after training show that SAPT works. SAPT has trained 447 delegates (from a variety of roles and organisations) at Leicester City training seminars.

8. Financial, legal and other implications

Financial Implications: None

Legal Implications: None

Other Implications

OTHER IMPLICATIONS	YES/NO	Paragraph Within Supporting information	References
Equal Opportunities	Yes		
Policy	Yes		
Sustainable and Environmental	No		
Crime and Disorder	No		
Human Rights Act	No		
Elderly/People on Low Income	Yes		

9. Background Papers – Local Government Act 1972: None

10. Consultations: None

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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 level¹.

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.

¹ 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 dementia¹. 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.

¹National 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.

¹ 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 annually².

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.

² 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

Leicestershire and Rutland	Leicester City
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) ³

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

³ 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)

Primary Care Trust Area	Numbers of people on a GP register Jan 2011	Numbers of people on a GP register reviewed in previous 15 months	% patients diagnosed with dementia whose care has been reviewed in the previous 15 months
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

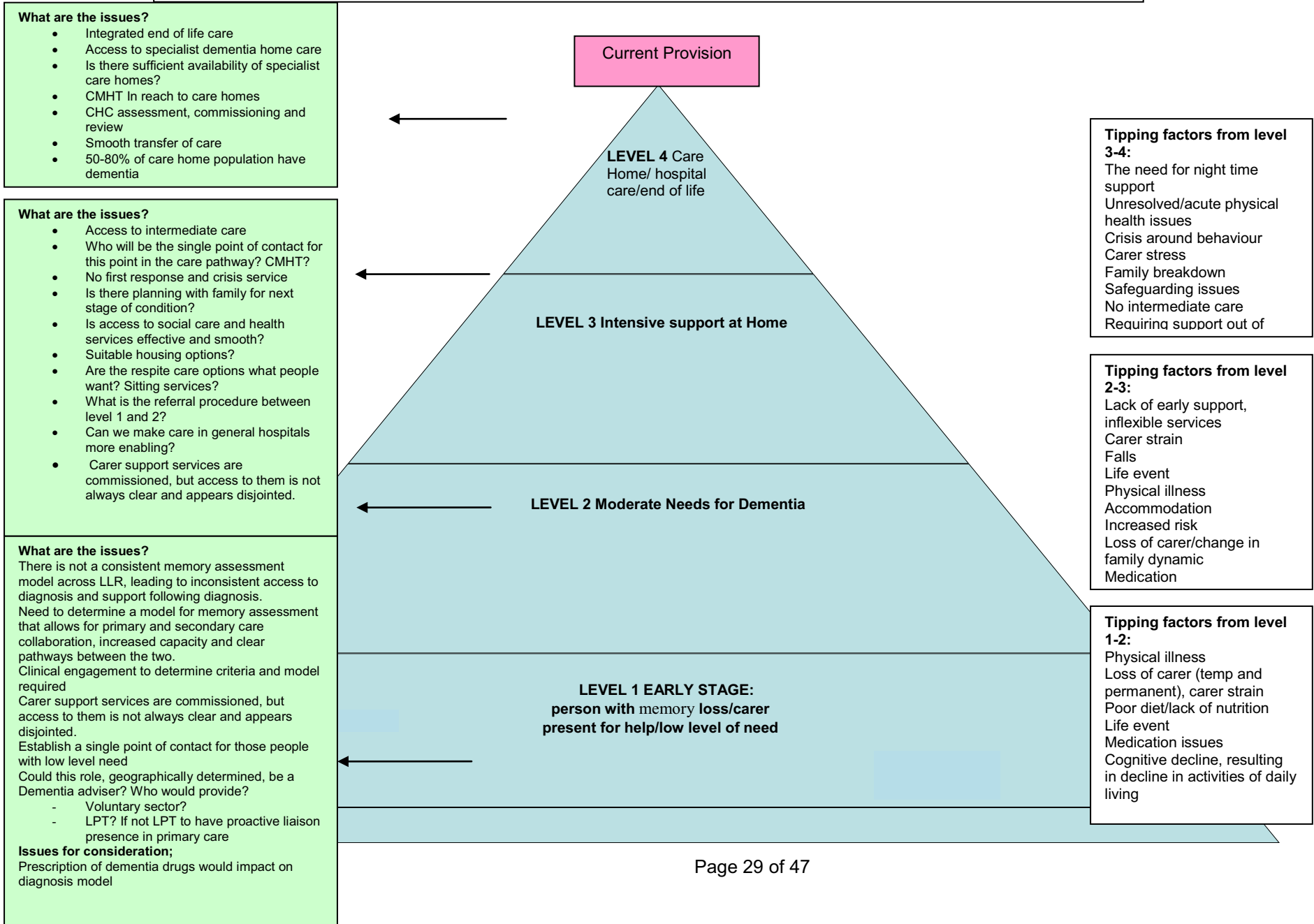
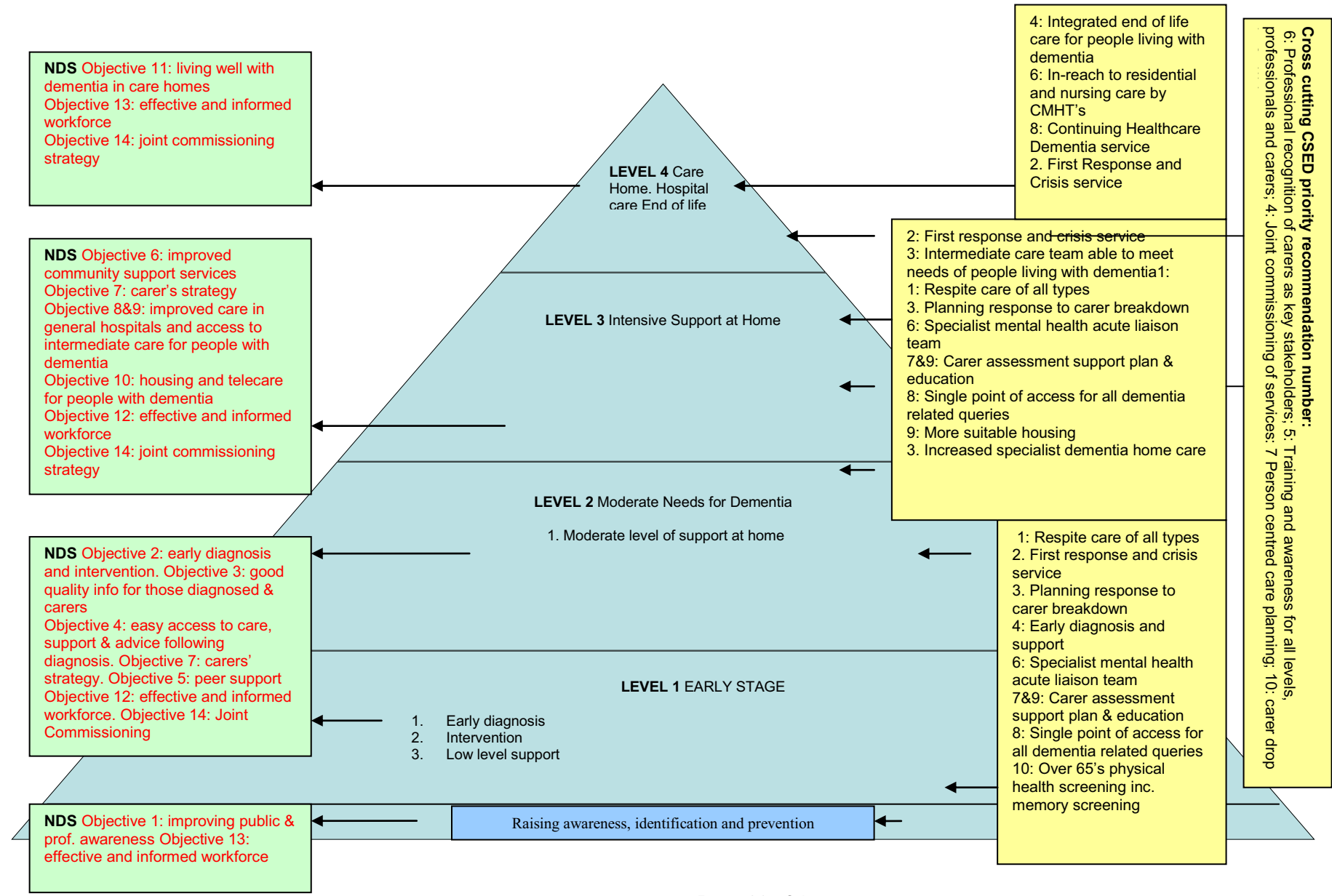


Diagram 2. Future Care Pathway
Leicester, Leicestershire and Rutland (LLR) Integrated Dementia Care pathway with reference to the National Dementia Strategy (NDS) and local strategic actions



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

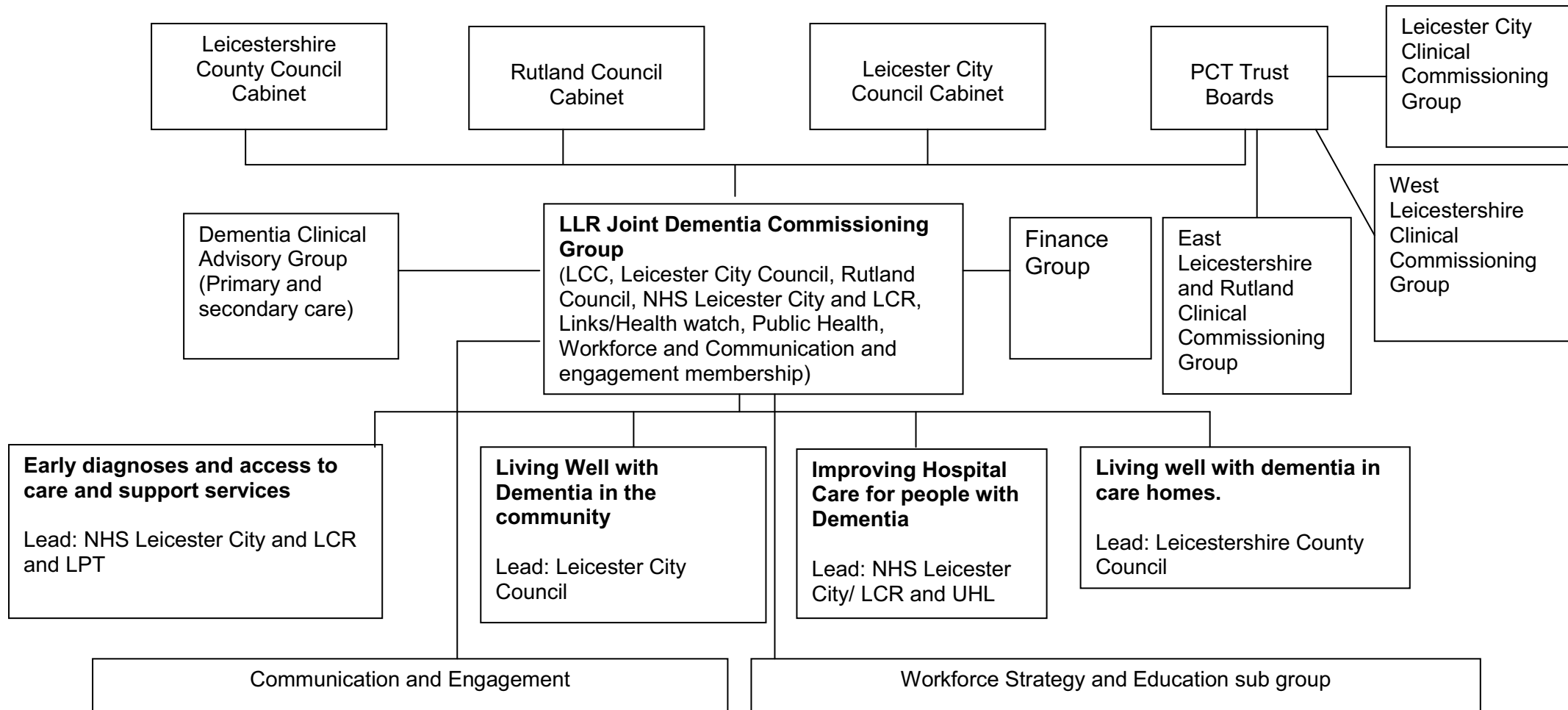
Quality and management

- 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

Date	Title	Attendees
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 th July 2011	Dementia carers event	Carers and service users
11 th July 2011	Dementia strategy launch LIN stakeholder event	Stakeholders from various organisations across LLR, such as LPT, UHL, Voluntary Sector organisations
12 th July 2011	East Leicestershire Clinical Care Group	GP's
25 th July 2011	Links workshop (LLR)	LLR wide representative
9 th August 2011	UHL Executive Board	Senior Management Team Consultants Nursing Representation
9 th August 2011	West Leicestershire Clinical Care Group	GP's
August date TBC	Leicester City Clinical Care Group	GP's
7 th 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.

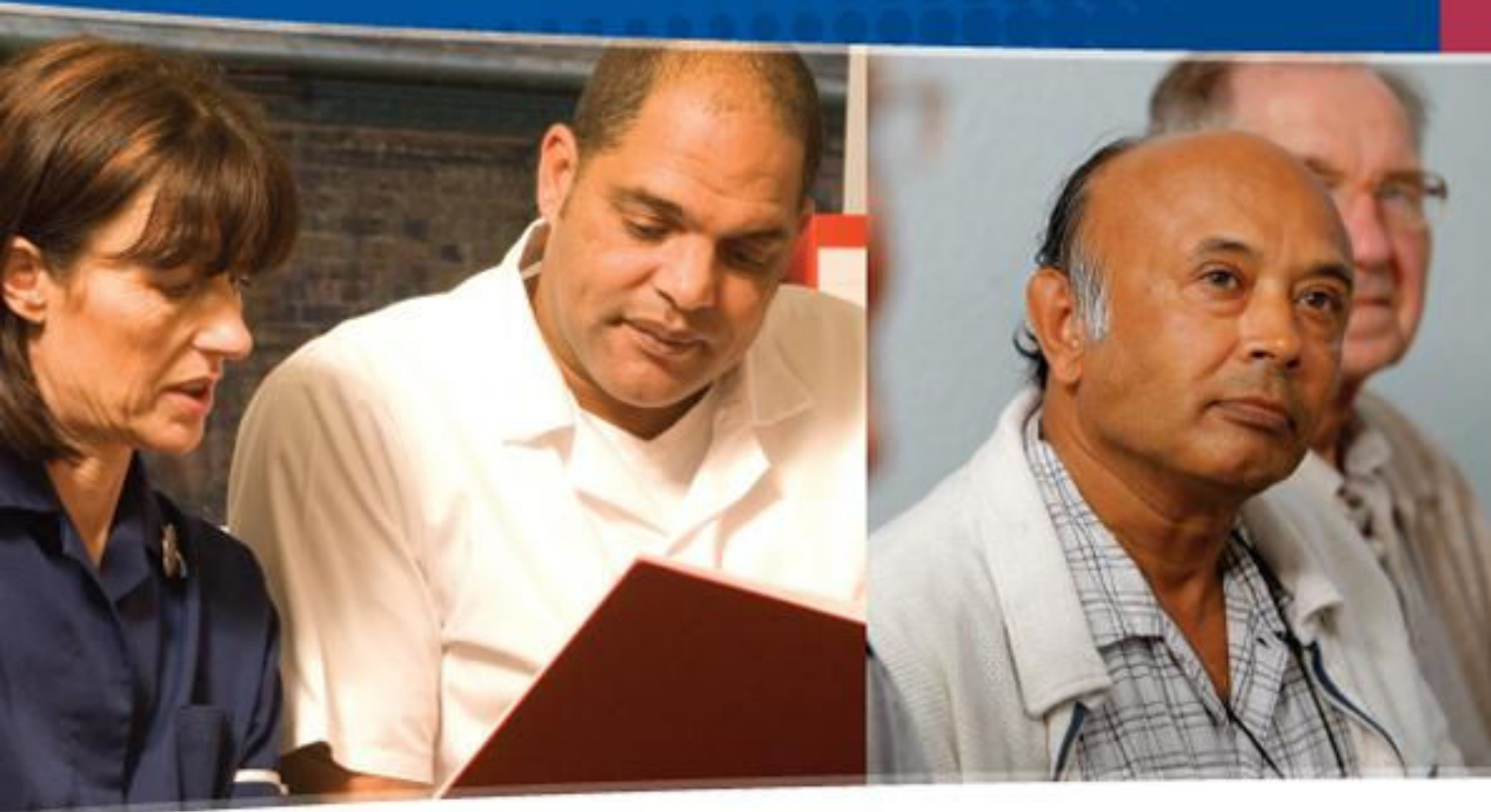
Sexual orientation

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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A Joint Specific Needs Assessment: Dementia in Leicester

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A Joint Specific Health Needs Assessment on dementia in Leicester

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Executive summary

Introduction

The development of health and social care for people with dementia is a key concern for Leicester. This Joint Specific Needs Assessment (JSpNA) is an overview of dementia care for the Leicester population. It highlights key issues and provides an indication of the likely level of need for those with dementia and their carers in the city. The following are some of the key points that can be drawn from this need assessment.

Methods

This Joint Specific Needs Assessment systematically reviewed the health issues within Leicester city of people with dementia and their carers. It assesses the impact of Dementia across Leicester, maps the current services, reviews effectiveness and summarises these findings.

Key Findings:

Population Affected

There are approximately 3,200 people with dementia in Leicester, with about 800 new cases occurring each year. Most people with dementia are aged 65 and over, but there are about 70 younger people with dementia. If dementia could be removed from the population about 250 deaths per year in those aged over 65 years could be averted.

The risk of having dementia thus increases with age, affecting 7.6% of the population aged 65 years and over. It is estimated that by 2030 the total number of people in this age group in Leicester will have risen by around 2%, from 35,400 to 51,300. In the same period it is also estimated that the number old elderly, those aged over 90 years, will more than double to 3,700 people.

Currently the vast majority of people aged over 65 years live in the community; 13,294 people in this age-group live alone and 1,250 live in care homes. Of the people aged over 65 with dementia living in Leicester it is estimated that 1,654 live in the community and 985 live in care homes. A high proportion of people aged over 65 years who live in care homes have dementia. The risk of a person living in a care home with dementia increases with age, such that more than 60% of those with dementia aged over 90 years are resident in a care home.

With regard to area of residence, most people over 65 years are resident on the outskirts of the city. There are many ward areas with more than 1,500 residents aged over 65 years. Knighton and New Parks wards have the highest number, whilst Evington and Thurncourt have the largest proportion of residents aged over 65 years.

Although Leicester is a diverse city, there are small numbers of people aged over 65 from black and minority ethnic (BME) backgrounds relative to the general population, but this is likely to increase substantially in future years.

Types of dementia

The term dementia describes a set of symptoms, including memory loss, mood changes, and problems with communication and reasoning. These symptoms are more severe than those experienced in normal ageing and occur when the brain is damaged by certain conditions, such as Alzheimer's disease, or a series of small strokes. The symptoms gradually get worse, with different needs emerging as the illness progresses. The severity of dementia can be categorised as mild, moderate or severe. Of the different types of dementia Alzheimer's disease is the most common, accounting for more than 60% of all cases; dementia related to vascular disease is the next most frequent (17%). A further 10% of cases are related to a combination of the 2. The mean survival with Alzheimer's disease is 7.1 years and 3.9 years with vascular dementia.

Service development

There are a number of services in Leicester currently delivering care for people with dementia and their carers. These include a memory assessment service, secondary care at University Hospitals Leicester and at Leicestershire Partnership Trust, primary and community health and social care services and local nursing and residential homes. However, there has never been a fully commissioned dementia care pathway. Current service provision has evolved often as a result of expertise on the ground rather than being commissioned effectively from the perspective of a patient's journey. There is a clear need for this to improve in order to meet the challenge of developing local services to meet the population need.

Delivering the *National Dementia Strategy* should help to meet this challenge. There are 5 local work streams aimed at developing services so that all people with dementia and their carers should live well with dementia. These groups report to the Leicester, Leicestershire and Rutland Joint Dementia Commissioning Group and include:

- Early diagnosis and access to care and support services
- Improved experience of hospital care
- Improved quality of care in residential/care homes work stream
- Personalisation of care and living well with dementia in the community work stream
- A workforce fit to deliver services to support the care pathway for dementia

A local dementia care strategy has been developed by a group of lead commissioners across health and adult social care. A joint commissioning approach to the problem of developing dementia care services is vital for the development of priority areas where partnership would add value in terms of improved outcomes and greater efficiencies. The aim of the joint commissioning group is to implement change which meets local needs, consistent with the national strategy and the wider policy context relevant to dementia care, including *Putting People First*, the *Carers'*

Strategy, the *End of Life Care Strategy* and the strategic shift to prevention and early intervention.

In order to meet the dementia care needs of the local population, there is a requirement to improve rates of early diagnosis. Currently only 40-50% of the estimated population with dementia are recorded on primary care disease registers in Leicester. With earlier diagnosis people may be able to benefit from medication and obtain earlier access to important information relevant to people with dementia and their carers.

The improvement in rates of early diagnosis is not just about improving primary care. Better rates of early diagnosis and improvements in dementia care generally, can only be achieved by developing the whole dementia care pathway. Commissioning models requirements suggest that there is a requirement for more staff focused on dementia care, and more investment in memory assessment services, general hospital liaison care and care for people living in the community.

Early diagnosis is likely to have an impact on prescribing rates. There is already a general upward trend in the cost of prescribing drugs for dementia in Leicester, including medications, such as the acetylcholinesterase inhibiting drugs, which have some therapeutic effect on Alzheimer's disease. Whilst the patent to one of these drugs expired in February 2012, making the medication less expensive, recent NICE guidance releasing Memantine for cases of moderate to severe dementia is a risk to prescribing budgets.

Carers

The health and wellbeing of carers is also an immediate urgent need. Early diagnosis will allow more timely access to information about dementia. It should also give patients and carers the opportunity to look at support options. These options are likely to be tied closely to the agenda for personalised budgets, respite care, care home support and end of life care. These factors mean more social care developments, better training for all of those involved in dementia care and closer working relationships between clinical staff and dementia care co-ordinators.

Thus is important that the dementia care pathway offers support which maintains independence, enabling those who wish to remain at home to do so if they can. There should be a flexible approach to respite; including enough respite in the home where a person with dementia is less likely to become confused, and a carer may be able to take time away from caring responsibilities. As there are high rates of physical and mental health problems amongst carers, it is also important for carers to have access to regular reviews of their health and wellbeing.

Finally, whilst dementia clearly impacts most on those people aged more than 65 years, specific attention needs to be paid to those people, about 1% of the population, who are under 65 and have early on-set dementia.

Mark Wheatley, June 2012

Recommendations

The following recommendations have been made for consideration by the Joint Strategic Needs Assessment Board and commissioners:

1. Policy implementation

Local organisations involved in dementia care, should follow the lead of the local authority in supporting the outcomes of the *National Dementia Declaration*.

Local implementation of the *National Dementia Strategy* should establish links to other relevant policies and initiatives; such as the *End of Life Strategy*, the *Falls Strategy*, the *Dignity in Care Campaign*, and local voluntary sector initiatives such as the Dementia Action Alliance.

2. Recommendations with regard to Primary Care

To note the observed and expected rate of dementia by general practice locality.

A primary care model supporting early diagnosis should be developed in which GPs are encouraged to use a cognitive assessment tool, watchful waiting of potential cases, referral for blood tests and brain scans, and referral to the Memory Assessment Service.

There should be shared care arrangements between primary and secondary care to enable people with dementia to have access to appropriate care in the community; including advice on medications, clear definitions about who is able to prescribe; and information about how support activities of living.

There should be an improvement in the number of people with dementia whose care has been reviewed by their GP in the previous 15 months.

GPs should better identify and meet the needs of carers. In order to facilitate this, commissioners should monitor GP QOF registers of carers.

All carers should be invited by GPs for an optional annual health check.

Recommendation: All primary care staff should have training about the needs of people with dementia and their carers appropriate to their role in the Dementia Care Pathway.

Primary care should participate in the review of anti-psychotic medication for people with dementia, in the context of the support required for providing non-drug treatments and a review of the skills available for managing people with dementia in care homes.

Recommendation: Members of the primary care team, including reception staff, should receive appropriate training to respond appropriately to people with dementia and their carers.

3. Recommendations for the development of the memory assessment service

The Memory Assessment Service should be properly commissioned, incorporating methods of review and challenge to monitor effectiveness. Effectiveness should be measured on: increasing the rate of diagnosis (to 80% in 3 years), increasing the proportion of people diagnosed with dementia whilst they are in the early stages of the disease and increasing the number of carers who have a positive service experience.

Recommendation: As a specialist service the Memory Assessment Service should be commissioned to focus on individuals presenting in primary care with symptoms of mild to moderate dementia (Cluster 18) and the treatment of those people in whom the disease has significantly altered (Clusters 19 and 20).

The Memory Assessment Service provider should engage with commissioners and primary care to develop shared care agreements so that people with dementia will have access to the treatment and care they require.

4. Social care developments

To ensure that people diagnosed with dementia, who are eligible for support, are given a personal budget. Those who are not eligible should be given appropriate advice and information.

The dementia care co-ordinators should be commissioned solely to work with people with dementia and their carers. Their role should be to provide advice and support across the patient pathway. Access to the service should be from a number of points, including self-referral, voluntary sector organisations, primary, secondary and social care. To engage better with primary care, there should be closer links between dementia care co-ordinators and GPs in their different localities.

Recommendation: All nursing and residential home staff should have training about the needs of people with dementia and their carers appropriate to their role in the Dementia Care Pathway.

There should be a specialist community care team to assess the needs of people with dementia living at home or in care homes. This team will advise carers and other local health and social care providers about assessment and management interventions for patients with problematic symptoms of dementia.

5. Secondary Care

Recommendation: Commissioners should find ways of obtaining more effective coding of the attendance of patients with dementia at the emergency department.

Recommendation: To develop an integrated service comprising mental and physical health care expertise to provide a standard approach to the assessment and recording of an older person's mental health status upon admission to secondary care.

Recommendation: The multi-disciplinary hospital liaison service should incorporate credible mental and physical health expertise to assess the needs of frail older people. This team will facilitate detection of dementia in hospitalised group of patients, by reviewing them, prioritising patients' needs and reduce the length of stay of patients with cognitive issues. Patients diagnosed by the team should be added to the dementia register held in primary care.

Recommendation: LPT patients should be analysed, under the new payment by results tariff in mental health services, to 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.

Recommendation: Members of the secondary care team, including reception staff, should receive appropriate training to respond appropriately to people with dementia and their carers.

6. Community health care services

To ensure that there is an integrated reablement and integrated care model that reflects the needs of people with dementia.

7. Community mental health care

To review the existing ICATS model of delivery, to develop a service focused on preventing admission to the older person's mental health inpatient wards, and facilitate timely discharge from in-patient care.

To review the options for commissioning a joint health and social care crisis response service, to support both users and their families/carers.

8. Supporting carers in Leicester

Recommendation: All carers should have a carer's assessment

Recommendation: Carers' assessments should include information about breaks options.

Recommendation: There should be a wide variety of models of respite care tailored to individual needs and available to carers using personalised budgets.

1. Introduction

What is a Joint Specific Needs Assessment (JSpNA)?

The JSpNA is a systematic method for reviewing the local health and social care needs of a population facing a specific issue, in this case, dementia. The JSpNA will lead to agreed priorities and actions which will improve the circumstances of those people with dementia and their carers. It will be used to inform the dementia commissioning plans and future local dementia care strategies and is part of the wider Leicester Joint Strategic Needs Assessment programme (<http://www.oneleicester.com/leicester-partnership/jsna/>).

Objectives

The objectives of this specific needs assessment are those which were set out in the original JSpNA Brief, and cover:

- A summary of the national and local policy and strategic background;
- A description of the population at risk of dementia, highlighting particular characteristics relevant to Leicester;
- An estimation of the current incidence and prevalence of dementia;
- An assessment of impact of dementia on individuals, families, carers and communities;
- A summary of evidence and guidance of effective prevention, treatment and care;
- A description and assessment, against evidence and best practice, of the current response to need in Leicester - including strategic approach, prevention, models of care, capacity, costs, usage and outcome;
- The identification of gaps and issues in services and interventions;
- A forecast of numbers affected and future population need;
- An indication of the strengths and limitations of the needs assessment;
- Recommendations.

In meeting these objectives, this needs assessment will aim to:

- Make best use of existing evidence and experience;
- Complement the *National Dementia Strategy*, not duplicate it;
- Ensure that the final product is relevant to its audience;
- Provide data and information that is locally relevant;
- Appropriately engage providers, service users and relevant voluntary organisations and groups;
- Contribute to future needs assessment through sharing lessons learned in the process of completion

Literature used

In order to meet the objectives of the JSpNA the literature used has been classified, adopting the categories developed by Shekelle et al¹ which are shown in the Table below. The category of evidence is recorded with each new reference in the text.

Table 1: Classification schemes for categories of evidence

Categories of evidence	
Ia	Evidence from meta-analysis of randomised controlled trials.
Ib	Evidence from at least one randomised controlled trial.
IIa	Evidence from at least one controlled study without randomisation.
IIb	Evidence from at least one other type of quasi-experimental study.
III	Evidence from non-experimental descriptive studies, such as comparative studies, correlation studies and case control studies.
IV	Evidence from expert committees' reports or opinions and/or clinical experience of respected authorities

What is dementia?

Dementia may be subdivided into different diagnostic categories. It is defined in the International Classification of Diseases, 10th revision, (ICD-10)² as a syndrome resulting from disease of the brain. It is usually chronic, progressive and results in impairment of multiple higher cortical functions. These impairments, usually of faculties such as memory, thinking and orientation, are commonly accompanied by deterioration in emotional control, social behaviour and motivation.

The potential impact of dementia can be seen when one considers that the brain is responsible for producing a person's every thought, action, memory and feeling; these are explained further in Appendix 1. Changes, related to normal ageing, occur in the brain as a person gets older³; these may mean that there is a slight decline in an older person's ability to learn new things or remember information. However, the changes which are related to dementia are more severe.

In order to inform the organisation of support services, and as dementia related diseases are progressive, dementias may be classified as mild, moderate or severe⁴.

- Mild: Mild cognitive decline shows problems in memory, concentration, remembering words or names, misplacing objects, difficulty in planning and performing tasks
- Moderate: Moderate cognitive decline includes forgetfulness of recent events and own history, impaired ability to undertake complex tasks, e.g. managing

finances. There are also noticeable gaps in memory and thinking, confusion about what day it is, being unable to remember own address and phone number, need for help in day-to-day activities

- Severe: Severe cognitive decline demonstrates worsening memory, loss of awareness of recent experiences and surroundings and may show behavioural changes. Individuals distinguish between familiar and unfamiliar faces but have difficulty remembering names, will need help dressing and toileting and tend to wander and become lost. In the final stages, individuals are unable to respond to their environment, to hold a conversation and will need help with much of their daily personal care

Diagnostic classification is important because the causes and treatments are different. Although treatment can slow the progression of dementia and help manage the symptoms in some people, currently there is no cure. The most frequently observed dementias are caused by plaques and tangles in the brain (Alzheimer's disease), the loss of connections between nerve cells in the brain (Alzheimer's disease, dementia with Lewy bodies) or the disruption in the blood supply to the brain (vascular dementia). Rarer causes can be genetic (Huntington's disease), or from alcohol misuse (Wernicke-Korsakoff disease) or infection (Creutzfeldt-Jakob Disease).

Alzheimer's disease is a degenerative cerebral disease which disrupts the processes that keep neurons healthy. The brains of people with Alzheimer's disease have characteristic neuro-pathological and neuro-chemical features. In particular, there are amyloid plaques and neurofibrillary tangles which are made of misfolded proteins, in those areas of the brain that are important for memory. Depending on their location in the brain, these plaques, proteins and tangles, will progressively undermine the ability of a person with Alzheimer's disease to undertake certain functions.

The clinical features of Alzheimer's disease include the following:

- Insidious onset, usually in late life with gradual development over a period of years
- Brain pathology with progressive loss of neurons leading to cerebral atrophy
- Progression apparent as increasing impairment of memory storage and retrieval, going on to global disorder of cognition, orientation, linguistic ability and judgement
- A clinical course which is accompanied by growing disability and dependency on care
- A variable rate of progression.

Vascular dementia refers to dementia which is caused by changes to the blood supply to the brain. It is also called arteriosclerotic or multi-infarct dementia and it is distinguished from Alzheimer's disease by its clinical features and course. It is common for mixed forms of vascular and Alzheimer's-type dementia to occur in people of older ages.

Typically vascular dementia is characterised by:

- A history of transient ischaemic attacks, intermittent disruption of blood supply to the brain; these could result in brief impairment of consciousness, fleeting pareses (inability to move) or visual loss
- Dementia following a succession of acute cerebrovascular accidents (strokes) or, less commonly, a single major stroke
- Mental deterioration resulting from a brain infarct, the death of brain cells, related to cerebrovascular disease; the individual lesions usually being small but cumulative in their effect.

Dementia with Lewy bodies⁵: Lewy bodies are tiny, spherical protein deposits, found in neurons, which disrupt the brain's normal functioning by interrupting the action of chemical transmitters such as acetylcholine and dopamine. Most cases of people with dementia with Lewy bodies were found to have Lewy bodies in the brain stem and the cerebral cortex⁶.

The symptoms of Dementia with Lewy Bodies are similar to Alzheimer's and Parkinson's diseases⁷. Indeed, Lewy bodies are usually found in the brain stems of people with Parkinson's disease, a progressive neurological disease that affects movement. A third of people with Parkinson's disease develop dementia and a third of people with Alzheimer's disease show evidence of Parkinsonism⁸. The aetiology of the disease is complex, but the onset is usually in old age and it is usually characterised by clinical features such as:

- Fluctuation in the level of cognitive impairment
- Visual and auditory hallucinations
- Paranoid delusions
- Depressive symptoms
- Falls or unexplained episodes of loss of consciousness.

Frontotemporal disorders result from damage to neurons in the frontal and temporal lobes of the brain. Gradually this damage may cause emotional problems, difficulties with communication, behaviour, recognising danger, walking and other movements. Frontotemporal disorders can be grouped into different types which encompass these symptoms⁹.

- Progressive behaviour/personality decline (such as in Pick's disease), characterised by apathy, reduced initiative, inappropriate and impulsive behaviour and emotional flatness or excess.
- Progressive language decline: For instance having difficulty understanding words, having difficulty in finding the right words, omitting words from sentences and difficulty in swallowing.
- Progressive motor decline: This includes Corticobasal syndrome, which is characterised by muscle rigidity, language or spatial orientation problems, problems operating simple appliances, problems with balance and walking, restricted eye movements, body stiffness.
- Frontotemporal disorder with Parkinson's disease includes slowed and stiff movement marked by Parkinson's disease.

- Frontotemporal disorder with amyotrophic lateral sclerosis (Lou Gehrig's disease) has symptoms such as muscle weakness, jerking and changes in behaviour and language.

Delirium is distinct from, but commonly associated with, dementia. It is a state characterised by:

- Fluctuating mental confusion, with reduced alertness and attention
- Disorders of perception, including misinterpretation of one's surroundings and, in many cases, fearfulness and agitation
- Tremor, sweating and tachycardia
- Coma in severe cases.

The causes of delirium include infection, cardiac failure and rapid withdrawal of alcohol or drugs. There may be an underlying predisposition related to old age and cognition. Although most episodes of acute or sub-acute delirium are responsive to medical treatment, the presence of underlying dementia in some cases means that there is a vulnerability to further episodes of delirium.

Early-onset dementias are those which affect people under the age of 65. Whilst Alzheimer's disease accounts for some of these cases, other causes, including those related to genetic conditions, are also important. For instance, people with Down's syndrome are at an increased risk for Alzheimer's disease. A survey of people with Down's syndrome¹⁰ estimated that the prevalence of dementia was 3.4% in those between 30–39 years and 40% at 50–59 years. Other conditions which are associated with the early onset of dementia include Huntington's disease and acquired brain injury¹¹. Early onset dementia is also associated with HIV-AIDS and Creutzfeldt - Jakob disease.

Some people may be identified as having symptoms of cognitive decline which do not meet clinical criteria for the diagnosis of dementia. In such cases there may be a diagnosis of **mild cognitive impairment (MCI)**¹². The definition of MCI used within the National Institute for Health and Clinical Excellence (NICE) clinical guideline CG42 on dementia¹³ is that it is a syndrome defined as cognitive decline greater than expected for an individual's age and level of education but which does not interfere notably with activities of daily life.

A proportion of people with MCI have been shown to develop some form of dementia over time. The rate of conversion from MCI to dementia depends on the diagnostic criteria used, the type of cohort studied and the length of observation time from diagnosis of MCI¹⁴. For people with MCI who are referred to memory assessment services and other specialist centres, the rate of conversion to dementia has been estimated to be around 18% per year¹⁵. Several different types of MCI have been proposed^{16 17}. Studies estimate that prevalence of MCI is between 5% and 25% in older people^{18 19 20}. However, most people with MCI, or subjective memory impairment, may present with symptoms other than cognitive impairment or do not report any symptoms.

Costs of dementia

Estimating the overall financial cost of care for people with dementia is difficult. They cut across all services, for instance the extent of the problem, often missed by health and social care services, can be seen in the impact that people with dementia have had on the work of the police. The Comprehensive Referral Desk of Leicestershire Police, established with a remit which includes providing a cohesive and comprehensive police approach to safeguarding adults at risk of harm²¹, reports that on average there are between 40 and 50 cases per month of people with dementia who require assistance from the police in Leicestershire.

People with dementia depend on informal care for much of the time, but even when they have formal care, for instance when they require care of an acute physical illness, the presence of a dementia is often not recorded. *Dementia UK*²² found that the total costs of dementia in 2007 amounted to £17.03 billion per annum, or an average of £25,472 per person with late onset dementia. Since 2007 the total cost of dementia has continued to rise: updated figures for 2010 put the cost at £20 billion with 750 000 people living with the condition.

The total annual cost per person with dementia in different settings is estimated as follows²³ on the Alzheimer's society website:

- People in the community with mild dementia - £14,540
- People in the community with moderate dementia - £20,355
- People in the community with severe dementia - £28,527
- People in care homes - £31,263.

These costs include those provided by formal care agencies as well as the financial value of unpaid informal care provided by family and friends. Costs were not available for the 2% of people with dementia under the age of 65. Over a third of the total cost (36%) was due to informal care; including an estimated £690 million in lost income for those carers who have to give up employment or cut back their work hours. This lost employment means a loss of £123 million in taxes paid to the Exchequer. Accommodation accounted for 41% of the total cost, with the greatest proportion of direct costs of dementia care associated with institutional support in care homes. This is often provided at a crisis point, is always costly and often precipitated by a lack of effective support. The King's Fund Report *Paying the Price*,²⁴ projects that the cost of dementia in England will increase by 135% from £14.8 billion in 2007 to £34.8 billion in 2026.

As most packages of care for people with dementia are typically provided through social services and are means tested, people with dementia often pay significant amounts towards their care. This places the burden of cost of care heavily on people with dementia and their families. Average residential care home costs in the UK are £479 per week, while average nursing home costs are £669 per week. Alzheimer's Society's 2008 found that the impact of charging for care cuts across all socio-economic groups and is not confined to people of moderate and higher means; the Alzheimer's Society called this the Dementia Tax. The *Dementia UK Report* also found many people are not receiving the quality of care they deserve and often have to pay substantial amounts of money for poor quality care.

The Alzheimer's Society's has a position on charging for care which supports a new system of funding and charging for care which:

- Ends the dementia tax and moves to a system where risk is shared beyond people with a specific medical condition like dementia.
- Delivers good quality care at a fair price.
- Abolishes the current fair access to care system, which means no one with lower level or moderate needs gets help.
- Recognises the role of unpaid carers and ensures that they are not financially disadvantaged by caring.
- Delivers consensus across our political parties, similar to that achieved over pensions policy.
- Provides early intervention and good quality care for all.
- Where the state provides a minimum level of care free to all. The basic package should incorporate guarantees about the care to be provided. Access to early intervention services, regular respite care and a guarantee that care will be of high quality are particularly important.
- A flexible system which allowed people with different levels of need to access different packages of state funded care²⁵.

As dementia is one of the major challenges facing modern Britain, there has been a move to ensure that concerted action is taken to improve dementia care, which has resulted in the *Dementia Action Alliance* and the *National Dementia Declaration*. This declaration contains seven desired outcomes for people with dementia and their carers:

1. I have personal choice and control or influence over decisions about me
2. I know that services are designed around me and my needs
3. I have support that helps me live my life
4. I have knowledge and know-how to get what I need
5. I live in an enabling and supportive environment where I feel valued and understood
6. I have a sense of belonging and of being a valued part of family, community and civic life
7. I know there is research going on which delivers a better life for me now and hope for the future²⁶.

There are a number of signatories to the declaration, including Leicester City Council²⁷. The local authority vision for the declaration is that for all people with dementia and their family carers to be able to continue to live a full, active and independent life in the community.

To do this the local authority aims to provide local leadership to organisations within Leicester to create an environment which is supportive of the needs of people with dementia and their family carers. The local authority is also committed to work in partnership to commission high quality based on evidence of need and of what works best for those living with dementia and their family carers.

Success will mean that the stigma attached to dementia is decreased; that people feel empowered to seek help early; will know where to go for support and what

services to expect; will have access to high quality care and support; and that professionals feel well informed.

Key challenges for Leicester, expressed by the local authority are:

- Winning the hearts and minds of all stakeholders about what is possible for people with dementia and putting them in control of choices about how they wish to live their life.
- Ensuring that staff working across the City Council and its partner organisations has the appropriate skills and knowledge to enable them to serve all citizens, including those with dementia.
- The impact on health and social care as a result of the savings which must be made to public sector finances.
- The need to maintain and improve joint working arrangements with NHS partners for commissioning and delivery, at a time when these partners are undergoing significant structural change.

The Local Authority plans to improve dementia care between now and 2014 include the development of a Leicester City specific strategy, taking forward the activities of the work streams, each with its own action plan.

Recommendation: Local organisations involved in dementia care, follow the lead of the local authority in supporting the outcomes of the National Dementia Declaration.

2. Policy Background

2.1 National Policy

The National Dementia Strategy (NDS) *Living Well with Dementia*²⁸ sets out a vision for a health and social care system in which people with dementia and their carers have access to beneficial care and support. It suggests that, with the collaboration of health and social care services, the third sector and carers, much can be done to maintain and improve the quality of life of people with dementia. In order to achieve this, however, there is a need to overcome the boundaries between health, social care and the third sector.

Politically, dealing with the issue of dementia has been further endorsed by the *Prime Minister's challenge on dementia*²⁹. In this the Prime Minister states that he is “determined that we will go further and faster on dementia – making life better for people with dementia and their carers, and supporting the research that will ultimately help us slow, stop and even prevent the condition.”

The key commitments in the challenge include, increased diagnosis rates through regular checks for over-65s, financial rewards for hospitals offering quality dementia care, improving standards care homes and domiciliary care better support for carers and better information for people with dementia and their carers (See Appendix 11).

When the strategy was published it was consistent with the wider policy context likely to be relevant to people affected by dementia. It was suggested that these policies would also strengthen the commissioning and delivery of services to people with dementia and their carers. The relevant other strategic initiatives included *Putting People First*³⁰, *Think Local, Act Personal*³¹ the *Carers' Strategy*³², the *End of Life Care Strategy*³³ and the strategic shift to prevention and early intervention. *The Dignity in Care* campaign and improvements flowing from the consultation on adult safeguarding were also pertinent to the vision set out in the NDS.

The NDS itself outlined 17 objectives to improve the quality of life for people with dementia and their carers. The objectives were presented in three broad themes:

- raising awareness and understanding
- early diagnosis and support
- living well with dementia

The objectives are presented in full in Appendix 2. In summary raising awareness of dementia will help to remove the stigma suffered by people with dementia and their carers and reduce fear and misunderstanding. More early diagnosis is intended to enable people with dementia and their carers to gain timely access to benefits and treatment. Living well with dementia includes a focus on improving carer support, and improvement in care along the whole dementia care pathway, including helping people to stay at home for longer if they so wished.

The NDS notes that these objectives had to be supported by actions to develop the workforce, plans to enable joint commissioning, and improved monitoring of services, evaluation and implementation. Following public consultation an Implementation Plan was developed, which set out the tasks ahead. This plan currently underpins the approach to joint commissioning for dementia care services.

Whilst this plan is not prescriptive, in that it does not suggest which services should be planned, commissioned, provided and delivered, it shows how the Department of Health will provide support nationally and regionally. The pace of implementation will inevitably vary depending on local circumstances and the level and development of services within each NHS and Local Authority area. The Implementation Plan describes the arrangements for what the Department of Health will do as an enabler for continued progress towards meeting all 17 objectives in the Strategy

The consultations confirmed the need for early diagnosis and intervention. Although some people argued that it is better not to tell someone if they have dementia, most believed they should have the right to be told. However, the consultations suggested that, despite this, people are currently likely to see specialist services at a point where there is little chance of specialist input improving their quality of life.

Other examples of suggested service improvements which emerged during the consultations included:

- GPs working side by side with mental health services
- GPs knowing how to spot the first signs of dementia
- Having one person who is responsible for dementia services in hospital
- Giving everyone with dementia their own personal dementia adviser to help them
- Helping people with dementia to stay in their own homes for longer

Given the progressive nature of dementia, the links between the NDS and the *End of Life Care Strategy* are clear. The *End of Life Care Strategy* suggests that as a society we do not discuss death and dying openly. It looks at caring for all people at the time of death, explaining that most deaths (58%) occur in NHS hospitals, with around 18% occurring at home, 17% in care homes, 4% in hospices and 3% elsewhere. This means that the demographics of death in relation to age profile, cause and place of death have changed over the course of the past century. At the beginning of the 20th century most people died in their own homes, acute infections were a much more frequent cause of death and a far higher proportion of all deaths occurred in childhood or early adult life.

The assumption behind the *End of Life Care Strategy* is that whilst some people die as they would have wished, receiving care in hospitals, hospices, care homes and in their own homes, many do not. Many people experience unnecessary pain and other avoidable symptoms. Some are not treated with dignity and respect, and many people do not die where they would choose.

In the light of this, the *End of Life Care Strategy* aims to ensure that people have the opportunity to discuss their personal needs and preferences with professionals. It is envisaged that all health and social care staff will be trained in communication

regarding end of life care, in assessing the needs of patients and carers and, where necessary, reconciling differing requirements. Thus, according to the *End of Life Care Strategy* the discussions of preferences will be recorded in a care plan so that every service involved will be aware of peoples' priorities and will take account of their preferences. The aim of recording such needs and preferences in a care plan is to coordinate care and support; ensuring that needs are met, irrespective of who is delivering the service.

The *End of Life Care Strategy* envisages a rapid specialist advice and clinical assessment wherever a patient may be, including access to dedicated 24/7 telephone help lines and rapid access homecare services and specialist palliative care outreach services to be established in every area. The *End of Life Care Strategy* is discussed in more detail in Appendix 3.

The *Dignity in Care Campaign*³⁴ aims to put dignity and respect at the heart of care services. Over 23,000 people have now joined the campaign as Dignity Champions; that is those people who have signed up in support of the need to deliver care services that respect dignity. They are part of a nationwide movement, working individually and collectively, to ensure people have a good experience of care when they need it. They include councillors, staff at all levels in NHS and social care, volunteers, service users, their carers and members of the public.

The campaign is about winning hearts and minds, changing the culture of care services and placing a greater emphasis on improving the quality of care and the experience of people using services including NHS hospitals, community services, care homes and home support services. It includes action to raise awareness of dignity in care and inspire local people to take action. Such actions include sharing good practice, innovation and transforming services by supporting people who make a difference

Carers feature largely in the key requirements of any dementia related service. They are also a high priority for the Coalition Government. The *Think Local, Act Personal* initiative, includes a qualitative review for carers in general, and *Recognised, valued and supported* focuses on the next steps for the Carers Strategy³⁵. These next steps include some which fit well with the people involved in caring for those with dementia.

The first priority area is ***identification and recognition of carers at an early stage***. This recognises the value of the contribution of carers and aims at involving them from the outset in the design and planning of care. It is congruent with carers of people with dementia and the need for early diagnosis. One of the main problems with identifying a person as a carer is that many carers do not identify themselves as such until they have been caring for a number of years³⁶. This often happens when the caring role gradually develops, or because carers may find it difficult to find time and energy to reflect on the future. One advantage of involving carers in planning care is that they are able to give expert understanding about the needs of the person for whom they are caring. Involving carers in the arrangements for planning a discharge from hospital, for example, may be important in reducing readmissions.

Another next step is **helping carers to realise their potential** (looking for instance at the number of carers at work or in education). This would include support for people who are at work and who also care for someone with dementia. This is where support for carers touches on wider legislation such as the Equality Act 2010, which recognised the vital role that carers play and the disadvantages which they may experience. Such legislation strengthens the protection of carers against discrimination in the workplace and when accessing services.

*A vision for adult social care: Capable communities and active citizens*³⁷ suggests that a plurality of providers should be available to match a variety of needs, including the needs of carers who require high quality care to enable them to work. Many carers consider that it is important for their own personal and financial wellbeing to be able to continue to work. So carers should be encouraged and supported to return to work.

The *Next Steps for the Carers' Strategy* also focuses on **carers having a life of their own outside caring**. This may depend on the context, but could mean the need for respite care or indeed the implementation of the personalisation agenda. Personalisation means that, as far as possible, all services and support available to carers should be tailored to their specific needs

Personalisation is seen as complementary to a 'whole-family' approach; an approach in which the views and cultural expectations are addressed and clarified when considering how to support a family. Personalisation will provide individuals, families and carers with more choice, control and flexibility³⁸. *A vision for adult social care* makes clear that councils should provide everyone who is eligible with a personal budget, preferably as a direct payment, by April 2013.

Whilst personalisation and personal budgets can take many forms, there is an anxiety amongst older carers about managing finances and about whether there will be no services to buy. Unless they so wish, carers will neither have to conduct their own procurement of services, nor will they have to manage the financial arrangements. There are different approaches suggested for the management of personalised budgets, including the use of intermediaries, such as voluntary organisations, or other models such as trusts or individual service funds.

*Recognised, valued and supported*³⁹ emphasises that in a call for views in the summer of 2011, carers suggested that priority should be accorded to reducing the amount of time taken in the assessment of carers and the people that they support. In order to expedite the assessment process some local authorities have developed a system for training people in the voluntary sector as assessors. *Recognised valued and supported* suggests that the Department of Health recognises that there is a need for flexibility in conducting assessments and that it will consider this issue in the light of work conducted by the Law Commission and the Commission on the Funding of Care and Support^{40 41}.

There are other initiatives which could be used to benefit carers. The QIPP (Quality, Innovation, Productivity and Prevention) programme could be relevant to supporting carers and the people they support. For instance QIPP long terms conditions work emphasises personalised care planning and supportive self-care in order to

maximise independence and minimise unnecessary stays in hospital. QIPP end of life care has focused on improving the identification of people who are approaching the end of life as well as planning care.

Another priority area is *supporting carers to stay healthy*. There is a relationship between poor health and caring which increases with the duration and intensity of the caring role. According to Carers UK⁴² carers are twice as likely to have poor health as those people who are not undertaking a caring role. This may be because of the psychological impact of caring, resulting from stigma, isolation, relationship problems and financial hardship. Carers are more likely to report high levels of psychological distress than non-carers, including anxiety, depression, loss of confidence and self-esteem⁴³. Poor physical health is also associated with caring, with carers suffering high rates of hypertension, cardiac problems and musculo-skeletal problems⁴⁴.

Caring may exacerbate existing inequalities in health⁴⁵. Of particular relevance to carers of people with dementia, looking after a spouse or a partner is particularly associated with additional health problems beyond those which may be attributable to other health inequalities⁴⁶. *Recognised valued and supported* also advocates prevention and early intervention for carers; highlighting timely access to relevant information, support at key stages along the care pathway. It suggests that carers should be encouraged to receive a health check and there should be health and wellbeing activities targeted at carers.

Another important lever in the delivery of better care for people with dementia is the current objective, set out in the *Payment by Results quality and Outcomes Indicators*⁴⁷, to have currencies and local prices established and in use during 2012-13. Mental Health Care Clusters⁴⁸ for payment by results could help to classify mental health service provision. With regard to dementia there are 4 care clusters of interest, which could be used to describe the progress of the illness:

Care Cluster 18: Cognitive Impairment (Low Need) - People who may be in the early stages of dementia (or who may have an organic brain disorder affecting their cognitive function) who have some memory problems, or other low level cognitive impairment, but who are still managing to cope reasonably well. Underlying reversible physical causes of the impairment have been ruled out.

Care Cluster 19: Cognitive Impairment or Dementia Complicated (Moderate Need) - People who have problems with their memory, and/or other aspects of cognitive functioning resulting in moderate problems looking after themselves and maintaining social relationships. Probable risk of self-neglect or harm to others and may be experiencing some anxiety or depression.

Care Cluster 20: Cognitive Impairment or Dementia (High Need) - People with dementia who are having significant problems in looking after themselves and whose behaviour may challenge their carers or services. They may have high levels of anxiety or depression, psychotic symptoms, or significant problems such as aggression or agitation. They may not be aware of their problems. They are likely to be at high risk of self-neglect or harm to others, and there may be a significant risk of their care arrangements breaking down.

Care Cluster 21: Cognitive Impairment or Dementia (High Physical or Engagement) - People with cognitive impairment or dementia who are having significant problems in looking after themselves, and whose physical condition is becoming increasingly frail. They may not be aware of their problems and there may be a significant risk of their care arrangements breaking down.

2.2 Local implementation

In Leicester the current model of care for people with dementia and their carers consists of a mix of services which have either developed by custom and practice, as a result of clinical experience, or from piecemeal commissioning of discrete projects which have not taken into account the whole patient pathway or experience. In order to improve this, the Joint Dementia Commissioning Group has established 5 work streams focusing on 23 local objectives for Leicester, Leicestershire and Rutland. The 23 local objectives are set out in more detail in Appendix 5. The 5 work streams are:

- Early diagnosis and access to care and support services (led by NHS Leicester, Leicestershire and Rutland and Leicestershire Partnership Trust)
- Improved experience of hospital care (led by NHS Leicester, Leicestershire and Rutland and University Hospitals of Leicester)
- Improved quality of care in residential/care homes work stream (led by Leicestershire County Council)
- Personalisation of care and living well with dementia in the community work stream (led by Leicester City Council)
- A workforce fit to deliver services to support the care pathway for dementia (led by NHS Leicester, Leicestershire and Rutland workforce development team)

The overall strategic direction of local implementation is linked to national policy and includes the main initiatives, such as:

- Increase the proportion of people with dementia receiving an early diagnosis
- Increase the proportion of people with dementia having a formal diagnosis
- Increase the number of patients and carers having a positive service experience
- Reduce average length of stay in hospital for patients with dementia
- Reduce number of people with dementia discharged directly from hospital to care homes as a new place of residence
- Reduce number of people discharged from hospital on antipsychotic medication, including a plan to review use of antipsychotic medication post discharge
- Reduce the use of antipsychotic medication for people with dementia
- Contribute to a reduction in unplanned admissions and readmissions of people with dementia to general and community hospitals
- Achieve better care at home and in residential care

The local care pathway is likely to cover a number of levels from pre-diagnosis right through to care home and hospital care, and is likely to include the following:

Community / Pre-diagnosis

- Advice and Information to the general public about symptoms such as memory loss and campaigns such as Stroke – Act F.A.S.T.⁴⁹
- Prevention and early Intervention strategy
- General Practice to undertake cognitive tests such as ADAS COG or MMSE; watchful waiting, referral to Memory Assessment Service, reassurance
- Diagnostic tests; blood tests, brain scan and diagnosis of clear cut cases in primary care
- Opportunistic assessment of frail elderly attendees at UHL, diagnosis of clear cut cases

Interdependencies with other work

- LLR Carers Strategy
- Frail elderly programme

Level 1: Early diagnosis and low level support (Care Cluster 18)

- Memory Assessment pathway: LPT Memory Assessment Service
- Early diagnosis based on assessment, diagnostic tests
- Initiate drug therapies for people with Alzheimer's disease
- Shared care protocols between Memory Assessment and Primary Care
- Dementia Care Co-ordinators to provide access to advice and information
- Dementia Cafés
- Initial contact with Community Mental Healthcare Teams

Interdependencies with other work

- LLR Carers Strategy
- Carer health checks
- Frail elderly programme

Level 2: Moderate support at home (Care Cluster 19)

- Continued support from Dementia Care Co-ordinators, linked to Primary Care
- Consistent detection of cognitive impairment in General Practice
- Opportunistic assessment by general hospital liaison team
- Opportunistic late diagnosis
- Support for people with dementia and carers from Community Mental Health Care Teams when necessary
- Carers support and education
- Intermediate care at home

Interdependencies with other work

- LLR Carers Strategy
- Carer health checks

- Intermediate Care and reablement
- Frail elderly programme

Level 3: Intensive support at home (Care Cluster 20)

- Support from General Practice
- Expert input from Memory Assessment Service
- Assessment from general hospital liaison team
- Links to district nurse and community matron teams
- Community Mental Healthcare Teams
- Social care support for people in a crisis
- Respite care programmes for carers
- Continued support from Dementia Care Co-ordinators

Interdependencies with other work

- Review of ICAT
- Falls Strategy
- Intermediate Care & Reablement
- Frail elderly programme
- LLR Carers Strategy
- Carer health checks

Level 4: Care home / hospital care (Care Cluster 21)

- Support from General Practice
- Expert input from Memory Assessment Service if necessary
- Assessment from general hospital liaison team
- Links to district nurse and community matron teams
- Community Mental Healthcare Teams
- Social care support for people in a crisis
- Respite care programmes for carers
- Continued support from Dementia Care Co-ordinators
- Care for carers following death of person with dementia

Interdependencies with other work

- End of Life strategy
- Falls Strategy
- Intermediate care
- Frail elderly programme
- LLR Carers Strategy

Recommendation: Local implementation of the National Dementia Strategy should have established links to other relevant policies and initiatives, such as groups delivering the *End of Life Strategy*, the *Falls Strategy*, the *Dignity in Care Campaign*, and local voluntary sector initiatives such as the Dementia Action Alliance.

3. Population of Leicester

Leicester is the largest city in the East Midlands. It is a mainly urban area of 73.3 km with a population of 306,631⁵⁰; it has a high population density of 4,182 people/km². 49% of the population, 151,277 people, are male; 155,354 are female (51%). The population is predicted to increase to about 346,000 by 2020. Projections indicate that Leicester will have a smaller proportion of people aged below 10 years and a larger proportion over 40 years.

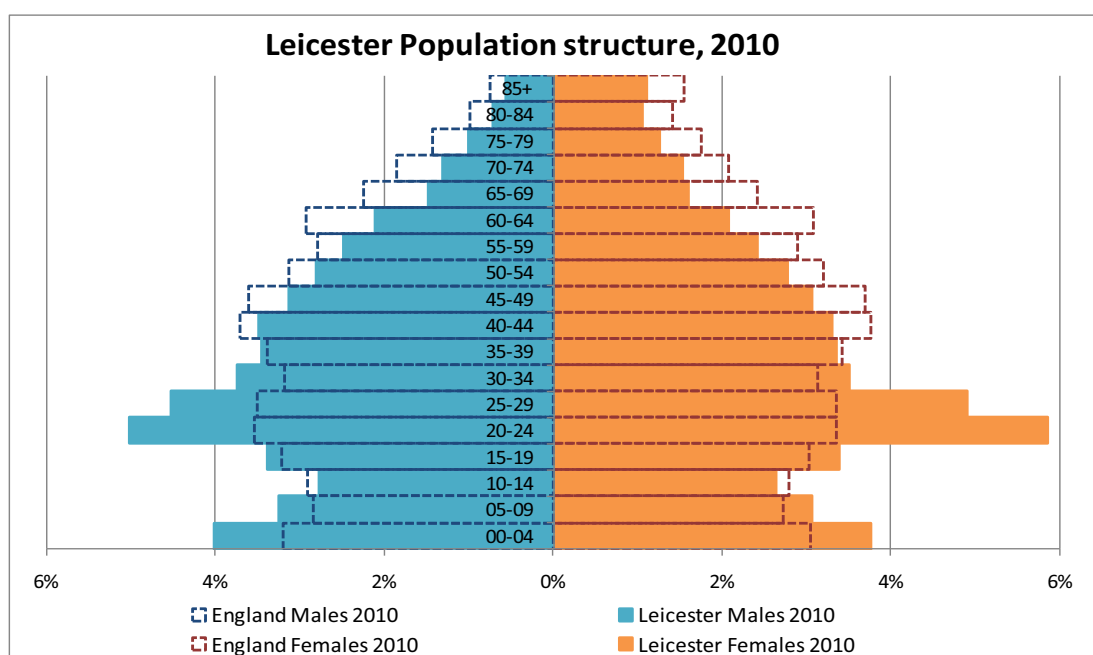
Average life expectancy in Leicester is lower than the average for England. Males in Leicester have an average life expectancy of 75.4 years (3 years below the England average) and females have an average life expectancy of 80.1 years (2.5 years below the England average).

3.1 Population structure of Leicester

Although Leicester is predicted to have a larger proportion of people aged over 40 years, currently the city has a relatively young population compared with the country as a whole, with a large proportion of the population aged below 40 years.

Numbers are particularly high for men and women aged 20-34, this may be due to inward migration of new communities and the large the student population who attend two universities. Only 11.6% of the population is aged 65 and over, equivalent to around 35,700 people, compared to around 16.5% for England as a whole.

Figure 1: Leicester Population structure, 2010



Data: Office for National Statistics (ONS) mid-2010 population estimates

3.2 Population over 65 years by ward area

Dementia disproportionately affects people aged 65 and over. The Leicester ward areas with the highest **number** of people aged over 65 years are Knighton and New Parks; each with over 2,000 people in this age group. The ward areas with the largest **proportions** of residents aged over 65 are Evington and Thurncourt, with around 20%.

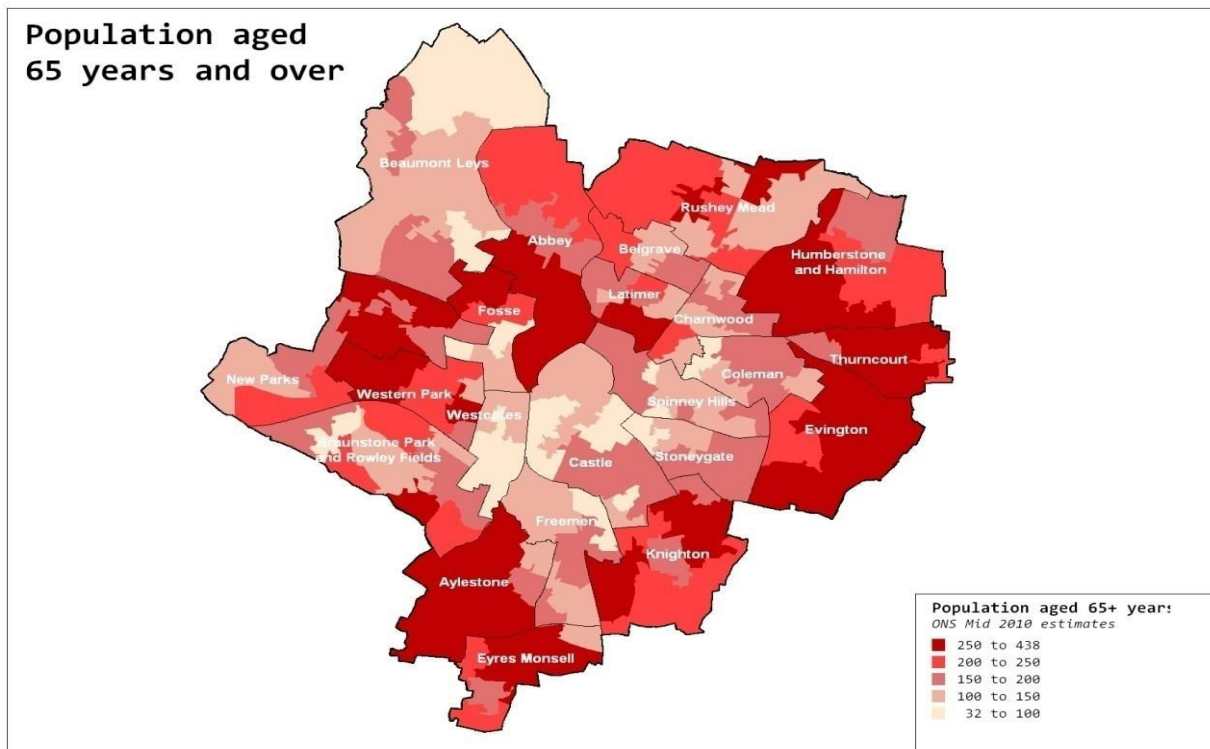
Table 3.1: Leicester Population aged 65+ by ward, 2010

Ward Name	All Ages	65-69	70-74	75-79	80-84	85+	Total 65+	% 65+
Abbey	13,770	460	438	367	365	290	1920	13.9%
Aylestone	10,826	429	409	334	291	338	1801	16.6%
Beaumont Leys	16,120	397	290	187	143	116	1133	7.0%
Belgrave	10,863	349	320	239	167	116	1191	11.0%
Braunstone Park and Rowley Fields	17,411	548	551	404	323	275	2101	12.1%
Castle	19,402	253	224	195	152	160	984	5.1%
Charnwood	12,272	372	302	172	141	109	1096	8.9%
Coleman	13,501	317	303	247	159	156	1182	8.8%
Evington	10,341	489	428	444	399	412	2172	21.0%
Eyres Monsell	11,530	394	423	374	300	255	1746	15.1%
Fosse	11,923	332	346	248	156	177	1259	10.6%
Freemen	10,310	242	269	171	128	142	952	9.2%
Humberstone and Hamilton	16,711	493	432	410	357	228	1920	11.5%
Knighton	15,592	673	611	549	516	475	2824	18.1%
Latimer	12,015	443	451	310	205	133	1542	12.8%
New Parks	16,667	608	517	395	325	413	2258	13.5%
Rushey Mead	15,845	626	571	442	272	249	2160	13.6%
Spinney Hills	21,832	581	528	378	202	204	1893	8.7%
Stoneygate	18,955	506	415	291	157	136	1505	7.9%
Thurncourt	10,019	454	455	454	337	278	1978	19.7%
Westcotes	9,312	177	141	110	100	71	599	6.4%
Western Park	9,505	333	290	274	271	292	1460	15.4%
Leicester	304,722	9,476	8,714	6,995	5,466	5,025	35,676	11.7%

Data: ONS mid-2010 population estimates

In general people aged over 65 years are resident in areas which are towards the outskirts of the city, particularly in the east and south, as shown in Figure 2 below. The need for dementia care is likely to be greater in these areas. This pattern of residence is also shown the by Mosaic Typology data (see pages 46-7)

Figure 2: Population aged 65 and over by lower Super Output Area in Leicester (LSOA)



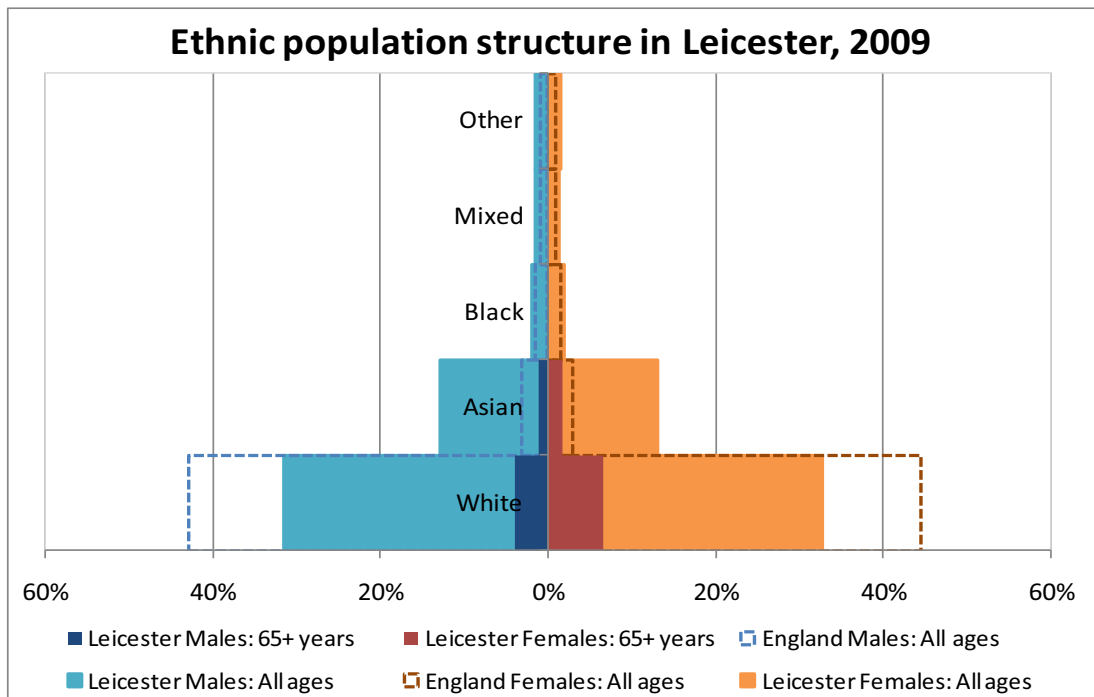
Data: ONS mid-2010 population estimates by LSOA

3.3 Ethnicity

When compared to the country as a whole, Leicester has a more ethnically diverse population. Office for National Statistics (ONS) population estimates show that Leicester has a Black and Minority Ethnic (BME) population of 36% whilst the proportion for England and Wales is 13%. The majority of Leicester’s BME population are from South Asian backgrounds; this group comprises 26% of the total population of the city. Most of the people from South Asian ethnic backgrounds are from India; 19% of the city population. People from black or black British ethnic backgrounds make up 4%, mixed ethnic groups 3% and other ethnic groups 3%, of the population.

It is estimated that there may be as many as 150 languages and/or dialects spoken in Leicester. Gujerati, Katchi, Punjabi, Urdu and Bengali are widely spoken. There are increasing numbers of people who speak Eastern European languages, such as Polish or Slovak, and East African languages such as Somali.

Figure 3: Ethnic population structure in Leicester, 2009



Data: ONS mid-2009 ethnic population estimates

3.4 Ethnicity of people aged over 65 years

Whilst the city as a whole is ethnically diverse, the majority of the people aged over 65 years are from White or White British ethnic backgrounds, making up 10% of the total population. Over 65s from Asian ethnic groups make up only 3% and less than 1% of the population are from other BME groups. There is a higher proportion of elderly within the White group (16%), whilst other BME groups have relatively fewer over 65s; 11% of Asian and 9% of Black groups are over 65.

With the predicted increase in the number of people over 65 years, meeting the needs of older people from BME groups will become an urgent issue in the near future.

Table 3.2: Ethnic population of over 60/65s in Leicester, 2009

Ethnic group	Leicester Males: All ages	Leicester Males: 65+ years	Leicester Females: All ages	Leicester Females: 60+ years	Leicester: All ages	Leicester: F 60+/M 65+ years
White	95,800	11,800	99,600	20,200	195,400	32,000
Asian	39,300	3,100	40,100	5,300	79,400	8,400
Black	5,700	400	5,800	600	11,500	1,000
Mixed	4,400	0	4,300	0	8,700	0
Other	4,900	100	4,400	100	9,300	200
Total	150,100	15,400	154,200	26,200	304,300	41,600
% White	31.5%	3.9%	32.7%	6.6%	64.2%	10.5%
% Asian	12.9%	1.0%	13.2%	1.7%	26.1%	2.8%
% Black	1.9%	0.1%	1.9%	0.2%	3.8%	0.3%
% Mixed	1.4%	0.0%	1.4%	0.0%	2.9%	0.0%
% Other	1.6%	0.0%	1.4%	0.0%	3.1%	0.1%
Total	49.3%	5.1%	50.7%	8.6%	100.0%	13.7%

Data: ONS mid-2009 ethnic population estimates

Table 3.3: Proportion of Ethnic populations over 60/65 in Leicester, 2009

Ethnic group	% 60/65+ within ethnic group
White	16.4%
Asian	10.6%
Black	8.7%
Mixed	0.0%
Other	2.2%
Total	13.7%

Data: ONS mid-2009 ethnic population estimates

3.5 Ethnicity of people aged over 65 years by ward area

Ward populations by ethnic group are currently only available from the 2001 Census. Leicester has seen large numbers of inward migration from countries such as Poland and Somalia since this Census, however this is unlikely to affect numbers in the over 65s.

The 2001 Census reported the highest number of over 65s from BME groups in Spinney Hills (1,074), Latimer (975), Stoneygate (716), Rushey Mead (618) and Belgrave (595).

Although there are problems projecting the population by minority ethnic group (see Appendix 6), the results of projections conducted for this needs assessment shows a projected overall decline in the numbers in the 'White' and 'Caribbean' groups and substantial increases in all other ethnic groups.

Table 3.4: Population projections by Ethnic group for Leicester residents of all ages

All ages	1991	1996	2001	2006	2011	2016	2021	2026
Leicester	281,450	291,050	282,750	288,500	290,850	293,950	297,600	301,450
White	197,250	191,400	180,400	171,650	162,450	153,450	144,100	134,050
Caribbean	4,750	5,450	4,750	4,700	4,450	4,100	3,900	3,700
African	1,200	1,750	3,700	7,800	12,250	17,750	24,850	33,800
Indian	64,500	72,650	72,500	76,550	77,700	78,650	78,950	78,250
Pakistani	3,000	3,650	4,350	5,550	6,600	7,700	8,850	9,850
Bangladeshi	1,150	1,550	1,900	2,350	2,750	3,150	3,450	3,800
Chinese	1,100	1,350	1,550	1,700	2,050	2,350	2,550	2,700
Other	8,550	13,200	13,550	18,100	22,600	26,800	31,000	35,200
White	197,250	191,400	180,400	171,650	162,450	153,450	144,100	134,050
SA	68,650	77,850	78,750	84,450	87,050	89,500	91,250	91,900
Black	5,950	7,200	8,450	12,500	16,700	21,850	28,750	37,500
Other	9,650	14,550	15,100	19,800	24,650	29,150	33,550	37,900
Total	281,500	291,000	282,700	288,400	290,850	293,950	297,650	301,350
ONS projections (2006)					315,500	333,300	349,400	378,600

Data: Danielis J, Looking at the 'Ethnic Population Forecasts for Leicester using POPGROUP' (a modelling tool)

Table 3.5: Population projections by Ethnic group for Leicester residents 65+ years

Age: 65+	1991	1996	2001	2006	2011	2016	2021	2026
Leicester	42,000	40,800	37,850	36,150	35,600	37,900	40,900	44,700
White	38,300	35,950	31,550	28,250	26,350	26,300	26,150	26,900
Caribbean	300	450	600	800	850	850	850	900
African	0	0	50	100	150	250	400	700
Indian	3,100	3,900	5,000	6,150	7,100	8,950	11,450	13,550
Pakistani	50	100	150	200	250	300	400	500
Bangladeshi	0	50	50	100	150	150	200	250
Chinese	50	50	50	50	50	100	100	150
Other	150	250	400	500	750	1,000	1,350	1,700
White	38,300	35,950	31,550	28,250	26,350	26,300	26,150	26,900
SA	3,150	4,050	5,200	6,450	7,500	9,400	12,050	14,300
Black	300	450	650	900	1,000	1,100	1,250	1,600
Other	200	300	450	550	800	1,100	1,450	1,850
Total	41,950	40,750	37,850	36,150	35,650	37,900	40,900	44,650
ONS projections (2006)					35,700	38,700	42,400	52,300

Data: Danielis J, Looking at the 'Ethnic Population Forecasts for Leicester using POPGROUP' (a modelling tool)

In the over 65s the biggest increases in numbers between 2011 and 2026 are predicted in the 'Indian' category, (which is estimated to almost double), 'Other' (more than double), 'African' (quadruple) and 'White' (2% increase). The projections from the ethnic modelling are lower than the ONS 2006 projections which show a much larger growth rate between 2021 and 2026 whilst the ethnic projections show a much steadier increase over the period.

3.6 Population projections

The overall population of Leicester is predicted to rise by nearly 65,000 over the next 20 years; from around 311,500 in 2010 to 376,000 in 2030. The number of over 65s is estimated to rise by around 2% or nearly 16,000 by 2030.

The largest increases are expected in the 65-69 year olds with an estimated increase of over 5,000. The number of people over 90 is predicted to be more than doubled by 2030 at 3,700. Such increases reveal the great care challenge to Leicester, posed by dementia.

Table 3.6: Projection of population over 65 in Leicester

Age / Year	2010	2015	2020	2025	2030
People aged 65-69	9,400	11,400	12,100	13,300	14,600
People aged 70-74	8,700	8,300	10,100	10,800	11,900
People aged 75-79	6,900	7,300	7,100	8,800	9,400
People aged 80-84	5,400	5,200	5,800	5,800	7,300
People aged 85-89	3,400	3,400	3,600	4,200	4,400
People aged 90+	1,600	2,000	2,400	2,900	3,700
Total 65 +	35,400	37,600	41,100	45,800	51,300
Total Leicester population	311,500	329,800	346,300	361,400	376,000
% of Population 65+	11.4%	11.4%	11.9%	12.7%	13.6%

Data: Projecting Older People Population Information System, www.poppi.org.uk

Table 3.7: Projection of percentage of population over 65 in Leicester

Age / Year	2010	2015	2020	2025	2030
People aged 65-69	3.0%	3.5%	3.5%	3.7%	3.9%
People aged 70-74	2.8%	2.5%	2.9%	3.0%	3.2%
People aged 75-79	2.2%	2.2%	2.1%	2.4%	2.5%
People aged 80-84	1.7%	1.6%	1.7%	1.6%	1.9%
People aged 85-89	1.1%	1.0%	1.0%	1.2%	1.2%
People aged 90+	0.5%	0.6%	0.7%	0.8%	1.0%
Total 65 +	11.4%	11.4%	11.9%	12.7%	13.6%

Data: Projecting Older People Population Information System, www.poppi.org.uk

3.7 Population projections: People living alone and in care homes in Leicester

The impact of dementia is heightened by the increased risk of an older person living alone. The need for well co-ordinated care for people living alone with dementia, to improve their quality of life, avoid premature entry into nursing and residential homes and avoid hospitalisation is a high priority.

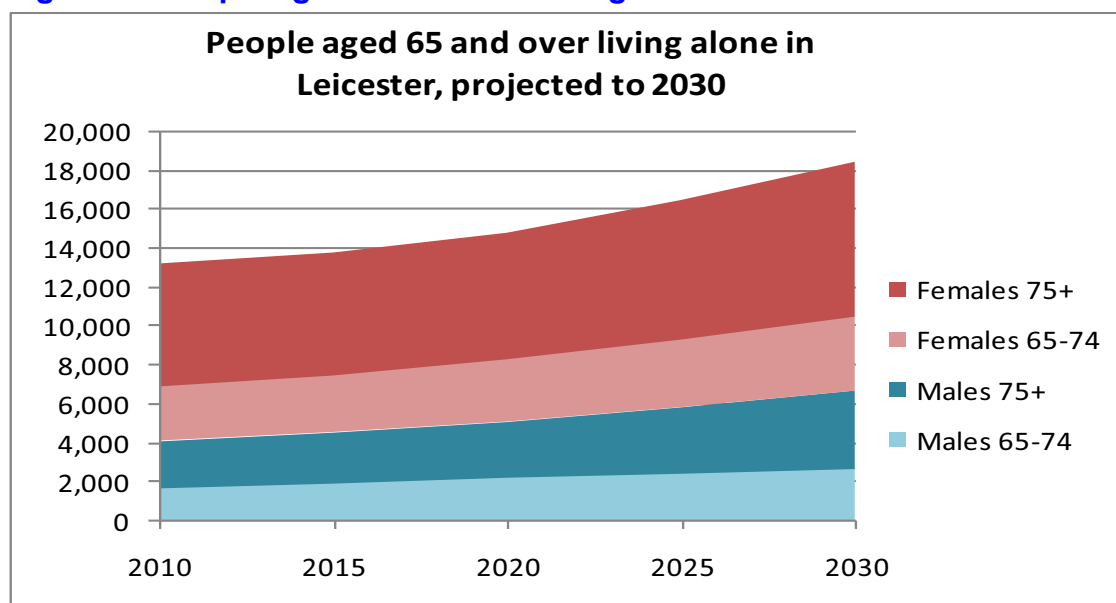
Currently, there over 13,300 people aged 65 and over live alone in Leicester and this is projected to rise to by around 40% to 18,500 by 2030. There are approximately twice as many females aged over 65 than males, and around 1.8 times more people over the age of 75 than aged 65-74 years.

Table 3.8: People aged 65 and over living alone in Leicester

People aged 65 and over living alone in Leicester	2010	2015	2020	2025	2030
Males aged 65-74 predicted to live alone	1,720	1,960	2,260	2,460	2,700
Males aged 75 and over predicted to live alone	2,380	2,584	2,822	3,366	3,978
Females aged 65-74 predicted to live alone	2,850	2,970	3,270	3,540	3,870
Females aged 75 and over predicted to live alone	6,344	6,344	6,527	7,198	7,991
Total population aged 65-74 predicted to live alone	4,570	4,930	5,530	6,000	6,570
Total population aged 75 and over predicted to live alone	8,724	8,928	9,349	10,564	11,969

Data: from www.poppi.org.uk

Figure 4: People aged 65 and over living alone in Leicester

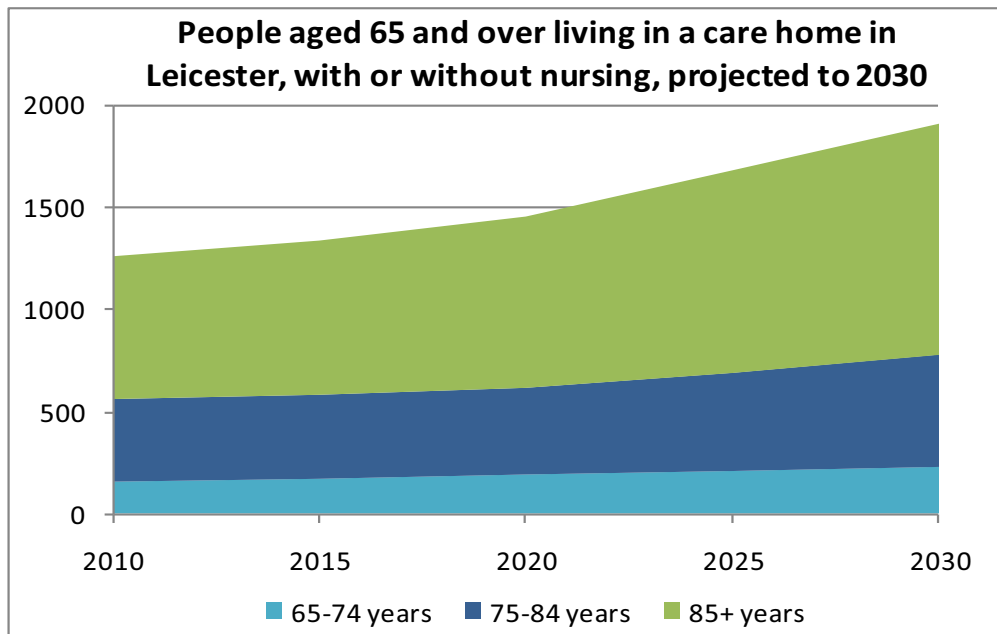


Data: from www.poppi.org.uk

The need for improved care and provision in institutional settings, monitoring psychoactive drug use and improving the quality of life for people with dementia is a present problem which will increase in importance.

The number of people over 65 living in a care home is projected to rise by around 50% from 1,250 (2010) to 1,910 in 2030. The majority of these patients are aged over 85; almost 60% are over 85 years, 28% are in the 75-84 age-group and 12% aged 65-74 years.

Figure 5: People aged 65 and over living in a care home in Leicester



Data: from www.poppi.org.uk

3.8 Population Segmentation

The demographic and lifestyle characteristics of different customer groups can be gained through analysis of market data such as Experian's Mosaic Public Sector. This includes data from a number of sources in order to provide an understanding of peoples' demographics, lifestyles and behaviours. It can be used to anticipate and plan future resource requirements, local area needs and to optimise the allocation of resources. There are 69 Mosaic household types, aggregated into 15 groups to create a classification that can be used at household or postcode level.

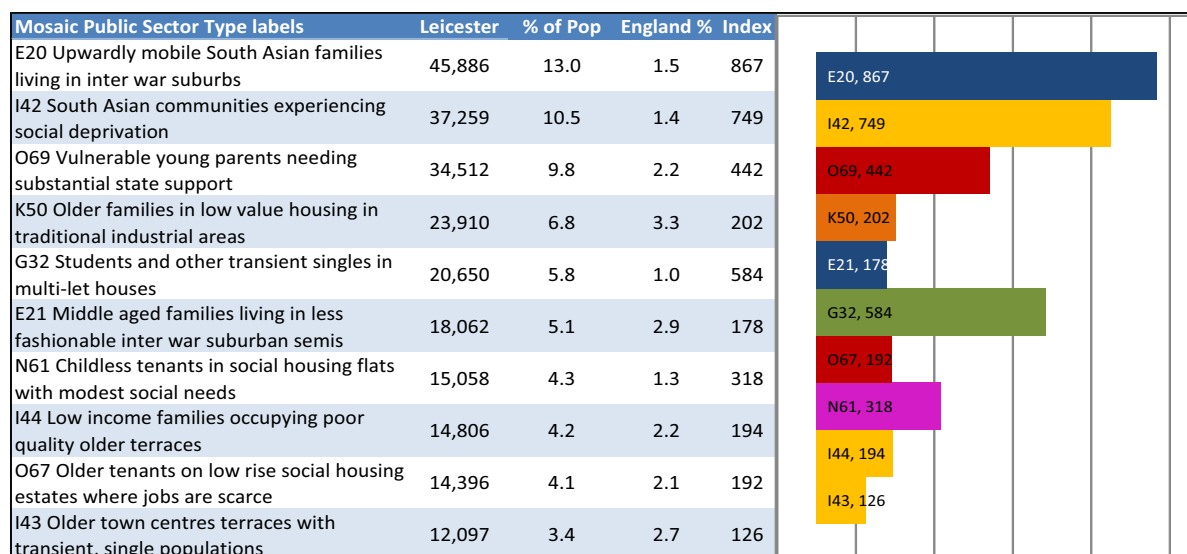
3.8.1 Mosaic groups and types in Leicester

The Mosaic groups found in Leicester are listed in Appendix 10. 22% of Leicester's residents are middle income families compared with 13% in England; 19% are lower income workers compared with only 8% nationally and 15% are families in low rise social housing whilst in England this group represents only 6% of the overall population.

The Lifestyle groups are further sub-divided into Types. The top 2 types within Leicester are 'Upwardly mobile South Asian families' and 'South Asian communities experiencing social deprivation', which together account for nearly a quarter of the population. The third largest group is also a deprived group; 'Vulnerable young

parents needing substantial state support'. The top 10 types shown below make up 67% of the population.

Figure 6: Top 10 Mosaic types in Leicester



3.8.2 Mosaic profile of over 65s in Leicester

The Mosaic Groups and Types reflect the most common household type within the 15 households of each postcode. Based on the postcodes of Leicester residents, the most common 3 groups in those aged over 65 are also the most common 3 groups for all ages of Leicester residents although the proportions vary slightly. The top 3 groups account for 50% of all the over 65s in Leicester and the top 10 groups account for 93% of all over 65 year olds.

The most common Mosaic Type in the over 65s is 'Upwardly mobile South Asian families' who represent similar proportions as in the whole population (13%). However, the number of over 65s in the group 'South Asian communities experiencing social deprivation' have much lower representation (6.7%) than in all residents (10.5%). The second most common type for over 65s is 'Older families in low value housing' (7.3%).

The chart shows the index of types that are over represented in the over 65s compared with the population of all ages in Leicester. There are over 3 times more 'Old people in flats subsisting on welfare payments', 2.3 times more 'Comfortably off industrial workers owning their own homes' and 1.4 times as many 'Older tenants on low rise social housing estates where jobs are scarce'.

Mosaic Group data confirms that the over 65s generally live towards the outskirts of the city, with very few in the City Centre and Knighton. Of the larger Mosaic groups, **upwardly mobile South Asian families** are found mainly in eastern Leicester, in Latimer and Stoneygate wards, with smaller numbers in Spinney Hills, Belgrave and Rushey Mead. The group **South Asian communities experiencing social deprivation** are also found in Spinney Hills ward with some cases in Charnwood

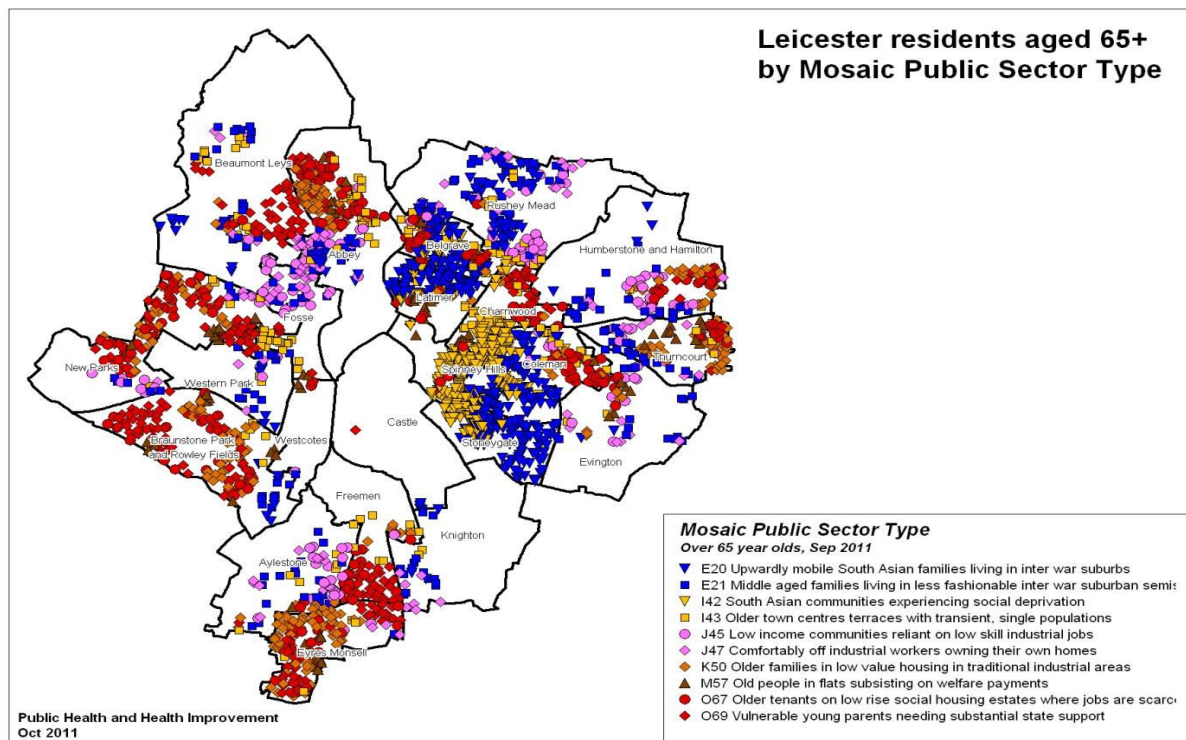
and Stoneygate. The group, *older families in low value housing* are found in Eyres Monsell with some in Braunstone and Thurncourt.

Figure 7: Over 65s in Leicester by top 10 Mosaic Types, compared with Leicester overall

Mosaic Public Sector Type	Leicester Pop aged 65+ years	% of Over 65s	Leicester %	Index	Index of top 10 Types
E20 Upwardly mobile South Asian families living in inter war suburbs	4,951	12.8	13.0	98	E20, 98
K50 Older families in low value housing in traditional industrial areas	2,847	7.3	6.8	109	K50, 109
I42 South Asian communities experiencing social deprivation	2,610	6.7	10.5	64	I42, 64
E21 Middle aged families living in less fashionable inter war suburban semis	2,386	6.1	5.1	120	E21, 120
O67 Older tenants on low rise social housing estates where jobs are scarce	2,265	5.8	4.1	143	O67, 143
O69 Vulnerable young parents needing substantial state support	2,190	5.6	9.8	58	O69, 58
J47 Comfortably off industrial workers owning their own homes	1,672	4.3	1.8	235	J47, 235
J45 Low income communities reliant on low skill industrial jobs	1,372	3.5	2.7	129	J45, 129
M57 Old people in flats subsisting on welfare payments	1,293	3.3	1.1	301	M57, 301
I43 Older town centres terraces with transient, single populations	1,231	3.2	3.4	93	I43, 93
Total	38,808	58.8	58.3		

Data: GP Patient Lists, Experian Mosaic groups

Figure 8: Over 65s in Leicester by top 10 Mosaic Types



3.9 Index of multiple deprivation

Quality of life and well being involve more than the absence of illness and disability. They are influenced by an individual's physical and social environment, and their perception of their environment. Poor health and well being is both a contributor to and a consequence of wider health inequality⁵¹. The *Independent Inquiry into Health Inequalities report*⁵² adopted a socio-economic model of health in line with the weight of scientific evidence. This model is shown in Figure 6, below.

Figure 9: Socio-economic model of influences on health



The model shows the main determinants of health which have a cumulative effect on health and wellbeing. At the centre are factors which cannot be altered, such as gender and genetic factors. Surrounding the centre are factors which can be modified. The first layer represents personal behaviour and individual lifestyle, which comprises factors that have the potential to promote or damage health, such as smoking and physical activity. The second layer is made up of social and community factors, in effect the impact of social interaction on sustaining health and the adverse effect of isolation. Layer three includes living and working conditions and the outer layer represents economic, cultural and environmental conditions prevalent in society as a whole.

Deprivation in Leicester is high and although there are some pockets of wealth, the majority of city areas experience extreme deprivation. The Index of Deprivation 2010⁵³ is a measure of poverty based on a number of criteria such as economic circumstances, health, crime, housing, educational achievement, skills and the environment. This measure ranks Leicester as the 25th most deprived of 326 Local Authority areas.

Over 40% of Leicester’s population live in the fifth (0-20%) most deprived areas nationally and a further 33% live in the 20-40% most deprived areas. Of these, 12% of Leicester’s population live in extreme poverty; over 36,000 people live in the 5% most deprived areas in England. Less than 1.5% of Leicester’s population live in the fifth least deprived of areas nationally.

Table 3.9: Leicester’s population by quintile of deprivation

Quintile of deprivation	Population	% Population
Q1 (0-20%)	124,467	40.6%
Q2 (20-40%)	103,155	33.6%
Q3 (40-60%)	52,033	17.0%
Q4 (60-80%)	22,796	7.4%
Q5 (80-100%)	4,180	1.4%
Total	306,631	100.0%

Data: Index of Deprivation 2010, ONS mid-2010 population estimates

There are similar proportions of Leicester’s population aged over 65 living in areas of deprivation.

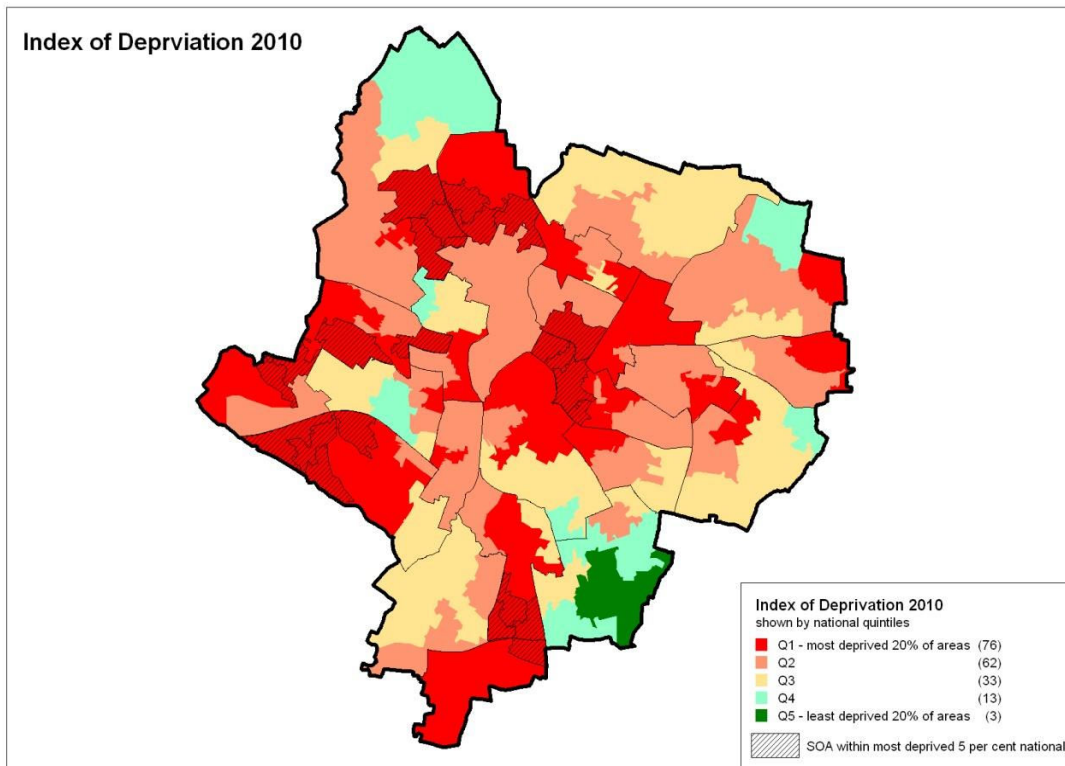
Table 3.10: Leicester’s population 65+ by quintile of deprivation

Quintile of deprivation	Population 65+	Over 65s as % all Over 65s	Over 65s as % total population
Q1 (0-20%)	13,361	37.5%	4.4%
Q2 (20-40%)	11,277	31.6%	3.7%
Q3 (40-60%)	7,479	21.0%	2.4%
Q4 (60-80%)	2,854	8.0%	0.9%
Q5 (80-100%)	668	1.9%	0.2%
Total	35,639	100.0%	11.6%

Additionally, Leicester has two lower super output areas (an LSOA has around 1,500 people) which rank 1st and 2nd for the most deprived areas in England overall for Education, Skills and Training. There are also two LSOAs ranking 2nd and 6th for the most deprived areas for Income nationally.

The index of deprivation 2010 has a supplementary index showing income deprivation affecting older people, expressed as the proportion of adults aged 60 or over living in Income Support, income-based Jobseeker’s Allowance or Pension Credit (Guarantee) families.

Figure 10: Index of deprivation (2010) in Leicester



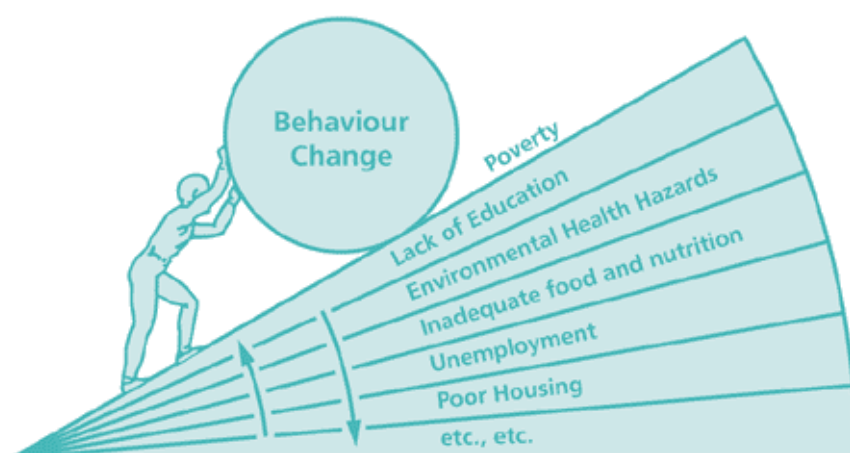
3.10 Indices of multiple deprivation as they affect older people

Many influences on health are underpinned by a social gradient, with conditions conducive to health becoming less favourable with declining social status. People from more deprived quintiles have a greater exposure to health hazards and risk factors, resulting in health inequalities. The *Annual Report of the Director of Public Health for Leicestershire 2001*⁵⁴ used a diagram (Figure 8 below) to show how promoting healthy lifestyles for people in disadvantaged circumstances is unlikely to be effective without appropriate support and structural changes. Marmot et al⁵⁵ suggested that the impact of this social gradient is such that better a social and economic position results in better health. One explanation for this is that relative deprivation may provoke negative emotional and cognitive responses to inequity⁵⁶.

The *Social Exclusion of Older People: Evidence from the first wave of the English Longitudinal Study of Ageing (ELSA)*⁵⁷ suggests that there are seven key characteristics that are most strongly related to an older person experiencing multiple exclusions:

- Age: being 80 and over;
- Family type: living alone, having no living children;
- Health: poor mental or physical health;
- Mobility: no access to private car and never uses public transport;
- Housing tenure: rented accommodation;
- Income: low income, benefits as the main source of income
- Telephone: those without access to a telephone.

Figure 11: Barriers to behaviour change based on socio-economic model (LHA, 2001)



Quality of life and well being of older people is a theme in the report *From welfare to Wellbeing*⁵⁸ which proposed a shift in the way that society and government address the aging population in order to tackle age discrimination and inequality. This report found that public services generally focus on the most vulnerable older people only at times of crisis rather than adopting an approach which would enable the wider older population to remain independent for as long as possible and live their lives to the full. It found that many older people are excluded from universal services.

Many older people are carers, according to the 2001 Census 5.2 million people in England and Wales did some caring and over 1 million people provided more than 50 hours a week of caring. More than half of these were over the age of 55 and many reported themselves as not in good health. Approximately 20% of people over the age of 50 provide unpaid care. The majority of carers under the age of 65 are female; those aged 65 and over are more likely to be male⁵⁹.

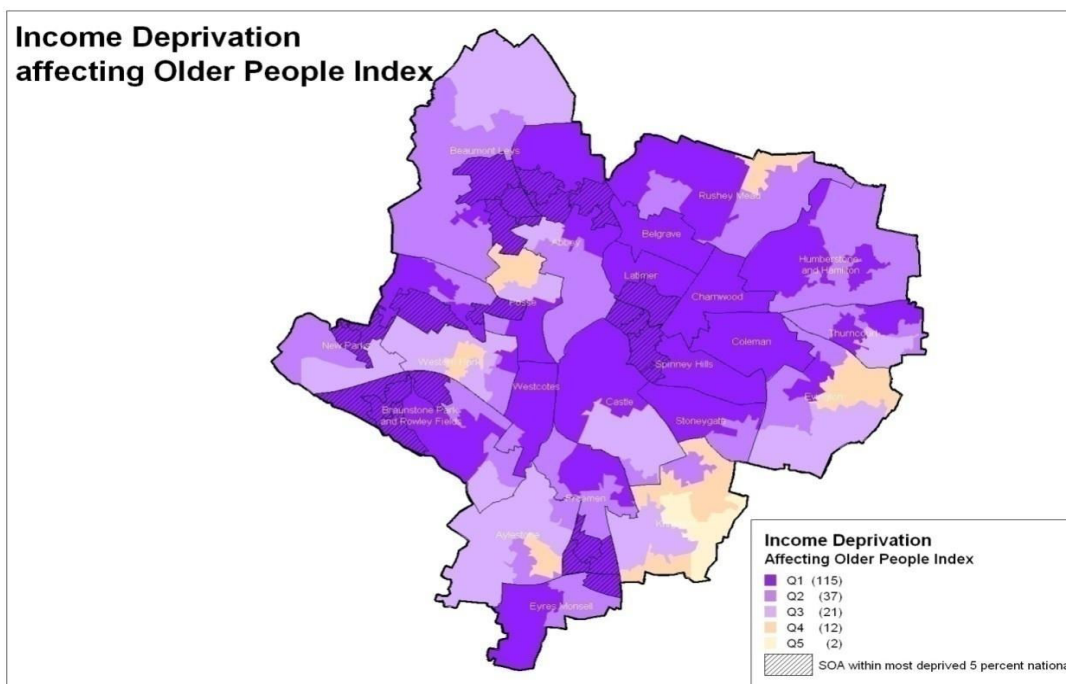
One aspect of material well being which is pertinent to older people is the issue of fuel poverty, a financial position where a household needs to spend more than 10% of its income on fuel in order to provide an adequate standard of warmth. Older people are at risk of fuel poverty because they rely on pensions, which provide an income which is lower than the general population. The impact on a person's health can be great; for instance the cost of fuel may cause people to have poor nutrition, either to eat or heat⁶⁰. The health of older people is more affected by cold stress⁶¹, they have a greater fall in core body temperature in response to the cold, and are more affected by excess winter mortality.

Housing is also problematic for older people, not just in relation to adequate heating, but also with regard to safety, access to disabled facilities. The report *Delivering Housing to an Ageing Population*⁶² suggested that older people want to live in their own homes, their local area and be involved in the local community for as long as possible. However, many old people live in poor quality accommodation, many have difficulties with mobility in the home, and older people fear falling in the home and have difficulty accessing adaptations and local amenities.

Social exclusion of older people may also be affected by transport or the fear of crime. With regard to transport, older people are more dependent on public transport and are more likely to have problems accessing local amenities. According to *Excluded Older People*⁶³ transport issues are problematic for older people. A *Sure Start to later life*⁶⁴ also suggested that poor transport, limited mobility and lack of services contribute to social exclusion. Fear of crime can have adverse effects on the lives of older people, reducing social contacts and their sense of well being. Evidence provided by Age Concern suggests that 25% of older people felt that⁶⁵ street crime was a problem in their area and that 72% believed that a person is more likely to experience crime as they get older.

Figure 10 below shows that Areas of high income deprivation are generally the same as areas of high multiple deprivation. However, there are areas in eastern Leicester (Rushey Mead, Belgrave, Latimer, Coleman, and Spinney Hills) which fall into the worst quintile nationally for Income deprivation affecting older people where they are in quintile 2 for the index of multiple deprivation.

Figure 12: Income deprivation affecting older people (2010)



Data: Index of deprivation 2010

4. Prevalence of dementia in Leicester

The *Dementia UK* report⁶⁶ used the Expert Delphi Consensus to produce estimates of the prevalence of dementia. It suggests that there are around 684,000 people with dementia in the UK, with around 574,000 (84%) resident in England. This corresponds to a prevalence of dementia for the population of England of 1.1%. Currently a large proportion of these people are likely to be undiagnosed.

The report also used the advice of UK and European experts to produce a consensus that:

- The prevalence of both early onset and late onset dementia increases with age, doubling with every five-year increase across the entire age range from 30 to 95-and-over.
- The prevalence of early onset dementia is higher in males than females for those aged 50–65, whilst late onset dementia is marginally more prevalent in females than males.
- Alzheimer’s disease is the dominant subtype of dementia, particularly among older people and in women.
- Frontotemporal dementia was considered to account for a substantial proportion of early onset cases among younger men.
- The report estimates that there are 11,392 people from Black and minority ethnic (BME) groups with dementia in the UK.
- There is a greater rate of early onset of dementia amongst people from BME groups (6.1% against 2.2% for the UK population as whole).
- The prevalence of dementia among people in institutions varied little by age or gender, increasing from 55.6% among those aged 65–69 to 64.8% in those aged 95 and over.

The consensus group advising *Dementia UK* also estimated that the prevalence of dementia among all those aged 65 years and over living in elderly mentally infirm homes was 79.9%, in nursing homes it was 66.9% and 52.2% in residential care homes.

With regard to deaths which are attributable to dementia, the report found that mortality attributable to dementia increases from 2% at age 65 to 18% at age 85–89 in males, and from 1% at age 65 to a peak of 23% at age 85–89 in females. Overall, 10% of deaths in men over 65 years, and 15% of deaths in women over 65 years are attributable to dementia. Annually, 59,685 deaths among the over 65s could have been averted if dementia were not present in the population. The majority of these deaths occurred among those aged 80–95 years. Delaying the onset of dementia by five years would halve the number of UK deaths due to dementia to 30,000 a year⁶⁷.

Launer et al⁶⁸ reviewed the estimates of the incidence of all dementia and Alzheimer’s disease derived from four European studies. They give the incidence rate for dementia as 2.5 per 1000 person-years (95% CI: 1.6–4.1) at age 65, rising to 85.6 (95% CI: 70.4–104) at age 90. These rates are inclusive of mild dementia.

4.1 Prevalence of dementia

This section presents information on the estimated prevalence of dementia in Leicester. This has been estimated by applying prevalence estimates for the UK⁶⁹ to Leicester's population.

Prevalence of late-onset dementia in the UK is relatively low in 65-69 year olds (1.3%), increasing with age to almost a third of the population aged 95 and over. The prevalence is slightly higher in females compared to males. In Leicester this would equate to around 1,690 females and 920 males aged 65 and over.

Table 4.1: Prevalence of late-onset dementia in the UK

Age (years)	Prevalence			Estimated number in Leicester		
	F %	M %	Total %	F	M	Total
65-69	1	1.5	1.3	49	68	123
70-74	2.4	3.1	2.9	113	125	253
75-79	6.5	5.1	5.9	251	157	409
80-84	13.3	10.2	12.2	427	226	662
85-89	22.2	16.7	20.3	486	203	691
90-94	29.6	27.5	28.6	262	115	373
95+	34.4	30	32.5	103	28	128
Total				1690	922	2639

Data: based on Alzheimer's Society. Dementia UK. The full report, 2007 applied to Leicester population

In people aged below 65 years dementia is much less common, affecting less than 1% of the population or around 70 people, in Leicester.

Table 4.2: Prevalence of early-onset dementia in the UK

Age (years)	Prevalence per 100,000			Estimated number in Leicester		
	F	M	Total	F	M	Total
30-34	9.5	8.9	9.4	1	1	2
35-39	9.3	6.3	7.7	1	1	2
40-44	19.6	8.1	14	2	1	3
45-49	27.3	31.8	30.4	3	3	6
50-54	55.1	62.7	58.3	5	5	10
55-59	97.1	179.5	136.8	7	14	21
60-64	118	198.9	155.7	8	13	20
45-64	66.2	99.5	84.7	28	43	72

Data: based on Alzheimer's Society. Dementia UK. The full report, 2007 applied to Leicester population

According to Dementia UK there were 1,436 people on general practice registers in Leicester with a diagnosis of dementia. This number is lower than expected when

the national prevalence rate is applied to the Leicester population. The actual number of people with dementia is estimated to be 3,191 people (Table 4.3).

Table 4.3: Prevalence of diagnosed and undiagnosed dementia in the UK

Age (years)	Prevalence		Estimated number in Leicester		
	F %	M %	F	M	Total
30-59	0.09	0.16	51	94	145
60-64	0.47	1.58	30	103	133
65-69	1.1	2.17	54	99	152
70-74	3.86	4.61	182	186	368
75-79	6.67	5.04	258	155	413
80-84	13.5	12.12	433	269	702
85-89	22.76	18.45	498	224	722
90-94	32.25	32.1	285	134	420
95+	36	31.58	108	29	137
Total			1898	1293	3191

Data: Dementia 2010

4.2 Incidence of dementia

Prevalence relates to the total number of people with dementia at any one time. Incidence shows the number of new cases. Applying the national incidence rates to Leicester's population gives an estimated 730 new cases of dementia each year.

Table 4.4: Incidence of late onset of dementia (per 1,000) in England and Wales

Age (years)	Rate per 100,000		Estimated number in Leicester		
	F	M	F	M	Total
65-69	6.3	6.9	31	31	62
70-74	6.1	14.5	29	58	87
75-79	14.8	14.2	57	44	101
80-84	31.2	17.0	100	38	138
85+	71.7	58.4	242	101	343
Total			459	272	731

Data: based on Medical Research Council Cognitive function and Ageing Study, 2005 applied to Leicester population

4.3 Types of dementia

Prevalence of different types of dementia varies between men and women and by age group. The figure below shows a summary of the overall proportions of types of dementia and the estimated numbers by applying these figures to the population of Leicester with dementia. Alzheimer's disease is the most common type, accounting

for over 60% of dementias, with vascular dementia the next common accounting for 17%. A mix of Alzheimer's disease and Vascular Dementia accounts for 10% of cases.

Table 4.5: Proportion of people with dementia by type

Age (years)	Proportion of people with dementia (%)	Estimated number in Leicester
Alzheimer's disease	62.0	1681
Vascular dementia	17.0	461
Mixed (AD and VD)	10.0	271
Dementia with Lewy bodies	4.0	108
Frontotemporal dementia	2.0	54
Parkinsons' dementia	2.0	54
Other	3.0	81
Total	100.0	2711

Data: based on Alzheimer's Society. Dementia UK. The full report, 2007 applied to Leicester population

4.4 Severity of dementia

This needs assessment has shown that one way of classifying dementia is by the headings mild, moderate or severe. The majority of the population has mild dementia (around 55%), 32% have moderate dementia and 13% severe dementia. As dementia is progressive, the proportion of people with severe dementia increases as people grow older; from around 6% in 65-69 year olds to 23% in 95 years and over. When these are applied to the Leicester population, there are 1,456 people with mild dementia, 850 with moderate and over 300 with severe dementia.

Table 4.6: Proportion of people with mild, moderate and severe late onset of dementia applied to the Leicester population

Age (years)	% with dementia			Estimated number in Leicester		
	Mild	Moderate	Severe	Mild	Moderate	Severe
65-69	62%	32%	6%	76	39	7
70-74	63%	30%	7%	160	76	18
75-79	57%	31%	12%	233	127	49
80-84	57%	32%	11%	377	212	73
85-89	54%	33%	13%	373	228	90
90-94	49%	33%	18%	183	123	67
95+	42%	35%	23%	54	45	29
Total				1456	850	333

Data: based on Alzheimer's Society. Dementia UK. The full report, 2007

4.5 Residential status

People with dementia will need different levels of care, depending on their age and severity of the disease. Estimates show around 73% of people aged less than 85 years with late-onset dementia live in the community (either in their own homes or with family/others) and around 27% live in a care home. This proportion increases with age, with over 60% of those with dementia aged over 90 living in care homes.

Table 4.7: Proportion of people with late onset dementia living at home and in care homes

Age (years)	% living in community	% living in care homes	<i>Estimated number in Leicester</i>	
			<i>Living in community</i>	<i>Living in care homes</i>
65-74	73.4%	26.6%	276	100
75-84	72.2%	27.8%	774	298
85-89	59.1%	40.9%	408	283
90+	39.2%	60.8%	196	304
Total			1654	985

Data: based on Alzheimer's Society. Dementia UK. The full report, 2007 applied to Leicester population

5. Mortality from Dementia

5.1 Deaths attributable to dementia

Dementia shortens the lives of those who develop the condition; the mean survival with Alzheimer's is estimated at approximately 7.1 years and 3.9 years for vascular dementia⁷⁰. People with dementia often have other health conditions so it is difficult to assess the contribution of dementia to the cause of death. A population attributable risk fraction has been developed based on empirical evidence (age, sex, death certificates acknowledging dementia) to show the theoretical contribution of dementia to cause of death.

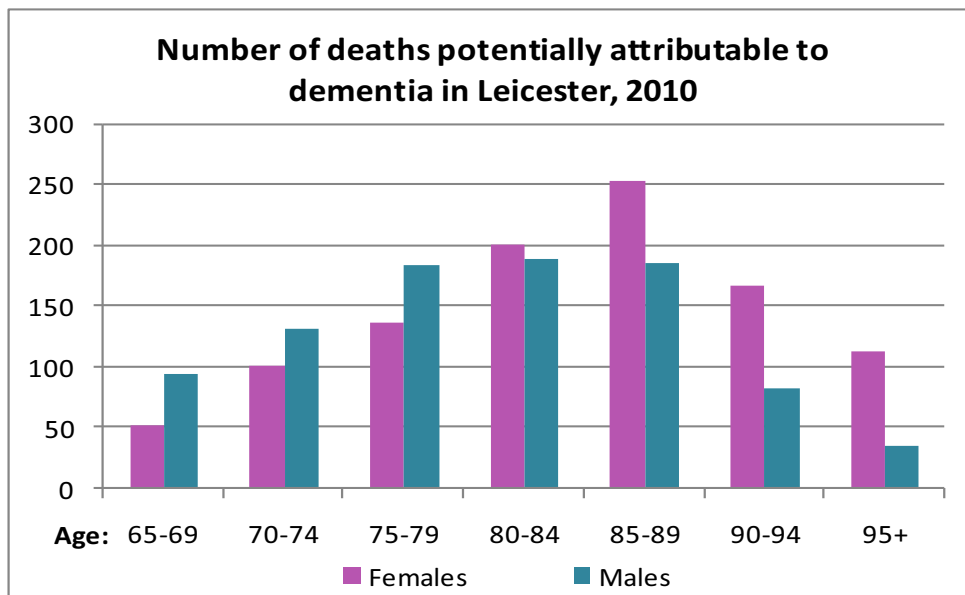
Table 5.1: Proportion of deaths theoretically attributable to dementia, 2010

Age group	Females		Female Deaths	Male Deaths	Female dementia deaths	Male dementia deaths	All
	AF	Males AF					
65-69	1%	2%	52	95	0.52	1.9	2.42
70-74	3%	3%	102	133	3.06	3.99	7.05
75-79	8%	7%	138	184	11.04	12.88	23.92
80-84	15%	12%	201	190	30.15	22.8	52.95
85-89	23%	18%	255	186	58.65	33.48	92.13
90-94	19%	14%	167	83	31.73	11.62	43.35
95+	21%	15%	113	35	23.73	5.25	28.98
All	15%	10%	1028	906	158.88	91.92	250.8

Data: based on Dementia UK, The Full Report 2007 Attributable fractions for dementia applied to Leicester deaths for 2010

Overall, around 10% of deaths in men and 15% of deaths in women are attributable to dementia. The proportion of deaths attributable to dementia increases from age 65 (1% in men, 2% in women) to a peak at 85-89 years (18% in men and 23% in women). These fractions have been applied to deaths in Leicester:

Figure 13: Number of deaths potentially attributable to dementia in Leicester, 2010



Data: based on Dementia UK, The Full Report 2007 Attributable fractions for dementia applied to Leicester deaths for 2010

If dementia could be removed from the population, around 250 deaths per year in the over 65s in Leicester would be averted. If the onset of dementia could be delayed by around 5 years, by a combination of public health improvement (cardiovascular risk factor reduction and diet) and preventative treatments, this could halve the prevalence of dementia in each 5 year age band and theoretically also halve the number of deaths attributable to dementia.

6. The role of primary health care

6.1 General practice and early diagnosis

One of the main issues for people with dementia and their carers is the availability of an early and accurate diagnosis. If a person with dementia is diagnosed early it enables them and their family and carers to engage with support services, plan for the future; an early diagnosis can reduce psychological distress⁷¹. For Briggs⁷² an early diagnosis can enable people to access knowledge about medical, psychological and social support which could improve morale, lessen carer stress and reduce admission to care homes⁷³.

However, evidence suggests that the majority of GPs feel inadequately trained in the diagnosis and management of dementia⁷⁴. They also feel that they have little to offer people with dementia⁷⁵, and find explaining the diagnosis of dementia particularly difficult⁷⁶. Many GP's find that patients do not want the stigma of a label of dementia; in response GPs are more likely to utilise vague symptomatic terms, such as 'mild memory problems', to describe early dementia.

Studies of relatives of people with dementia also suggest that, from their perspective, physicians are reluctant to make a diagnosis^{77 78}. In consequence, less than two thirds of GPs felt that it was actively important to look for symptoms. The National Audit Office (NAO) report, *Improving services and support for people with dementia*⁷⁹ found that GPs' attitudes could hamper early diagnosis, that there was a common perception among GPs that little could be done for a person with dementia even if the illness was diagnosed early. It also found that GPs' confidence in diagnosing dementia had fallen in the period since 2004. Only 31% felt that they had enough training to diagnose and manage the disease and 70% felt that they had too little time to spend on people with dementia⁸⁰.

Similar findings were described in the Audit Commission report, *Forget Me Not*⁸¹. This showed that 40% of GPs are reluctant to diagnose dementia early, the majority of GPs do not use protocols to help diagnose dementia, and that fewer than 50% of GPs felt that they had sufficient training for the diagnosis and treatment of people with dementia.

To some extent the a lack of urgency attached to diagnosing and addressing the disease may explain why, despite the apparent benefits of early diagnosis, the numbers of people who are diagnosed are lower than the estimated prevalence; in effect a diagnosis gap.

6.2 Cases of dementia on GP registers in Leicester

In 2011 there were 1,436 people in Leicester registered as having dementia, whilst the estimated prevalence of dementia in suggested that there are 2639 people with the disease. Table 9.1 shows that this means that 54.4% of the population estimated to have dementia have been diagnosed. In many respects this diagnosis gap confirms that Leicester is no different to the rest of the UK. However, the gap

between reported and estimated prevalence in Leicester has reduced since 2010, when there were an estimated 2,606 people with dementia in Leicester of whom only 1,100 were on GP registers (42.2% of the estimated total)⁸². The likelihood is, though, that GPs may be more aware of potential cases of dementia than the formal QOF registers indicate, and they could be more involved in early diagnosis.

Table 6.1: Numbers of people with dementia in Leicester projections and proportions on the dementia register (Source, *Dementia UK (2007)* ⁸³)

Primary Care Trust Area	Estimated number of people with dementia in 2011	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 on the register
Leicester City	2639	3023	14.5	1436	54.4

Table 6.2 shows the 2011 Leicester QOF register data by GP locality. The expected number of people with dementia is greatest for Leicester City Central, with 1,046 cases expected from a list size of 120,839. The greatest expected prevalence is 1.3% for the NEL Cluster; the age profile of this locality is older than the other localities.

Table 6.2: QOF expected and actual prevalence of dementia by GP locality 2011

Locality	Dementia Register	Listsize	QOF Prevalence 2011	Expected Number with dementia*	Expected prevalence	% Diagnosed
Leicester Primary Care Group	481	108563	0.4%	832	0.8%	57.8%
Leicester City Central	306	120839	0.3%	1046	0.9%	29.2%
Millennium Health	277	78864	0.4%	728	0.9%	38.1%
NEL cluster	372	56822	0.7%	749	1.3%	49.7%
Leicester Total	955	366135	0.3%	2523	0.7%	37.8%

With regard to actual QOF registrations, Leicester Primary Care Group had 481 of 832 expected cases of dementia registered (57.8%); NEL Cluster have 372 cases of dementia registered, out of an estimated 749 (49.7%); Millennium Health had 277 registered from an estimated 728 cases (38.1%); Leicester City Central had 306 registered from an estimated 1,246 cases (29.2%). Whilst the numbers of cases diagnosed and registered has improved since 2011, this data suggests that particular activity could be focused on Leicester City Central.

Recommendation: To note the observed and expected rate of dementia by general practice locality.

6.3 General practice role in improving diagnosis of dementia

To improve rates of early diagnosis, there is a need for GPs to conduct cognitive tests, such as ADAS-Cog or Mini Mental State Examination, to assess patients in periods of watchful waiting and to make referrals to the Memory Assessment Service. Such tests can be used to assess a number of different mental abilities including short and long-term memory, attention span, language and communication skills, and ability to plan and to understand instructions. Whilst the results of such assessments may be confounded by factors, such as by a person's educational background they are recognised as being of value in providing a baseline, and the MMSE is also recommended by NICE⁸⁴ when deciding whether a drug treatment for Alzheimer's disease should be prescribed.

There are other tests involved in the diagnosis of dementia, for example a range of blood tests to rule out other possible causes of symptoms, such as a vitamin B deficiency or syphilis, and a review of medication, which may have been contributing to a person's symptoms. Such tests may also help to differentiate between the different types of dementia. Referral to specialists should be focussed upon cases such as determining the presence of dementia as opposed to MCI and normal ageing; in effect determining a person who comes under Care Cluster 18.

GPs can also be involved in the diagnosis of dementia in those cases which do not require specialist input for diagnosis. This would include those cases of people with moderate or severe dementia who have not been diagnosed. Many such cases may be more straightforward to diagnose, in particular those people whose condition has deteriorated, who are labelled as confused and who have already become progressively dependent. These cases come under Care Clusters 19 and 20.

Recommendation: A primary care model should be developed to for GPs to be involved in early diagnosis of people with dementia, using a cognitive assessment tool, watchful waiting of potential cases, referral for blood tests and brain scans, and referral to the Memory Assessment Service.

This recommendation links to Strategic Priority 1 of the local dementia commissioning strategy and to objective 2 of the national dementia strategy.

In order to facilitate greater involvement of primary care in the diagnosis and treatment of people with dementia there should be shared care arrangements between primary care and secondary care providers (currently Leicestershire Partnership Trust). Given the changes to the technical appraisal on medications for Alzheimer's disease, the loss of patent protection for donepezil and the use of memantine as a first line treatment for moderate to severe Alzheimer's disease, shared care arrangements are immediately necessary.

Such agreements should enable secondary care to focus on those people requiring complex early diagnosis or complex treatment. The agreements should also ensure that there is increased access to appropriate treatment. There are a number of service providers which could be used to deliver this service but, given possible lack of capacity in general practice, the best option is most likely to be a separate provider working closely with local practices and social care.

Recommendation: There should be shared care arrangements between primary and secondary care to enable people with dementia to have access to appropriate care; including medications and support with activities of living.

The NICE quality standards also suggest that early diagnosis will allow patients and carers to receive information about their condition and local support options. It will also allow people with dementia to have ongoing care planned and evaluated. QMAS data records the number of people with dementia whose care had been reviewed in the previous 15 months. This data shows that in January 2011 821 of the 1380 people registered with dementia in Leicester (59.5%) had their care reviewed in the preceding 15 months. In effect, only 31% of the population who are expected to have dementia have had a review of their care in the previous 15 months.

Table 6.3: Numbers of people registered with dementia in Leicester who have had a review in the last 15 months (Source, QMAS Data Jan 2011)

Primary Care Trust Area	Numbers of people on a GP register Jan 2011	Numbers of people on a GP register reviewed in previous 15 months	% patients diagnosed with dementia whose care has been reviewed in the previous 15 months
Leicester City	1380	821	59.5

Recommendation: There should be an improvement in the number of people with dementia who have been reviewed by their GP in the previous 15 months.

6.4 Primary care support for carers

Given the detrimental impact of caring on a person’s mental health and wellbeing, primary care support for carers of people with dementia is also essential. General practice can be decisive in assessing the capacity of a carer to cope, assessing the health and wellbeing of those family members contributing to care and ensuring that they have information about the services and benefits which are available to them⁸⁵.

One of the main areas which may benefit carers, and which could be offered in primary care, is flexibility. The recognition that caring is difficult and not straightforward. For example, that sometimes aspects of daily routine, such as getting out of the house or waiting in busy reception areas, are difficult for carers and the care recipient. In response to this primary care should offer greater flexibility for carers. In order to raise awareness that everyone has a role in dementia care local work stream 5 is involved in developing a workforce which is fit for purpose, reviewing the feasibility of offering training courses aimed at different levels.

Recommendation: GPs should better identify and meet the needs of carers. In order to facilitate this they should keep up to date QOF registers of carers or there should be strict monitoring of current QOF requirements for the care of patients with dementia.

Recommendation: All primary care staff should have training about the needs of people with dementia and their carers appropriate to their role in the Dementia Care Pathway.

As part of the QOF for dementia, there is an obligation to consider carers' needs. In addition there is potential for a separate carers' register to be held by each general practice as part of the quality and outcomes framework. This should be used to facilitate the offer of an annual health check for carers of people with dementia.

Recommendation: All carers should be invited for an optional annual health check.

6.5 The wider primary care team

Although GPs are the leaders of primary health care teams, these teams comprise a wide range of roles. In primary care people with dementia are more likely to be in the care of Community Mental Health Teams, although GPs, district nurses, community matrons and community psychiatric nurses (CPNs) may be involved at some point during the care pathway. Supporting people at home, with regular home visits may provide the best means of reviewing each case, encouraging caregivers and monitoring the need for further action. CPNs are often engaged in such care; Hughes and Summerfield found that about 60% of the CPN caseload was involved in caring for older patients⁸⁶.

Once a diagnosis is in place, or when the person's condition deteriorates a package of care may be needed with contributions from a number of services. Patients who have co-existing medical or surgical conditions may require access to a wide range of services, which are often accessed through primary care. For example, an older person with dementia and a fractured neck of femur may need orthopaedic surgery, geriatric assessment, liaison psychiatry and the support of rehabilitation services. Eventually there may be a need for long term residential or nursing care.

This will demand the involvement of services covering primary, secondary and social care. Effective co-ordination of specialist medical, general medical, community nursing and social welfare services is therefore a prerequisite of dementia care, and the contribution of primary health care teams is a major component of this care provision. It will also require that the workforce is developed so that the members have confidence in adapting their actions and communication in order to respond appropriately to people with dementia and their carers. The training that the workforce receives should be based on the common core principles for supporting people with dementia⁸⁷ (See Appendix 12), or training which reflects their role in the wider team.

Recommendation: Members of the primary care team, including reception staff, should receive appropriate training to respond appropriately to people with dementia and their carers.

7. Memory Assessment Service

7.1 Memory Clinics

A diagnosis of dementia is often made at a memory clinic, although it is important to add that not all people attending a memory assessment service will have dementia. Some people who have been referred to a memory clinic may have cognitive impairment that does not meet the criteria for dementia⁸⁸. But memory assessment clinics require consideration because they are significant participants in early diagnosis.

Memory clinics emerged in the USA in the 1970s, and were principally aimed at identifying people in the early stages of dementia. Since 1983 there has been a similar development in the UK. Wright and Lindesay⁸⁹ identified 20 memory clinics in the Britain and Ireland (14 in England, two in Wales, three in Scotland and one in the Irish Republic). Of these clinics 12 had started within the preceding three years. Most patients were referred by physicians (GPs, psychiatrists or geriatricians), but some clinics accepted family or self-referrals, and nearly all took patients from outside their own areas. All provided a multi-disciplinary assessment (psychiatric, psychological and geriatric) and most shared a common core of tests and investigations (physical examination; MMSE; full blood count; urea and electrolytes; thyroid and liver function tests; vitamin B12 and folate levels; serum glucose).

In the Wright and Lindesay survey, the proportion of patients found to be suffering from dementia varied from under 20% to nearly 100%, indicating major differences in patient selection and clinic function. Similar surveys are varied in their findings. Luce et al⁹⁰ reviewed 100 referrals to a memory assessment service and found that about 57% of attendees had probable or possible dementia; the remainder had other conditions or cognitive deficits that did not meet the criteria for dementia. When Bannerjee et al⁹¹ examined the diagnostic profiles of people referred to a memory assessment service they found that 63% of people referred to the service had some form of dementia, with the remainder having either other conditions or no illness.

In practice, in the UK, many people with dementia never receive a diagnosis. Using prescription rates of cholinesterase inhibitors as a proxy for the diagnosis of Alzheimer's disease, the NAO found that the UK was in the bottom third of EU countries in diagnosing people with dementia. This was before NICE guidance suggested the drugs should be restricted to a smaller group of patients⁹². *Facing Dementia*⁹³ showed that the reported time taken to diagnose Alzheimer's disease, after the symptoms are first noticed, is 32 months in the UK; longer than France (24 months), Spain (18), Italy (14) and Germany (10).

7.2 Memory Assessment Service in Leicester

The Memory Assessment Service in Leicester is integrated in Outpatient Departments and other clinics in the city. This means that they are not exclusively focused on memory assessment. There are four catchment areas, south west and south east, north west and north east Leicester. The service is linked closely to the

2 Community Mental Health Teams (CMHTs), which provide multi-disciplinary assessment and care for older people, including those with dementia, in the city. The Memory Assessment Service is provided by Leicestershire Partnership Trust (LPT), whilst the CMHTs are provided by both LPT and Leicester City Council (LCC).

The memory assessment component of these outpatient services have developed through custom and practice, in response to a perceived need. This means that the Memory Assessment Service has never been properly commissioned; although there is a process currently underway to commission it as part of the implementation plan for the national dementia strategy.

Recommendation: The Memory Assessment Service should be properly commissioned, incorporating methods of review and challenge to monitor effectiveness.

The Memory Assessment Service in Leicester offers assessment, diagnosis and therapy for people with dementia; it aims to facilitate early identification of the illness, in line with the vision of the NDS. The severity of the deterioration in cognitive function is defined by a global assessment which includes a cognitive function assessed by structured examinations, such as the MMSE score.

Each Memory Assessment Service clinic is held 2 to 3 times per week, with each serving 7 to 8 patients. Referrals to the service are made by primary and secondary care, residential and nursing homes. Whilst the aim of the service is to facilitate early diagnosis, much of the workload also currently comprises the care of those who already have a diagnosis of dementia whose condition has worsened. The need to be seen by clinicians at the Memory Assessment Service has always been greater than the clinical capacity. The average waiting time to be seen is about 6 to 8 weeks, with some people who are waiting much longer before they are able to access an assessment or reassessment.

Every clinic has a ratio of more follow up cases to new ones. One of the main reasons for this is that currently there is no agreed means to discharge on-going patients elsewhere for longer term follow up and monitoring. In addition, the absence of locally agreed shared care arrangements means that the cholinesterase inhibitor medications, which are used to treat Alzheimer's disease can only be prescribed by experts in the field of old age psychiatry. As it currently stands, if patients are discharged back to primary care they would no longer have access to the medication they require. The need for shared care arrangements is even more important given the impact of the recent review of the NICE technology appraisal guidance 111 in which donepezil, galantamine and rivastigmine are recommended as options for managing mild as well as moderate Alzheimer's disease.

Given this workload, one way of better utilising the expertise on offer at the Memory Assessment Service, is for service to focus on the cases in which diagnosis is complex; such as distinguishing between normal ageing and dementia.

The latest NICE technical appraisal recommends that memantine be used an option for managing moderate Alzheimer's disease for people who cannot take AChE inhibitors, and as an option for managing severe Alzheimer's disease. Prescription

of memantine is also recommended as a way of reducing the high levels of anti-psychotic prescribing for the behavioural symptoms of dementia, such as aggression, agitation, shouting and sleep disturbance.

Clinicians estimate that, as a result of the recommendations of the NICE technical appraisal, there is likely to be an increase in the prescribing budget of an estimated £1.2 million for Leicester, Leicestershire and Rutland over the coming year or so. So a review of the local prescribing of anti-psychotic medication is required to ensure that the Memory Assessment Service is aligned to the findings of the report, *The use of anti-psychotic medication for people with dementia*⁹⁴ (Bannerjee, 2009) and the guidance in the latest NICE technology appraisal guidance.

Recommendation: The primary care model should review the use of anti-psychotic medication in the context of support systems existing for providing non-drug treatments and a review of the skills available for managing people with dementia in care homes.

7.3 Developing the Memory Assessment Service in Leicester

The local Memory Assessment Service should be commissioned to provide good quality early diagnosis and intervention for patients with mild and moderate dementia, based on criteria laid out in NICE Clinical Guideline 42⁹⁵. The aims of the service, which are outlined by the Department of Health in the Dementia Commissioning Pack could include:

- Effective diagnosis (i.e. high diagnostic accuracy including sub-typing) made early in a timely manner
- Effective communication of the diagnosis to the person with dementia and their family
- Advice on appropriate treatment, information, care and support after diagnosis.

The objectives of the service should be:

- to promote and facilitate early identification and referral and encourage eligible patients to attend assessment
- to provide a high-quality accurate diagnosis of dementia that is communicated in a person-centred way to both the person with dementia and their carers and which meets the individual needs of the person with dementia and their carers
- to provide diagnosis early in the disease
- to ensure that the service is readily accessible and meets the range of needs of the local population, including minority groups
- to ensure that people with dementia and their carers have appropriate information that allows them to manage their care more effectively along the pathway and understand how to access other assistance
- to engage people with dementia and their carers in decisions about the care options available to them, including the development of personal care plans
- to ensure continuity of care across the pathway and integration with other care providers
- to ensure that the service is delivered in a considered, timely and co-ordinated manner

- to provide opportunities for people with dementia to be included in research studies.

Referral to the Memory Assessment Service should be a clinical decision based on the possibility that the individual presenting in primary care has mild to moderate dementia. This will be made by the GP on the basis of presenting symptoms, a review of past history and the exclusion of other acute medical reasons. The GP should produce a brief, objective measure of cognition as part of the referral information arrangements, consistent with NICE Clinical Guideline 42, as outlined in Chapter 6 of this needs assessment. The Memory Assessment Service should be for people with mild to moderate dementia.

Adults should be referred to the memory service if they meet the following criteria:

- The person is presenting with symptoms consistent with suspected dementia rather than a physical or functional mental illness.
- The person does not have an existing clinical diagnosis of dementia.

There is also evidence that a service of this nature can release funds back into health and social care systems⁹⁶. Diagnosis of people with severe dementia could take place in primary care, with or without the support of specialist dementia services.

Where the diagnosis is one of no illness, the patient should be notified of the outcome and the information shared with the patient's GP. Where there is a diagnosis of another illness it would be expected that the Memory Assessment Service should share the diagnosis with the patient and, if it is appropriate, initiate urgent treatment or referral for physical or mental disorder if required and then discharge to GP. The Memory Assessment Service provider should give advice on further treatment needed and shall share this information with the patient's GP.

Where there is a diagnosis of dementia commissioners would expect that the memory service provider should give a clear and full explanation of the diagnosis, prognosis and the treatment plan. The service provider should address any initial concerns or requests for information from patients and their carers and families. In cases of dementia where medication is available, the service provider should discuss the diagnosis, prognosis and further care, including medication as part of the treatment plan. Where the diagnosis is one of mild cognitive impairment (MCI) the memory assessment provider shall share the diagnosis with the patient and the patient's GP. In such cases the patient should be discharged to their GP, who should be encouraged to re-refer the patient if the clinical picture changes.

With regard to the overall outcomes from the Memory Assessment Service, there are potential links to the NICE quality standards and NHS outcomes framework, giving 3 potential headline outcomes focusing on an increase in the proportion of people with dementia having a formal diagnosis and the quality of care received. The potential outcomes for the commissioned memory assessment service could be:

- Increase in the proportion of people with dementia having a formal diagnosis compared with the local estimated prevalence (target 80%; 2256 people in Leicester)
- Increase in the proportion of people with dementia receiving a diagnosis while they are in the mild stages of the illness
- Increase in the number of patients and carers who have a positive service experience

Recommendation: As a specialist service the Memory Assessment Service should be commissioned to focus on individuals presenting in primary care with symptoms of mild to moderate dementia (Cluster 18) and the treatment of those people in whom the disease has significantly altered (Clusters 19 and 20).

Recommendation: The Memory Assessment Service provider should engage with commissioners and primary care to develop shared care agreements so that people with dementia will have access to the treatment and care they require.

8. Meeting carers' needs

8.1 Evidence of carers' views

National policy initiatives, such as *The Carers' Strategy, Putting People First* and *Think Local, Act Personal*, focus on the experience of people in receipt of care and the needs and views of their carers. Evidence from national and local consultations, individual interviews and focus groups offer experiences of carers, and compelling testimony to the difficulty of living well with dementia.

The husband of a woman with dementia in a residential home said:

"I would go home and cry. She (my wife) hardly knew me and I don't think that she knew where she was – but she used to beg me to take her with me. The care staff had to try to distract her to stop her clinging to me." ⁹⁷

From the same leaflet a daughter of a man with dementia said:

"My dad deteriorated before my eyes. He seemed to disappear – and I thought – no one knows who he really is. No one knows that he was once someone really special with enormous talent." ⁹⁸

Dementia usually progresses from mild disturbances of recent memory and abstract thinking through to a late stage, which can be characterised by loss of identity, unintelligible speech, incontinence and impairment of mobility⁹⁹. The person with dementia therefore becomes increasingly dependent on daily care and supervision. Care needs include support with activities of daily living, such as washing, dressing, eating and toileting.

Much of the burden of care falls to informal carers; these are most likely to be spouses or children¹⁰⁰. Carers often experience social isolation, stress and high rates of depression^{101 102}, yet their own needs often go unmet¹⁰³. A carer's health and well being is often the cause of a person's admission to nursing or residential care. Carer's health may also be related to the issue of elder abuse by relatives and other informal carers.

8.2 Role and effectiveness of respite care

For carers of people with dementia, respite care seen is a potentially important way of maintaining the quality of life for themselves and the people for whom they are caring. A systematic review of 10 randomized controlled trials, 7 quasi-experimental studies and 5 uncontrolled studies¹⁰⁴ showed that for all types of respite, the effects upon caregivers were generally small. However, although many studies reported high levels of caregiver satisfaction, there was no reliable evidence to suggest that respite care delays either entry to residential care or adversely affects frail older people.

A review of respite services and short-term breaks for carers for people with dementia had mixed findings with some policy implications¹⁰⁵. The benefit of respite to some extent depended on whether the break was aimed at preventing future service use (for instance residential care) or for the immediate relief of the carer¹⁰⁶.

The review looked at a number of models of respite care and feedback from consultations with carers. It found that day care services, those which are provided outside of the home but not involving overnight stay, were of benefit to carers and the person with dementia. Whilst there was some evidence to suggest that day care may prevent entry to long term care, the evidence as to whether day care is cost effective was equivocal; 2 economic evaluations suggested that day care might be cost effective whereas 2 suggested that day care could provide higher benefits only at a higher cost.

There were also mixed findings with regard to the impact on the carer and the person with dementia. Some studies showed improvement or stabilisation for the person with dementia, whilst some showed no positive effects. Similarly for carers some studies showed improvements in physical and mental health and wellbeing, whilst others showed no positive effects. With regard to accessing day care services, problems related to regular attendance at day care acted as an obstacle to using such services.

Evidence for the effectiveness of respite breaks away from home for one night or more was also equivocal. Organising such breaks was perceived to be difficult. There were some physical and emotional benefits for the carer, with increased sleep for example, but also guilt in using respite services. Some people believed that it helped them to continue in the caring role. For the person with dementia, however, there was mixed evidence as to the benefit on their activities of living there was little evidence that overnight respite delayed admission to long term care.

Other models which were considered included in-home and host family respite. In-home care involves a care worker sitting with the person with dementia. Host family respite sees the person with dementia and the carer take breaks together by staying with another family.

Evidence suggests that carers have high levels of satisfaction with in-home respite care and that there was some advantage in maintaining family routines. It was difficult to separate the impact of in-home respite from the demand for other types of respite care or the reduction of the demand for long-term residential care. Carers reported positive outcomes from host-family respite, especially when they wanted to spend time together with the care recipients. It was generally preferred to the alternative of the person receiving care staying in a residential home.

There was some evidence to suggest that support packages which comprise different services may delay permanent admission to long term residential care. However, a minority of studies show that residential respite can worsen service user health. The Social Policy Research Unit (SPRU) found that sometimes there was a contradiction between the value that carers put on respite care and their actual experience of respite; this was also a finding in the Social Services Inspectorate report *Getting the Right Break*¹⁰⁷. In *A real Break*¹⁰⁸ there is stress laid upon

defining breaks, making it clear who they are for, preparing for the break as well as the quality of the service. The SPRU team produced a respite pyramid to consider in planning respite services (see Appendix 8). This emphasises the need for respite care to be based on individual assessment, on going evaluation and that respite should be appropriate to the needs and circumstances of the carer and the care recipient. This model also suggests that respite services are most effective when they are underpinned by knowledgeable and supportive doctors, responsive social services, accessible information and supportive care networks.

8.3 Evidence from Department of Health demonstrator sites

The University of Leeds produced an evaluation of the Department of Health Demonstrator Sites aimed at improving the health and wellbeing of carers as part of the National Carers' Strategy. These sites looked at the quality and effectiveness of a range of approaches towards breaks for carers, the delivery of annual health checks and ways of supporting carers in NHS settings¹⁰⁹.

The sites showed that strong multi-agency partnerships, inclusive of voluntary organisations, are required to identify and engage carers. Such links can be developed without an unduly disrupting health and social care workloads. However, it was found that to encourage GPs to engage with carer support, some sites needed to adopt special approaches and invest considerable effort.

Most carers felt they benefitted from the services offered. Flexible and personalised breaks were shown to be of positive benefit for many carers. There was evidence that this had the potential to prevent the deterioration of carers' health and to sustain carers in their caring role. Health checks led to sustained self-care and healthier behaviour for some carers.

The evaluation report also found that carer support can save costs to the providing organisation and to the health and social care sector generally. These cost savings included the prevention of hospital or residential care admission, supporting carers to sustain their caring role, earlier identification of physical and mental health problems in carers, efficiency savings in GP practices and assisting carers to undertake paid work.

With regard to policy recommendations, the evaluation and the government consultation on the *Future of Care and Support* were considered by the authors as an opportunity to put some of the findings into practice. These included:

- Involving a diverse range of carers in service development. These carers would be suitably trained and arrangements for their engagement based on flexible local partnerships, involving agencies which are trusted by carers which may be outside the health and social care system.
- A recognition that effective carer support at the local level should always include varied carer support services, which can be adapted to meet individual needs.
- Better support for carers with: health problems and stress; information on how to access suitable support, services, equipment and home adaptations for those they care for; income maintenance and pensions protection during and

after caring; self-care, healthy lifestyles and maintaining a life outside of caring; access to education, training, work and leisure; emergency planning; and how to access occasional or regular breaks from their caring role.

- Hospitals should routinely identify and support new carers, centring their efforts on wards where patients have received a new diagnosis or are due to be discharged and on out-patient clinics. Support should be timely and co-ordinated.
- Every GP practice should be encouraged to identify a lead worker for carer support, who can assist in carer identification, help in referring carers to suitable local services, and ensure carers' access to health appointments and treatments is not impeded by their caring circumstances. These workers may require carer awareness and carer support training. The action guide 'Supporting Carers', for GPs and their teams, published by the PRTC and the RCGP in October 2011 provides detailed suggestions for practical ways of taking this forward (PRTC and RCGP, 2011).
- All staff who interact with carers, in hospitals, GP practices, local authorities and in the voluntary sector should be trained to consider how caring responsibilities can impact on a carer's health and well-being and be equipped to advise on how a carer can access a health and / or well-being check.
- All relevant organisations should regularly offer carer awareness training to their staff.

8.4 Supporting carers in Leicester

This needs assessment has shown that the contribution of carers in supporting vulnerable people has been acknowledged in National Carers Strategy. If families and carers did not care for their loved ones, it would cost the government £104 million a year. 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; including short stays in residential accommodation, 'respite at-home', short-stay sitting services, day care services, befriending services and dementia cafes.

All carers of a social care client can be offered a carer's assessment. In 2011/12 1,233 carers received an assessment. As a result of receiving a carers' assessment or review, carers over the age of 18 receive support in the form of respite or a carer specific service or they receive information and advice. According to carers' assessment data, in the period 2011/12 there were 705 (57%) carer's services supplied and 528 (43%) cases where information and advice was given. For adults aged >65 advice and information is more likely to be given. The services provided include:

- Domestic Tasks - examples include shopping, cleaning and laundry.
- Meal preparation - meal preparation is for the person being cared for to give the carer a break from cooking.
- Day Care - If the carer needs a bit of a break from caring for someone, we could provide one day a week day care. However, the person being cared for must be in agreement and would need to benefit from this service.

- Respite Care - You may need a longer break from caring for a holiday, for example.
- Professional support - this could be advice and/or emotional support.
- Equipment - there may be equipment that could benefit a carer.

Carer assessment and support is usually initiated once a person living with dementia comes into contact with services. This emphasises the importance of early diagnosis; as people caring for someone with dementia who have not accessed services are often missed. So some carers are not aware 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 cope¹¹⁰.

Feedback from local stakeholders, including users and carers, has been consistent with the national findings. This feedback includes a series of engagement events with stakeholders, some of which were externally facilitated and local surveys. One local survey suggested that carers generally used shorter breaks (<24 hours), rather than longer ones. 34% of carers had used services providing a break from caring of 24 hours or less compared with 26% who had used breaks services lasting more than 24 hours. Reasons for not accessing services include concerns that the person they were caring for would refuse the service, the cost of services, information about services and the opportunity to choose a holiday rather than a conventional service. The quality of current services did not appear to be an issue. About half of the respondents indicated a willingness to use Direct Payments.

Survey respondents were asked first which services they had heard about. The 'most known' services were breaks purchased via the Carers' Personal Budgets scheme (48%) and residential respite organised by the council (46%). Respite at home services had a lower recognition rate (38%). The service with the lowest recognition was Adult Placement/Shared Care (5%).

Other questions asked about services actually used. 52% of respondents had used at least one of the breaks services. The most commonly-used services were breaks purchased via a Carers' Personal Budget (28%) followed by residential respite organised by the council, although at half of the level, 14%.

The group that had used breaks services had high satisfaction rates: 40% very satisfied and 46% quite satisfied, with most of the remainder opting for the middle rating of 'neither satisfied nor dissatisfied'. 40% of the service-using group said that they may have used other services if they had known about them.

The group of questions for carers who had not used services firstly asked respondents to identify which barriers to accessing services were significant to them: 22% said that not knowing about the services was an issue, but there were higher scores for concerns about cost (24%) and for the care recipient refusing respite (23%).

All respondents were asked whether they would be interested in using a Direct Payment to organise and purchase respite or other breaks: 49% said they would be, although more than a third of these carers said they would require help to use the

Direct Payment. The remaining half of respondents split almost equally between “I would not be interested” (24%) and “don’t know” (27%).

There are many barriers to accessing breaks, such as information and acceptability and cost. For Mansfield¹¹¹ the future focus of work to improve carer experience includes ensuring that ‘time off’ is adequately covered at the outset in the assessment of carers’ needs. It should also include the provision of information about breaks options, direct payments (and the support available to assist with using them) and charging. In addition, there needs to be increased collaboration with service users and carers to increase the acceptability of options to people with care needs.

These ideas are reinforced by the carers’ strategy for LLR, currently being updated. This states a vision for carers in Leicester, Leicestershire and Rutland in which:

- Carers are identified early on in their caring role
- Carers’ needs are identified early on and that early action is taken to support them in their role helping them to retain their independence
- Carers feel their contribution is recognised, that they are listened to and that their opinion is respected
- Carers have a meaningful contribution to the process of planning support and services
- Carers are supported to fulfil their educational and employment potential
- Carers can access personalised support to enable them to have a full life, both in their families and outside
- Carers are supported to remain mentally, emotionally and physically well
- Carers are supported to be independent and remain independent

In order to fulfil this with regard to carers of people with dementia, there needs to be flexible approach to respite care, in particular greater provision of respite in the home and access to personalised budgets. Carers will also benefit from the improvement of services along the dementia care pathway, in particular with the impetus towards memory assessment and early diagnosis, better communication with dementia care co-ordinators, better communication with primary and secondary care providers and a highly trained workforce providing health and social care in the community or in care homes.

Recommendation: All carers should have a carer’s assessment

Recommendation: Carers’ assessments should include information about breaks options.

Recommendation: There should be a wide variety of models of respite care tailored to individual needs and available to carers using personalised budgets.

9. Social Care

9.1 Role of social and community support in dementia care

Social and community support services are of great importance in the care of people with dementia. The services commissioned by the local authority may range from the provision of information to practical help such as domiciliary and respite care. This care is based upon an assessment of need. Since the 1990s there has been a concern that the resources which are available to local authorities are not sufficient to meet the needs of the population¹¹², and that this has contributed to the perception that there has been a decline in the quality of provision.

Liaison between NHS and local authority departments for the care of people with dementia has not always been effective. An underlying cause of this is the division between NHS care, free at the point of access, and social care provision. As social care is provided outside the NHS, often by local authorities and third sector organisations, charges often apply which are usually means tested. The variation of costs and service provision has also led to arguments about a 'post-code' lottery.

In the past this problem was sometimes resolved by long-stay hospital beds. In the mid-1980s old-age psychiatry services had on average 3.4 long-stay beds per 1000 population aged over 65¹¹³. However, changes in national policy have resulted in a shift and a decline in bed numbers, with beds now mainly available in nursing and residential homes.

Only 8% of nursing homes cater explicitly for older people with mental ill health. However, the prevalence of dementia in both residential and nursing homes is high, and hidden by poor rates of diagnosis. Darton¹¹⁴ reported that 67% of admissions to nursing and residential homes have significant cognitive impairment, although only 39% had been diagnosed as having dementia; 34% of all admissions displayed behaviour problems. Given such a high rate of undiagnosed dementia, there are likely to be many more cases in nursing and residential homes. In this context, and given the complexity of looking after a person with dementia, it is not surprising that surveys of homes in the UK suggest a wide variation in the quality of care¹¹⁵.

General criticism of those nursing and residential homes which are less satisfactory often centres on untrained staff, the inappropriate use of sedative medication, lack of properly structured activity programmes for residents, inadequate documentation and isolation from local communities. Care homes are regulated by the Care Quality Commission¹¹⁶ and advice in choosing a care home is offered on the NHS Choices website¹¹⁷. Sheltered housing may be available in some areas, but may not be suitable for people with nursing care needs.

The NICE-SCIE guideline suggests best-practice advice on the care of people with dementia and on support for their carers. It focuses upon the principles of person-centred care and asserts

- The human value of people with dementia, regardless of age or cognitive impairment, and those who care for them

- The individuality of people with dementia, with their unique personality and life experiences among the influences on their response to the dementia
- The importance of the perspective of the person with dementia
- The importance of relationships and interactions with others to the person with dementia, and their potential for promoting well-being.

The principles emphasise the imperative in dementia care to consider the needs of carers, whether they are family and friends or paid care-workers, and to consider ways of supporting and enhancing their input to the person with dementia. This is described as ‘relationship-centred care’ and is the focus of much of the developments in national policy guidance.

Overall, as with primary care, the challenge to provide better social care is to address the substantial gap between met need and expected need. Ideas as to how to meet this gap, which have emerged through analysis and consultation include:

- An integrated approach to meet the needs of older people with mental ill health
- A service specifically targeted at younger people with early onset dementia
- Better training for staff providing care to older people with dementia.
- Better service provision specifically designed to meet the needs of people with dementia (e.g. respite care or intermediate care).
- Better local authority residential and respite provision.
- Expansion of the range and capacity of services to support carers.
- Expansion of the service provision for BME older people with mental health needs
- Targeted provision to maintain engagement of people with dementia and their carers in the community
- Addressing the disproportionate investment in specialist resources compared to investment in lower level voluntary and community sector services to specifically support people with dementia and their carers.
- Addressing the limited capacity in the provision of specialist community mental health teams to undertake their educative and liaison roles.

9.2 Social and community support services in Leicester

Available evidence suggests that support services exist and are being accessed by people with dementia both at home and in residential accommodation. However, the numbers in receipt of care are below the expected prevalence of dementia.

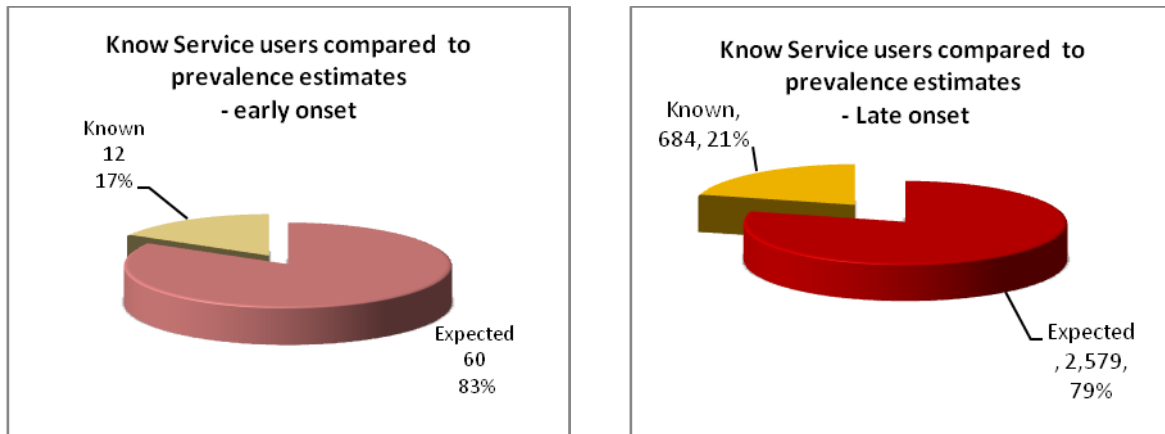
In Leicester nearly 1,600 people aged over 65 were receiving social care for Mental Health problems in 2010-11. 288 people over 65 years had completed social care assessments for mental health problems in that period. Of these, 97 (33%) were recorded as dementia¹¹⁸; this is less than 4% of the expected number of people estimated to have dementia in Leicester.

The Referrals, Assessments and Packages of Care statutory returns to central government show there were 255 living in Leicester with dementia receiving support from Adult Social Care in the year 2007/08, (240 People aged 18-64 and 11 people

aged 65 and over). The majority were receiving support to live at home. Again, this is far fewer than the expected number.

Carefirst records show that about 680 people with dementia received support in 2007/08. The majority of these were women and the largest proportion of social care support is for residential and home care. Those people in receipt of this are more likely to be from White/White British or Asian/Asian British ethnic backgrounds.

Figure 14: Dementia service users known to social care compared to expected prevalence



Given that only about 680 people with dementia are known to be in receipt of social care services, compared with approximately 2,700 people with dementia living in Leicester, there is a substantial gap. Whilst those who are not receiving care may be accessing support from the voluntary sector or paying for themselves, the fact remains that there is a large proportion of unmet need. This gap is likely to increase with the ageing population.

Table 9.1, below, shows that the demand for services differs by ethnicity and, in consequence, the demand for services could change as the proportion of older people from BME background in the local population increases.

Table 9.1: Current provision of service to users with Dementia by ethnicity

Ethnic group	Services	Clients	% of demand	% of ethnic demand
Any Other Ethnic Group	Resid. Care - Lt	2	0.29%	0.29%
Asian/Asian British Ethnic Backgrounds	Day Services / C.S.S	8	1.17%	16.33%
	Direct Payments	1	0.15%	2.04%
	Family Carer Respite	1	0.15%	2.04%
	Home Care	28	4.09%	57.14%
	Mobile Meals	1	0.15%	2.04%
	Nursing Care - Lt	5	0.73%	10.20%
	Resid. Care - Lt	5	0.73%	10.20%
Black/Black British Ethnic Backgrounds	Day Services / C.S.S	5	0.73%	31.25%
	Home Care	5	0.73%	31.25%
	Mobile Meals	2	0.29%	12.50%
	Nursing Care - Lt	2	0.29%	12.50%
	Resid. Care - Lt	2	0.29%	12.50%
White/White British Ethnic Backgrounds	Day Services / C.S.S	43	6.29%	6.97%
	Direct Payments	3	0.44%	0.49%
	Extra Care	5	0.73%	0.81%
	Family Carer Respite	19	2.78%	3.08%
	Home Care	205	29.97%	33.23%
	Interim Res Care	2	0.29%	0.32%
	Mobile Meals	27	3.95%	4.38%
	Nursing Care - Lt	66	9.65%	10.70%
	Professional Support	1	0.15%	0.16%
	Resid. Care - Lt	239	34.94%	38.74%
	Resid. Care - St	7	1.02%	1.13%

9.3 Personalisation

In those cases where people require ongoing support there are a number of services available, depending on the level of the individual assessed need. Services are aimed at supporting an individual to live as independently as possible, for as long as possible. There are some care options available to support people with dementia and their carers, of which perhaps the most important is personalisation.

This needs assessment has shown that Personal Budgets were introduced as part of the National Personalisation Agenda in adult social care. These budgets aim 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 managed services. It means 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 to help make sure services become more personalised and to get the right results for people.

- **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.
- **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.
- **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.
- **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.

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.

There is a national drive that by 2013 all individuals accessing support from social services 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.

Leicester City Council has implemented Self Directed Support, with all new service users accessing personal budgets and existing users transferring following a review. It also has an established reablement service with health and social care input. The service provides intensive free care and support for 4 to 6 weeks; aimed at enabling a person to regain and maintain their independence. The objective 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 under pinned by joint commissioning arrangements, joint working arrangements and a joint investment plan.

Recommendation: 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.

9.4 Other services in the community

One of the benefits of early diagnosis is that there in place there is that those people who have been newly diagnosed with dementia, and their carers, will receive written and verbal information about their condition, treatment and support options. This will also give people with dementia the opportunity to discuss and make decisions, together with their carers, about the use of advance statements, decisions about treatment, priorities of care and power of attorney¹¹⁹. To facilitate this a number of different initiatives, provided under the umbrella of social care, should be better incorporated into the patient pathway.

In Leicester the Dementia Care Co-ordinators have a role in providing advice and support to people with dementia and their carers. There are currently 8 dementia care co-ordinators, following the successful one year pilot in which one co-ordinator looked after the needs of 179 people. Of the 8 co-ordinators currently in post, 6 are based in localities, with the other co-ordinators focusing on re-ablement and the single point of access to the service. The co-ordinator role is to improve the quality of life for people with dementia and their carers by providing links to information and support, resources and partnership working with available services. The co-ordinators provide advice on assistive technology and social support throughout the disease process.

In the pilot year they were particularly successful in liaising with the current memory assessment service, although links with primary care were disappointing. Yet, in a service in which early diagnosis is the key, there is a clear role for communication about advice and support. The dementia care co-ordinators are essential to the delivery of practical information to help and advise people with dementia and their carers.

Recommendation: The dementia care co-ordinators should be commissioned solely to work with people with dementia and their carers. Their role should be to provide advice and support across the patient pathway. Access to the service should be from a number of points, including self-referral, voluntary sector, primary, secondary and social care. To engage better with primary care, there should be closer links between dementia care co-ordinators and GPs in their different localities.

In Leicester the memory cafe offers the opportunity for people to discuss issues around dementia as well as getting peer support and professional advice. It is planned that the cafes will feature discussions or speakers on topics such as benefits and assessments, keeping safe in the home and dealing with the emotional impact of dementia. They are free to attend and carers are welcome to come along either on their own or with care recipient.

Currently there is one café, based at Eyres Monsell Community Centre, though future venues are planned at African Caribbean Centre in Highfields, Belgrave Neighbourhood Centre and New Parks Community Centre.

Assistive Technology is provided by Leicester City Council following an eligibility assessment by Adult Social Care. The technology can be a piece of equipment or a service that can enable a range of people to remain independent and safe in their own homes, by helping them to manage risks or making it easier to fulfil activities of

daily living. It can help people to remain independent by reminding them to take medication, allowing safer cooking, helping people to keep in touch and alerting emergency services more quickly. The full list of solutions includes a picture phone, voice alarm reminders, a falls detector gas and smoke sensors¹²⁰.

9.5 Care delivered in residential and nursing care homes

There are 108 care homes in Leicester; most appear to have some residents with dementia, although 58 are listed as doing so according to www.carehome.co.uk. Some of the residents will never have been diagnosed with dementia. Improved care in nursing and residential homes is crucial to the development of an improved dementia care pathway.

Past evidence suggests that despite dementia care being a core function of the health and social care workforce, formal care services are struggling to deliver good quality dementia care; identifying the lack of an informed and effective workforce. *Home from home*¹²¹ found that staff members in many care homes do not have the skills required to provide good quality dementia care. It is vital therefore for the commissioned services to include a range of quality standards, such as those presented by the Care Quality Commission and NICE and the local LLR wide Dignity in Care Programme.

The standards which need to be met are at least that people with dementia should have an assessment and ongoing personalised care plan, that they receive care appropriate to their needs, including palliative care and care for anxiety which may be caused by non-cognitive symptoms. There are different mechanisms which may be used to try to meet these standards.

The Quality Assessment Framework (QAF) is a commissioning tool which aims to improve quality care. It may be used to ensure that care recipients have an assessment of their support needs and any associated risks, that they have an up-to-date support and risk management plan and that their care managed by skilled staff and involve other professional carers as appropriate.

Another lever for improving the care delivered in care homes, adopted by the local strategic work streams, is to focus on the development of the local workforce to meet the training and skills of the local service providers, as laid out in the objectives of work stream 5 of the LLR Joint Commissioning Group. This is important because national focus group evidence shows how people with dementia and carers viewed the care which they received from nurses. Some evidence is highly critical:

“They stand at the bottom all laughing at you....And I didn’t take that....People laugh at people with Alzheimer’s but you don’t expect nursing staff to.”¹²²

The themes in this particular focus group evidence also included the need for dignity and respect, person-centred care and communication. Again the feedback is testimony of the difficulty in caring for someone with dementia. For instance, carers speaking about the toileting needs of someone with dementia:

“In this particular home they change their pads at certain times of day, i.e. morning, lunchtime, afternoon 4pm and eve. But not everyone needs to be changed at the same time. I got shouted at by one of the carers; ‘she was changed at lunchtime’. May well have been, but she’s dirty now. These people are not in care homes for a week, but have often been in there 12 or 15 years. So surely she can be changed not by the clock but by need. But you can’t keep going to the nurses as they don’t listen.”¹²³

Recommendation: All nursing and residential home staff should have training about the needs of people with dementia and their carers appropriate to their role in the Dementia Care Pathway.

Another important approach, and one which is part of the *National Dementia Strategy* implementation programme, is to develop a service to support care homes to provide better care. The aim of this would be to provide specialist dementia expertise to give advice and support in primary care for better assessment and management of people with problematic symptoms of dementia and other complex presentations. More timely appropriate interventions should enable people to remain at home for as long as this is their preferred place of care and could reduce the number of unplanned admissions and readmissions to hospital. The potential outcomes for improved community based services could be:

- Reduction in the use of antipsychotic medication for people with dementia in care homes, at home and other residential settings
- Contribute to a reduction in unplanned admissions and readmissions of people with dementia to general and community hospitals from care homes, home and from other residential settings
- Increased patient and carer satisfaction

This specialist dementia service would be designed to provide sufficient capacity and skilled resources to advise and support primary care practitioners in the treatment, care and management of people with problematic symptoms of dementia or other complex presentations, whether they are living at home, in care homes or other residential settings. It could work with relevant health and social care organisations to ensure that service protocols are in place to raise awareness of the service and to deliver a seamless service for patients. Relevant services would include GPs and primary health care teams, other community health services, acute care, including hospital discharge planning services, memory assessment services and voluntary organisations. During care home visits, it would be expected that the service provider will take all opportunities to model good standards of care and ensure knowledge transfer of good practice with care home staff.

Recommendation: There should be a specialist community care team to assess the needs of people with dementia living at home or in care homes. This team will advise carers and other local health and social care providers about the assessment and management interventions for patients with problematic symptoms of dementia.

10. Secondary Care

People with dementia who are physically ill may require acute in-patient care in a general hospital. The care for those people, who have dementia and a physical health problem, often by necessity, occurs on wards where there are patients who do not have dementia. In some areas there has been a focus on augmenting the geriatric medical team with clinicians who have mental health experience.

It is interesting to note that, compared with older people in general the rate of cognitive impairment is raised among elderly patients admitted to acute hospital¹²⁴. Cognitive impaired patients are often admitted with delirium, or become delirious while in hospital. They have, on average, a significantly longer hospital stay than other patients of the same age¹²⁵, and they have a less favourable prognosis¹²⁶. Despite the high prevalence of cognitive disorders in the elderly, past evidence suggests that clinicians are often unaware that a problem exists unless the patient's behaviour is disturbed¹²⁷.

This is a common problem nationally; for the mental health needs of older people often remain undetected, with the result, in some cases, that appropriate treatment is not initiated¹²⁸. The NAO found that some general hospital services even worked hard not to make a diagnosis of dementia for fear it would delay discharge.¹²⁹ Failure to diagnose dementia is an independent predictor of a poor outcome for the patient and for the service.

People with dementia often have complex problems and may stay in hospital for longer than other people who go in for the same condition. There is often a lack of co-ordination between the hospital and care providers at the point of discharge. The longer length of stay may worsen symptoms of dementia and be detrimental to the individual's well-being. Discharge to a long-term residential care home becomes more likely and antipsychotic drugs are more likely to be prescribed¹³⁰. The dementia commissioning pack suggests that although there are examples of good quality general hospital care, where the challenges of dementia are recognised and addressed, there are also widely reported cases of substandard or neglectful care¹³¹.

10.1 Emergency inpatient admissions for dementia at UHL

There are relatively few hospital admissions with a main diagnosis of dementia; in 2010-11 there were 143 admissions, equivalent to around 40 per 10,000 over 65s, which is an increase on the previous 2 years.

These admissions had an average length of stay of over 40 days with approximately 25% discharged within a week (13% within 1 day, and 12% within 2-6 days), 25% discharged between 1 week and 28 days, and 50% staying in hospital for over 28 days.

Table 10.1: Emergency hospital admissions with a main diagnosis of dementia for Leicester residents

Year	2008-09	2009-10	2010-11
Bed days	4488	3795	5761
Average Length of stay	45.4	42.0	41.8
Emer adms for dementia	109	102	143
Population 65+	35665	35676	35639
Crude rate per 10,000 65 year olds	30.6	28.6	40.1

Data: Hospital inpatient dataset, Secondary uses Service

There were around nine times more hospital admissions with any diagnosis of dementia (main or secondary diagnosis) than for dementia as the primary cause. Where dementia was a secondary diagnosis, around a quarter of the admissions were due to 'Symptoms and signs', 18% due to injury and poisoning, 14% due to respiratory conditions and 8% cardiovascular conditions.

Table 6.2: Emergency hospital admissions with any diagnosis of dementia for Leicester residents

Year	2008-09	2009-10	2010-11
Bed days	16087	16813	21289
Average Length of stay	16.6	14.9	15.6
Emer adms for dementia	907	1055	1246
Population 65+	35665	35676	35639
Crude rate per 1,000 65 year olds	254.3	295.7	349.6

Data: Hospital inpatient dataset, Secondary uses Service

Figure 16: Primary diagnosis of admissions with any diagnosis of dementia for Leicester residents

Primary diagnosis code	Primary diagnosis description	Adms 2010-11
S72	Injuries to hip, thigh	1008
N39	Other disorders of urinary system	680
J18	Influenza and pneumonia	468
S01	Injuries to head	330
S00	Injuries to head	260
G40	Epilepsy	231
F00	Dementia in Alzheimer's disease	225
S52	Injuries to elbow, forearm	200
R07	Pain in throat and chest	162
R54	Senility	152
		3716

Data: Hospital inpatient dataset, Secondary uses Service

10.2 Emergency Department attendances for dementia

Emergency department (ED) data does not have completed coding for diagnosis, so it is difficult to estimate the number of people attending ED through dementia-related causes. However, it is possible to determine inpatients admitted through ED.

Recommendation: Commissioners should find ways of obtaining more effective coding of the attendance of patients with dementia at the emergency department.

10.3 Secondary care and the dementia care pathway

The importance of general hospital care to the dementia patient pathway has been further emphasised by work undertaken in a recent survey of patients at UHL. As part of this survey¹³², for a 10 week period between February and April 2011, all patients attending the Acute Medical Unit (AMU) at the Leicester Royal Infirmary, aged 70 or over, were assessed for frailty using the local operational definition of frailty and the Rockwood Frailty Score, enabling assessment from the very fit through to those who are severely frail.

Overall, 2,425 people were admitted to the AMU during the 10 week study period, of whom 1,165 (48%) were 70 years or older. It was found that frail people¹³³ comprise approximately 3% of all Emergency Department attendees at any one time, 10% of all patients on the AMU, and approximately 50% of patients on base wards within UHL^{134 135}.

Of those aged >70, 843 individuals were assessed representing 898 separate admissions, some patients having attended on more than one occasion. The mean age was 83.0 years (95% CI 82.5-83.4) and 378 (42.9%) were male. As the survey sought to estimate the prevalence of frailty, individual episodes rather than individual patients were assessed. The UHL frailty criteria characterised 61% of patients as frail and 58% of people had delirium or dementia.

Such a high prevalence of frailty, delirium and dementia in a general hospital setting suggests that there is a case for the development of a multidisciplinary liaison service offering both mental and physical health expertise. The development of a liaison service could provide a standard approach to the assessment and recording of cases. It will also pick up on expertise at UHL for the assessment of a delirium risk assessment tool, which has been developed in partnership with the East Midlands HIEC and De Montfort University.

Such specialist liaison services are advocated both in the national dementia strategy and in NICE/SCIE guideline on dementia¹³⁶ as ways of

- Providing support and advice on making the diagnosis of dementia and other mental health conditions

- Providing support and advice on management and care planning, including discharge planning for people with confirmed or suspected mental health problems and behavioural management problems
- Contributing to education and training for hospital staff
- Contribute to the governance, audit and development of policies and procedures for good quality health care.

Recommendation: To develop an integrated service comprising mental and physical health care expertise to provide a standard approach to the assessment and recording of an older person's mental health status upon admission to secondary care.

This integrated service is already being developed, for as part of the 2011/12 Transformation Fund Project, called Frail Older People's Initiatives (Interface Geriatrics), the Frail Older People's Advice and Liaison Service (FOPAL) merged with mental health services for older people with the intention of forming a comprehensive liaison service.

Since the transformation funded FOPAL development, the dementia case finding CQUIN, highlighted in the Prime Ministers Challenge on dementia, has been introduced. FOPAL appears to be ideally placed to contribute to awareness about, and diagnosis of, dementia in the many people who attend secondary care with dementia without a confirmed diagnosis.

The service could provide the necessary expertise to implement a systematic approach to assessment and recording of dementia cases, without which there will continue to be under reporting of the numbers of people living with dementia accessing general hospital care. Between November 2011 and April 2012 907 FOPAL had 907 patient episodes; 401 patients had dementia, of whom 255 required a new diagnosis. Of the 401 patients seen 133 (33%) were referred to the older persons community mental health team, 30 (7%) were transferred to LPT in-patients and 238 (59%) required no further input.

It is important therefore to commission a liaison service combining credible physical and mental health clinical expertise to assess patients with physical health needs and cognitive impairment in both inpatient and outpatient settings. This service should have effective links to memory assessment services, older persons' mental health services and primary care.

The links with primary care are essential, to ensure that any newly diagnosed cases of dementia are added to the register and that the GPs are involved in rationalising prescribed medication and signposting people to support services as soon as possible. Such a multi-disciplinary approach should also improve service user and carer experience of services, ensure that people with dementia are treated appropriately and, with shared care protocols, will also contribute to the diagnosis of people with dementia and ensure that people with dementia have access to appropriate treatment.

There is further evidence to suggest that, if such a service was properly commissioned, there would be an impact on factors such as hospital admissions and

a patient's length of stay in hospital care. Over the past 3 years, in UHL, the average length of stay for someone with dementia has been measured as 10.98 days. People with dementia have not been routinely called back to review their cognitive status. It is envisaged that if a multidisciplinary team is commissioned, so that it can assess the cognitive status of the frail elderly patient in outpatient settings it will reduce length of stay. Additional benefits should include a reduction in the number of people discharged to care homes as a new place of residence, a reduction in the prescription of anti-psychotic medication and better experience for patients and carers.

Recommendation: The multi-disciplinary hospital liaison service should incorporate credible mental and physical health expertise to assess the needs of frail older people. This team will facilitate detection of dementia in hospitalised group of patients, by reviewing them, prioritising patients' needs and reduce the length of stay of patients with cognitive issues. Patients diagnosed by the team should be added to the dementia register held in primary care

10.4 Older persons' mental health in-patients

In addition to secondary care in general hospitals, the NHS across Leicester, Leicestershire and Rutland currently commissions 80 in-patient assessment and treatment beds from LPT, located at the Evington Centre. This in-patient facility is designed for people aged over 65 years with organic mental health problems, and are predominantly used by people with dementia. In 2009/10 there were 315 admissions to these beds with an average length of stay of 68 days. The primary reason for admissions related to family/carer breakdown, which contributed to 42% of the total number of admissions. Family/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

There is a need for commissioners to review the high proportion of discharges to care homes, and a need for more information from this particular secondary care service. It is important that further analysis is undertaken to review the outcomes from these episodes of care and to record the care cluster of the person admitted.

Recommendation: That in-patients and discharges at LPT are analysed, under the new payment by results tariff in mental health services, to 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.

10.5 Staff training needs

In *Counting the cost*¹³⁷ the Alzheimer's Society explored the quality of dementia care provided in general hospitals and surveyed people with dementia, carers and nursing staff. The report found that carers were dissatisfied with the overall quality of dementia care provided, that people with dementia are staying in hospital far longer than other people who go in for similar procedures and that when individuals do leave hospital they have deteriorated in terms of their physical health; they were often malnourished, dehydrated or constipated. It was also found their dementia had progressed whilst they were in hospital, in that they were more confused and distressed and more dependent.

As with other areas, therefore, there is a need to raise awareness about dementia in secondary care and the training needs of all people involved in secondary care should be considered. The *Alzheimer's Society* report found that only 12% of nurses felt that they had enough pre-registration training in dementia, 76% of nurse managers said that the fact that nursing staff had not been given pre-registration training in dementia was a key challenge in providing good dementia care.

Recommendation: Members of the secondary care team, including reception staff, should receive appropriate training to respond appropriately to people with dementia and their carers.

11. Community health care for people with dementia

This element of the patient pathway is linked to general practice and social care. For primary care for people with dementia also includes input from community psychiatric nurses (CPN), district nurses, and community matrons; these services are now provided by LPT, and they are commissioned by local NHS. The services also include intermediate care provision, which is defined as a short term intervention limited to 6 weeks, which are now provided by LPT in conjunction with Leicester City Council, and commissioned by NHS Leicester City and Leicestershire County and Rutland.

District nursing and community matrons look after physical health care needs, and are likely to be involved in dementia care only if the person with dementia or their carer has a physical health requirement. This important nursing resource is also likely to be particularly important in the delivery of end of life care.

Intermediate care aims to support people on discharge from hospital, before they are able to go home, and also to avoid hospital admissions. 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; a strange environment can exacerbate the symptoms of confusion associated with dementia, the Intermediate Care teams do not necessarily have support of a CPN and access to some community hospital beds is inconsistent.

In Leicester there are two facilities available to 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. As 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, this service is perhaps most appropriate for people in the earliest stages of dementia.

Although there are intermediate care and re-ablement services across LLR for both health and adult social care, the care pathways are not joined up, sometimes resulting in pressure 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/carers.

Recommendation: To ensure that there is an integrated reablement and integrated care model that reflects the needs of people with dementia.

The Community Mental Health Teams for Older People are provided by LPT and Leicester City Council. In Leicester there are 2 Community Mental Health Teams (CMHTs) offering a multi-disciplinary assessment and treatment service for older people with complex mental health needs. Thus this 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, reduce the need for an admission to hospital and recovery following admission, and aims to reduce admission into residential and nursing care.

The health and social care staff also collaborate in supporting people with dementia and their carers in the community. As the teams incorporate social workers, occupational therapists, and mental health expertise, they are able to support people with behavioural symptoms which result from dementia.

The community mental health care service also includes the Integrated Clinical Assessment and Treatment Service (ICATS), which is provided by LPT and commissioned by NHS Leicester City and Leicestershire County and Rutland.

The ICAT 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 CMHTs 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/carers.

Recommendation: Review the existing ICATS model of delivery, to develop a service focused on preventing admission to the older person's mental health inpatient wards, and facilitate timely discharge from in-patient care.

Recommendation: Review the options for commissioning a joint health and social care crisis response service, to support both users and their families/carers.

12. Medication for Alzheimer's disease

12.1 Medication in Alzheimer's disease

As there is no cure for Alzheimer's disease, current medication focuses on treating symptoms. This medication does not aim to slow the progression of the disease, but Drugs may be prescribed to dementia patients to slow the rate of cognitive decline. Acetylcholinesterase inhibiting drugs are used in the treatment of Alzheimer's disease, specifically for mild to moderate disease. The benefit is assessed by repeating the cognitive assessment at around 3 months.

The treatment of Alzheimer's disease includes three acetylcholinesterase (AChE) inhibitors donepezil, galantamine and rivastigmine, which are recommended as options for managing mild to moderate Alzheimer's disease, and memantine, which is recommended as treatment for those with severe Alzheimer's disease or as an option for managing people with moderate disease who are intolerant of or have a contraindication to AChE inhibitors.

Currently there are special conditions in which such treatment should be used, and these including:

- Treatment should only be initiated by specialists in dementia care. These include psychiatrists, such as those specialising in learning disability, neurologists, and physicians specialising in the care of older people.
- The continuation of this treatment should be considered only if it is seen to be having a worthwhile effect on a person's cognitive, global, functional or behavioural symptoms.
- Patients who continue on treatment should be reviewed regularly using a cognitive, global, functional and behavioural assessment.
- Unless there are locally agreed protocols for shared care this treatment should be reviewed by an appropriate specialist team.
- Carers' views on the patient's condition should also be sought at the time of the baseline and follow up assessments.

The latest NICE technical guidance suggests that if an AChE inhibitor is prescribed then the drug with the lowest acquisition cost, taking into account the daily dose and the price per dose once shared care has started, should be the first course of treatment (the costs of treatment are presented in Appendix 13). However, an alternative AChE inhibitor could be prescribed if it is considered appropriate, based on clinical judgements such as adverse events, adherence, medical co-morbidity, the possibility of drug interactions and dosing profiles.

Clinicians are encouraged to use a range of appropriate evidence to assess a patient with Alzheimer's disease and the need for treatment. This includes cognition scores, assessments of any physical, sensory or learning disabilities, and communication difficulties. Clinicians are also encouraged to be mindful of the need to secure

equality of access to treatment for patients from different ethnic and cultural backgrounds and make any adjustments that they consider to be appropriate.

12.2 AChE inhibitors

Of the three treatments for mild to moderate Alzheimer's disease, Rivastigmine (Exelon) and Donepezil (Aricept) are AChE inhibitors which work by increasing the concentration of acetylcholine at sites of neurotransmission. Galantamine (Reminyl) is an AChE inhibitor, which works both by increasing the concentration of acetylcholine at sites of neurotransmission and modulates activity at nicotinic receptors.

The NICE guidance committee considered evidence from randomised controlled trials that these medications are effective when compared to a placebo. For instance, trials with Donepezil and Galantamine showed a statistically significant difference in their favour versus placebos. For both Donepezil and Galantamine there were trials which reported statistically significant benefits to patients when cognitive scales were used. A Cochrane review concluded that high doses of Rivastigmine offered statistically significant benefits in patients with mild to moderate Alzheimer's disease versus placebo.

A key driver of cost effectiveness in the NICE Guidance was treatment which leads to a delay in institutionalisation. According to the guidance, the evidence suggested AChE inhibitors offer benefits over best supportive care for cognitive, functional and global outcomes, and may offer some benefit in behavioural outcomes, although the nature and extent of behavioural benefits are uncertain. When compared with best supportive health and social care each of the AChE inhibitors showed a cost saving.

12.3 Memantine

The fourth treatment, Memantine (Ebixa) is recommended as an option for managing Alzheimer's disease for people with moderate Alzheimer's disease who are intolerant of or have a contraindication to AChE inhibitors, or for people with severe Alzheimer's disease. It is an N-methyl-D-aspartate (NMDA) receptor antagonist that blocks the effects of pathologically elevated tonic levels of glutamate that may lead to neuronal dysfunction. It is in effect a glutamate moderator. One of the reasons

The NICE Guidance Committee considered the results of randomised controlled trials for Memantine and concluded that it offers symptomatic benefit in cognitive, functional, global and behavioural outcomes, although the size of this benefit is uncertain. It also looked at evidence for the clinical effectiveness of Memantine as an adjunct to AChE inhibitor treatment but noted that there was no statistically significant benefit for combination treatment with Memantine and AChE inhibitors for cognitive, functional, behavioural or global outcomes.

Antipsychotic medications (also known as neuroleptics or major tranquillisers) are also used for the treatment of restlessness, aggression and psychiatric symptoms in people with dementia. Clinical trials suggest that this type of drug can reduce aggression and, to a lesser extent, psychotic symptoms over a period of three months. However, there is no evidence that these drugs improve restlessness or

other non-aggressive behavioural symptoms^{138 139}. Clinical trials show that the benefits are very limited over longer periods¹⁴⁰ and that such medication can be safely stopped after three months, with no worsening of behavioural symptoms in most people¹⁴¹. The two drugs with the best evidence of effectiveness are Risperidone and Aripiprazole^{142 143} of which Risperidone, has been licensed specifically for the treatment of severe and persistent aggression in people with Alzheimer's disease that have not responded to other therapies. However, clinicians say that the use of some anti-psychotic medication is essential for some people with dementia. There is no evidence of any beneficial effects of antipsychotic medication for the symptoms of people with dementia with Lewy bodies, and there are currently no clinical trials looking at these drugs in people with vascular dementia.

There is an impetus to reduce the number of people with dementia who have been prescribed anti-psychotic medication. In particular, the use of Memantine for cases of moderate to severe dementia may enable this to happen, although there is a risk to prescribing budgets. As Memantine is a glutamate moderator, it may protect neurological functions and improve behavioural symptoms. The latest NICE technical guidance suggests therefore that Memantine will be the first line treatment to manage the behavioural symptoms associated with some dementias.

12.4 Cost of dementia medication in Leicester

The cost of prescribing drugs for dementia shows a general upward trend over the time period 2008-09 to 2010-11. As the treatments should currently only be initiated by those who specialise in dementia care, the costs are attributed to the memory assessment service, with a limited amount currently in primary care. Table 12.1 below show the quarter spend on medication for Alzheimer's disease for 2010-11. The total spend for the period was £385,924.29 for 2048 patients.

Table 21.1: Cost of prescribing drugs for dementia

2010-11	Quarter 1			Quarter 2			Quarter 3			Quarter 4		
	No. of Patients	No. of Items	Actual Cost	No. of Patients	No. of Items	Actual Cost	No. of Patients	No. of Items	Actual Cost	No. of Patients	No. of Items	Actual Cost
Donepezil	95	124	£22,584.01	94	125	£24,388.74	86	120	£20,440.55	81	108	£21,604.39
Galantamine	277	381	£47,840.17	286	393	£53,308.93	297	447	£54,699.00	308	436	£60,383.31
Memantine	53	83	£12,541.11	56	79	£11,678.51	65	103	£17,033.66	83	102	£18,460.85
Rivastigmine	25	38	£5,320.15	24	35	£6,019.25	21	31	£4,794.32	21	25	£4,827.34
Totals	450	626	£88,285.44	460	632	£95,395.43	469	701	£96,967.53	493	671	£105,275.89

13. Future direction for commissioning dementia care

Commissioning dementia services is a rapidly developing area, with many national commitments offering opportunities for the development of effective interventions. The new services are centred upon primary care, with the improvement in rates of diagnosis part of the NHS Outcomes Framework. This JSpNA has shown that the future direction includes:

Increasing rates of diagnosis: The commissioning challenge for the Clinical Commissioning Group is to ensure that primary, secondary and specialist dementia health care have a recognised role in the diagnosis of dementia and that the diagnosis is effectively communicated to primary health care as the holders of the registers of people with dementia and their carers.

Deciding where the diagnosing takes place: This issue relates to the best use of expertise in memory assessment and secondary care, and the capacity of primary care services to be involved in early recognition. The costs of treatment should become clearer with the move to payment by results in mental health care.

Ensuring that there is a credible patient pathway following diagnosis; The future direction here is for health and social care commissioners to work closely together to build a patient pathway which offers quality care and credible support for care recipients and their carers. This should reduce the costs of acute hospital care and care home admission and

Appropriate prescribing: Commissioners will need to work with primary, secondary and specialist care areas to review patients' medication and to reduce the inappropriate prescribing of anti-psychotic medication. They may be able to use CQUIN schemes to do this.

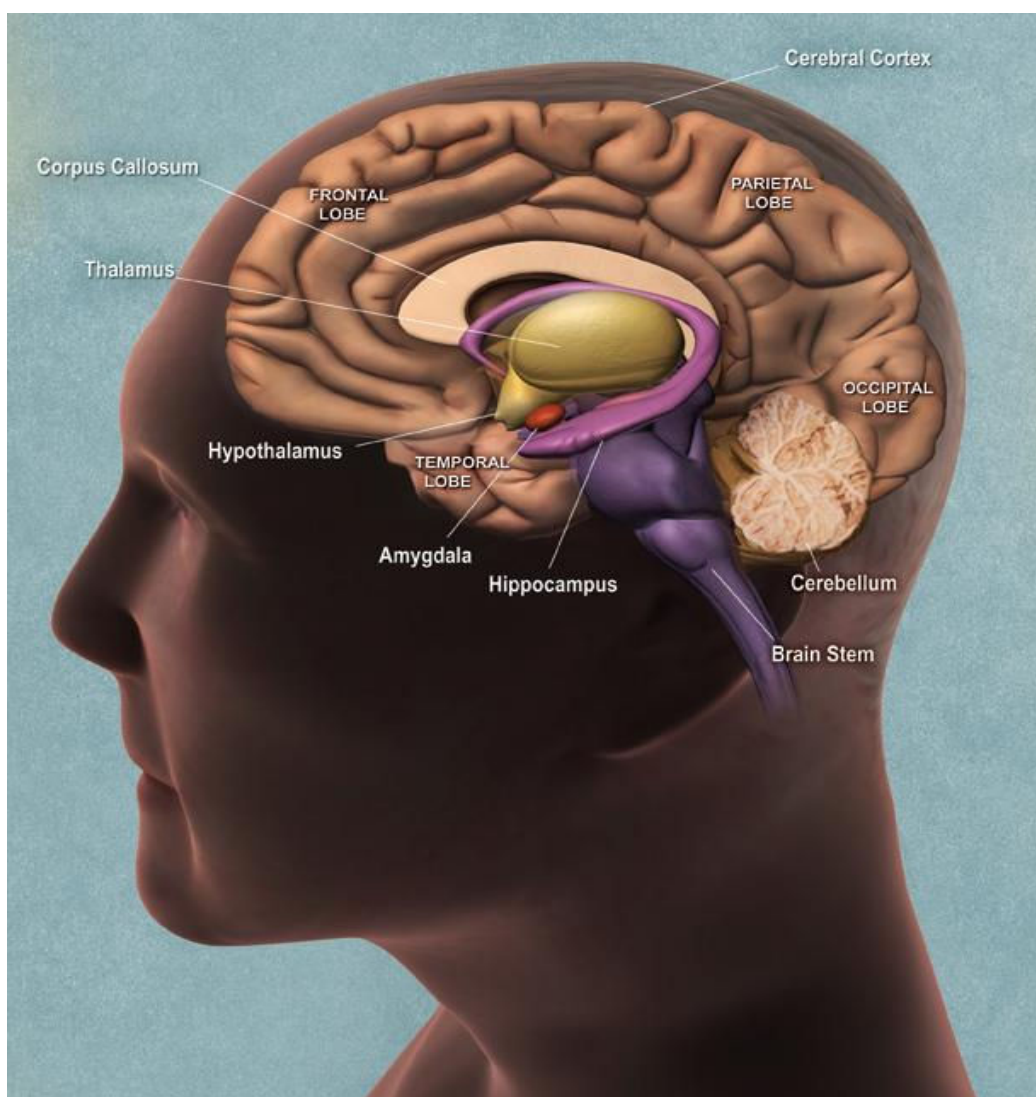
Ensuring that the dementia care workforce is able to deliver high quality care: As the care of people with dementia has an impact across many different health and social care services, it is crucial that the workforce is trained in the common core principle for supporting people with dementia.

14. Appendices

14.1 Appendix 1: The brain

Dementia is one of many disorders which affect the brain and central nervous system. Changes, related to normal ageing, occur in the brain as a person gets older¹⁴⁴. These changes may mean that there is a slight decline in an older person's ability to learn new things or remember information. However, the changes which are related to dementia are more severe.

Figure 1: Lateral view of the human brain¹⁴⁵



Blood supply to the brain must be continuous. Although the brain constitutes about 2% of the human body, it uses about 20% of the oxygen supply¹⁴⁶. Any interruption of the supply of blood to the brain is likely to result in unconsciousness. The blood supply to the brain also contains glucose for energy. If the blood circulating to the

brain is low in glucose then confusion, dizziness, convulsions and unconsciousness may result.

The cerebral hemispheres account for most of the weight of the brain. They are principally connected by a bundle of transverse fibres called the corpus callosum. The left hemisphere helps a person to focus on details, such as face recognition, whilst the right is concerned with broad background, such as the relative position of objects in space.

Each cerebral hemisphere is subdivided into four lobes by fissures; the lobes are also related to different functions. The frontal lobe controls functions such as memory, thought, organisation and movement. The parietal lobe is linked to perception and sensory information; the occipital lobe is concerned with vision and the temporal lobe, with smell, taste and sound.

The cerebellum is divided into hemispheres and lobes. It is widely accepted to be a motor area of the brain¹⁴⁷, concerned with certain subconscious movements in the skeletal muscles. These are movements which are required for co-ordination, maintenance of posture and balance¹⁴⁸. Recent studies have also suggested that the cerebellum is important area for a person's emotions¹⁴⁹.

The brain stem consists of the medulla oblongata, pons varolii and the midbrain. The lower end of the brain stem is a continuation of the spinal cord. It controls those functions which keep a person alive, such as the heart rate and breathing. The medulla oblongata conducts motor and sensory impulses between the brain and the spinal cord. It contains the nuclei of origin for several pairs of cranial nerves concerned with hearing and balance, swallowing, salivation and taste. The pons varolii acts as a bridge between different parts of the brain and the brain and spinal cord. It also contains the nuclei for paired cranial nerves related to chewing and for the sensations of the head and face. The midbrain helps to relay auditory and visual information, and there are portions of the midbrain, called the red nucleus and the substantia nigra, which are involved in the control of body movement.

The main structures of the diencephalon are the thalamus and the hypothalamus. The thalamus is a structure above the mid brain in which some sensations, such as pain, temperature and pressure are interpreted. The hypothalamus is a structure below the thalamus which is related to the internal regulation of the body, homeostasis. It controls and integrates the autonomic nervous system (which is linked to functions such as heart rate, digestion, contraction of the urinary bladder); it is the link between the nervous system and the endocrine system; it is associated with feelings of rage and aggression; it controls normal body temperature; it regulates food intake and produces the sensation of thirst.

The thalamus and hypothalamus are also linked to the limbic system. This system connects the brain stem and the cerebral cortex. It controls emotional aspects of behaviour which are linked to survival, such as pain, pleasure, docility, sexual feelings and affection. Other components of the limbic system include the hippocampus, which is important for short term memory and learning, and the amygdaloid nucleus which is linked to fear.

Neurons are composed of a cell body, the axon, and dendrites. Neurons communicate with each other through axons and dendrites. Once at the end of an axon the signal reaches a synapse, a gap, which is overcome either by an electric impulse or a chemical messenger, called a neurotransmitter. There are over 40 transmitter substances in the brain¹⁵⁰.

Acetylcholine (ACh) is a transmitter released by neurons throughout the body. As long as it is present at the junction between a muscle and a nerve it can stimulate or excite a muscle fibre almost indefinitely. The transmission of a continuous succession of impulses by ACh is prevented by an enzyme called Acetylcholinesterase (AChE) or cholinesterase. There is evidence that a deficiency in ACh is linked to dementia¹⁵¹.

Other neuro-transmitters have been found to have an association with different illnesses. Dopamine is a transmitter which leads to excitation, emotion and subconscious movements of skeletal muscles. Neurons containing dopamine are located in the midbrain. In Parkinson's disease the neurons which release dopamine have been found to have degenerated. Serotonin is a transmitter, concentrated in the brain stem, the production of which leads to excitation. It is known to modulate mood, emotion, sleep and appetite and thus is implicated in the control of numerous behavioural and physiological functions. Decreased transmission of serotonin is thought to play a key role in the aetiology of depression¹⁵².

14.2 Appendix 2: National Dementia Strategy Objectives

1. Raise awareness of dementia and encourage people to seek help

Public and professionals will be more aware of dementia and will understand dementia better. This will:

- Help remove the stigma of dementia
- Help people understand the benefits of early diagnosis and care
- Encourage the prevention of dementia
- Reduce other people's fear and misunderstanding of people with dementia

2. Good-quality, early diagnosis, support and treatment for people with dementia and their carers, explained in a sensitive way

All people with dementia will have access to care that gives them:

- An early, high-quality specialist assessment
- An accurate diagnosis which is explained in a sensitive way
- Treatment, care and support as needed after the diagnosis
- Local services which are able to see all new cases promptly

3. Good-quality information for people with dementia and their carers

- People with dementia and their carers will be given good quality information about dementia and the services available at diagnosis and during their care

4. Easy access to care, support and advice after diagnosis

- People with dementia and their carers will be able to see a dementia adviser who will help them throughout their care to find the right information, care, support and advice

5. Develop structured peer support and learning networks

People with dementia and their carers will be able to:

- Get support from local people with experience of dementia
- Take an active role in developing local services

6. Improve community personal support services for people living at home

- There will be a range of flexible services to support people with dementia living at home and their carers
- Services will consider the needs and wishes of people with dementia and their carers

7. Implement the New Deal for Carers

- Carers will have an assessment of their needs, get better support and be able to have good quality short breaks from caring

8. Improve the quality of care for people with dementia in general hospitals

People with dementia will get better care in hospital because:

- It will be clear who is responsible for dementia in general hospitals and what their responsibilities are
- The people responsible for care will work closely with specialist older people's mental health teams

9. Improve intermediate care for people with dementia

- There will be more care for people with dementia who need help to stay at home

10. Consider how housing support, housing related services, technology and telecare can help support people with dementia and their carers

Services will:

- Consider the needs of people with dementia and their carers when planning housing and housing services
- Try to help people to live in their own homes for longer

11. Improve the quality of care for people with dementia in care homes

Services will work to ensure:

- Better care for people with dementia in care homes
- Clear responsibility for dementia in care homes
- A clear description of how people will be cared for in care homes
- That there will be visits from specialist mental health teams
- Better checking of care homes

12. Improve end of life care for people with dementia

- People with dementia and their carers will be involved in planning end of life care
- Services will consider people with dementia and their carers when planning local end of life services

13. An informed and effective workforce for people with dementia

- All health and social care staff who work with people with dementia will have the right skills to get the right care, get the right training and get support to keep learning about dementia

14. A joint commissioning strategy for dementia

- Health and social care services will work together to develop systems to identify the needs of people with dementia and their carers best meet these needs

15. Improve assessment and regulation of health and care services and of how systems are working

- There will be better checks on care homes and other services to make sure people with dementia get the best possible care

16. Provide a clear picture of research about the causes and possible future treatments of dementia

- People will be able to get information from research about dementia
- Identify gaps in research information and do more to fill the gaps

17. Effective national and regional support for local services to help them develop and carry out the strategy

- More good quality information to develop better local services for people with dementia

14.3 Appendix 3: End of life care strategy

The *End of Life Care Strategy* suggests that for most people high quality end of life care should include:

- Being treated as an individual, with dignity and respect
- Being without pain and other symptoms
- Being in familiar surroundings
- Being in the company of close family and/or friends

In the light of these factors, the *End of Life Care Strategy* aims to ensure that people have the opportunity to discuss their personal needs and preferences with professionals. It is envisaged that all health and social care staff will be trained in communication regarding end of life care, in assessing the needs of patients and carers and, where necessary, reconciling differing requirements. Thus, according to the *End of Life Care Strategy* the discussions of preferences will be recorded in a care plan so that every service involved will be aware of peoples' priorities and will take account of their preferences.

The aim of recording such needs and preferences in a care plan is to coordinate care and support; ensuring that needs are met, irrespective of who is delivering the service:

- Every organisation involved in providing end of life care will be expected to adopt a coordination process, such as the Gold Standards Framework
- Local end of life care coordination centres will be established to coordinate care across organisational boundaries
- End of life care registers will be piloted and established to ensure that every organisation which will be involved in care is aware of a patient's wishes

The *End of Life Care Strategy* envisages a rapid specialist advice and clinical assessment wherever a patient may be, including:

- Access to dedicated 24/7 telephone help lines and rapid access homecare services
- Specialist palliative care outreach services to be established in every area

The high quality care and support during the last days of a person's life was envisaged to include:

- A care pathway approach for management of the last days of life, such as the Liverpool Care Pathway¹⁵³, across England
- Facilities to be provided to support relatives and carers who wish to stay with a patient in hospital

The strategy also suggests that end of life care will be monitored and assessed to ensure quality, with best practice being identified and spread so that others may benefit. As part of this,

- A national intelligence network will be established to collect, analyse and publish data on service quality performance
- A dedicated multi-professional national support team will work with commissioners and providers to identify and spread good practice
- Surveys of bereaved relatives and carers will be introduced
- Comprehensive analysis of complaints relating to end of life care will be undertaken
- The national *End of Life Care Research Initiative* will be launched to improve understanding of how best to care for people reaching the end of their life and support those caring for them.

14.4 Appendix 4: Dignity in Care 10 Point Dignity Challenge

The *Dignity in Care* campaign was launched following a number of listening events around the country to find out what dignity in care meant to different people. The issues raised at these events resulted in the development of the 10 point Dignity Challenge. The challenge depicts what high quality services that respect people's dignity should include:

- Zero tolerance of all forms of abuse
- Supporting people with the same respect you would want for yourself or a member of your family
- Treating each person as an individual by offering a personalised service
- Enabling people to maintain the maximum possible level of independence, choice and control
- Listening and supporting people to express their needs and wants
- Respecting a person's right to privacy
- Ensuring people feel able to complain without fear of retribution
- Engaging with family members and carers as care partners
- Assisting people to maintain confidence and a positive self-esteem
- Acting to alleviate people's loneliness and isolation.

14.5 Appendix 5: Local Policy 23 objectives

The 5 local work streams are tasked to deliver 23 objectives:

1. To increase early diagnosis and access to interventions for people with dementia
2. To commission a single point of contact for people living with dementia at each step of the care pathway to improve access to advice and services
3. To strategically review the pathway for memory assessment and commission a service that is integrated into a health and social care pathway
4. Improved management of causes of behavioural and psychological symptoms in dementia via a LLR wide implementation of prescribing guidelines
5. To commission a shared model of care allowing prescribing in both primary and secondary care to benefit those living with dementia and encourage service efficiency
6. To review the existing ICATs model of delivery to develop a service focused on preventing admission to the older people's mental health in-patient wards and facilitate timely discharge
7. To review options for commissioning a joint health and social care crisis response service to support people with dementia and their families/carers
8. To commission an integrated intermediate care model across health and social care that is able to support GPs to look after the physical health care needs of people with dementia
9. To commission integrated reablement services that reflects the specialist needs of people with dementia and delivers a pathway that reduces hospital admissions and reduces delayed discharges
10. To develop an integrated health and social care community based pathway to reduce length of stay in hospital, reduces the need for hospital admission and is able to meet the mental and physical health care needs of people with dementia
11. To ensure consistent detection of dementia within a hospital setting and the development of appropriate care pathways
12. To ensure all family carers have access to dementia support services as early as possible and to ensure that a carers assessment is completed
13. To commission a range of respite services to support carers in their caring role
14. To ensure that people with dementia are given a personal budget if eligible of support and that self funders are given appropriate advice and information about services available to them
15. To develop community based dementia services to allow people to use their personal budgets
16. To increase specialist dementia home care and ensure it is high quality and enables choice and control for the individual
17. To ensure that the use of assistive technology is embedded into care pathways across health and social care
18. To ensure that housing strategies commission life time community based accommodation that can support older people and those with dementia

19. To ensure that all people diagnosed with dementia have access to advice and information
20. To ensure that all services that are commissioned meet a range of quality standards including NICE and CQC
21. LLR wide implementation of prescribing guidelines
22. Review access to specialist support and other in-reach for people living in care homes
23. Ensure that workforce is commissioned to deliver services to support the care pathway for dementia

These objectives are expected to:

- Increase in the proportion of people with dementia receiving a diagnosis while they are in the early stages of the illness
- 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
- Reduce the average length of stay in hospital for patients with dementia
- Reduce the number of people with dementia discharged directly from hospital to care homes as a new place of residence
- Reduce the number of people discharged from hospital on antipsychotic medication
- Increase the number of people having a plan to review use of antipsychotic medication post discharge
- Reduce the use of antipsychotic medication for people with dementia in care homes, at home and other residential settings
- Contribute to a reduction in unplanned admissions and readmissions of people with dementia to general and community hospitals
- Achieve better care at home and in residential care

14.6 Appendix 6: Projections by ethnic group

Leicester currently has a population which is younger than the national average. The population of the city is also characterised by young, ethnic minority populations. Over time, these ethnic minority groups will age, so that they will form a larger proportion of the elderly population. This will have an impact on the service provision.

14.6.1 Projection method

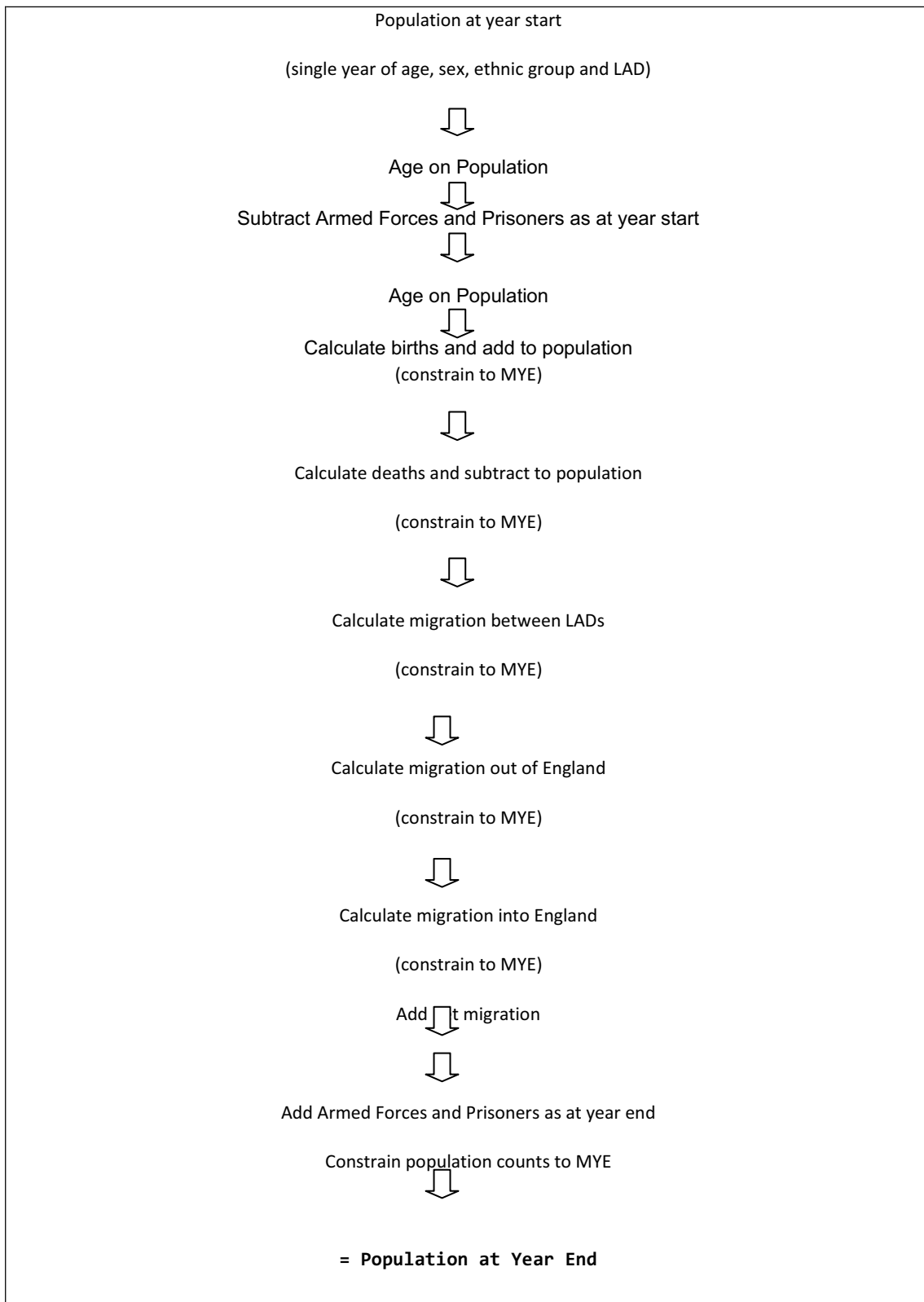
The population projections in are based on the 'aging on' of population at the start of the year, with adjustments for members of the armed forces and prisoners, births, deaths, migration in and migration out of the country. In order to estimate these projections by ethnic category, this requires completion and consistency in reporting of ethnic categories.

14.6.2 Problems with population projections by ethnic categories

Population projections by ethnic group are problematic for a number of reasons. The Census collects ethnic data by asking the population to identify themselves into one of the listed ethnic categories and there is an assumption that this will provide accurate data that can be compared overtime. However, there are reasons as to why this is not the case:

- Use of pre-determined Census ethnic categories (rather than self-identification)
- Introduction of new ethnic categories (e.g. 'Mixed' categories in 2001)
- Instability of responses to ethnic categories
- Notion of self-reporting (exceptions include Census 2001 where the respondent was asked to answer for every member in the household, births, deaths)
- Use of consistent ethnic categories across relevant datasets

Process of Producing Population Estimates by Ethnic Group



Source: Large & Ghosh (2006)¹⁵⁴

14.7 Appendix 7: Classification of dementia

The International Classification of Diseases, tenth revision (ICD-10) provides the following categories of dementia:

F00 Dementia in Alzheimer's disease

F00.0 Dementia in Alzheimer's disease with early onset

F00.1 Dementia in Alzheimer's disease with late onset

F00.2 Dementia in Alzheimer's disease, atypical or mixed type

F00.8 Dementia in Alzheimer's disease, unspecified

F01 Vascular dementia

F01.0 Vascular dementia of acute onset

F01.1 Multi-infarct dementia

F01.2 Sub-cortical vascular dementia

F01.3 Mixed cortical and sub-cortical vascular dementia

F01.8 Other vascular dementia

F01.9 Vascular dementia, unspecified

F02 Dementia in other diseases classified elsewhere

F02.0 Dementia in Pick's disease

F02.1 Dementia in Creutzfeld-Jakob's disease

F02.2 Dementia in Huntingdon's disease

F02.3 Dementia in Parkinson's disease

F02.4 Dementia in human immunodeficiency virus (HIV) disease

F02.8 Dementia in other diseases classified elsewhere

F03 Unspecified dementia

14.8 Appendix 8: Planning effective respite

A Good Break
Maintenance or
Improvement of the carer's
health, well-being and/or
quality of life

Effective respite services and short-term breaks are:					
Based on assessment and on-going review	Appropriate to the need and circumstances of the carer	Appropriate to the age culture, condition and stage of illness for the care recipient	Able to maintain or improve the well-being of the care recipient	Delivered by appropriately trained and caring staff	Affordable to the carer

Effective respite services and short-term breaks are underpinned by:							
Knowledgeable and supportive doctors	Appropriate management of the condition (e.g. medication and equipment)	Responsive social services	Accessible information	Fair and easy to understand benefits and charging systems	Well-coordinated services	Supportive carers networks	Helpful family, friends and neighbours

14.9 Appendix 9: Potential patient outcomes from the memory assessment service

Outcome	Action
1. No illness	Advise outcome of assessment to GP including any recommendations
2. Other illness (including depression)	Initiate urgent treatment or referral for physical or mental disorder if required or discharge to GP with advice on treatment or referral
3. Dementia (no medication)	Talk through timely interventions; signpost and refer to resources/support available. Advise GP of outcome and recommended next steps
4. Dementia (medication)	Talk through timely interventions, including medication. Signpost and refer to resources/support available. Advise GP of outcome and recommended next steps
5. Possible dementia (MCI)	Advise GP to re-refer if symptoms persist or increase

14.10 Appendix 10: Mosaic Groups in Leicester

Comparison of Mosaic groups in Leicester and England

Mosaic Public Sector Groups	Leicester	%	England	%	Pen. %	Index	
E Middle income families living in moderate suburban semis	78,661	22.45	6,750,377	13.01	1.17	173	
I Lower income workers in urban terraces in often diverse areas	65,146	18.59	4,320,659	8.33	1.51	223	
O Families in low-rise social housing with high levels of benefit need	53,873	15.37	2,956,632	5.70	1.82	270	
G Young, well-educated city dwellers	44,803	12.79	4,567,853	8.80	0.98	145	
K Residents with sufficient incomes in right-to-buy social housing	30,378	8.67	4,718,598	9.10	0.64	95	
J Owner occupiers in older-style housing in ex-industrial areas	18,895	5.39	4,183,126	8.06	0.45	67	
N Young people renting flats in high density social housing	17,546	5.01	2,480,603	4.78	0.71	105	
M Elderly people reliant on state support	8,968	2.56	1,887,321	3.64	0.48	70	
H Couples and young singles in small modern starter homes	7,973	2.28	2,396,762	4.62	0.33	49	
F Couples with young children in comfortable modern housing	7,539	2.15	2,962,555	5.71	0.25	38	
C Wealthy people living in the most sought after neighbourhoods	4,963	1.42	1,848,118	3.56	0.27	40	
B Residents of small and mid-sized towns with strong local roots	4,168	1.19	4,498,119	8.67	0.09	14	
D Successful professionals living in suburban or semi-rural homes	4,123	1.18	4,504,874	8.68	0.09	14	
L Active elderly people living in pleasant retirement locations	3,397	0.97	1,836,109	3.54	0.19	27	
A Residents of isolated rural communities	0	0.00	1,968,327	3.79	0.00	0	
Total	350,433	100	51,880,033	100	0.68	100	

14.11 Appendix 11: Actions in the Prime Ministers challenge on dementia

Driving improvements in health and care

- Increase diagnosis rates through existing checks for over-65s ensuring that GPs and other health professionals make patients aged 65 and over aware of memory clinics and refer those in need of assessment. From April 2013, there will be a quantified ambition for diagnosis rates across the country, underpinned by robust and affordable local plans.
- Financial rewards for hospitals offering quality dementia care From April 2012, £54m will be available through the Dementia CQUIN payment framework to hospitals offering dementia risk assessments to all over-75s admitted to their care. From April 2013, this will be extended to the quality of dementia care delivered. Also, for April 2013 access to all CQUIN rewards will be dependent on delivering support for carers in line with the NICE/SCIE guidelines.
- An Innovation Challenge Prize of £1m NHS staff can win up to £1m for innovative ideas for transforming dementia care.
- A Dementia Care and Support Compact signed by leading care home and home care providers
- Promote the information offer pioneered by the NHS South West, which will be launched on 28 March 2012 and rolled out across the south by the end of 2012 From April 2013, information will be available in all other parts of the country. We will also be setting out in the Care and Support White Paper further steps to ensure all people receiving care and support get better information to support their care choices.
- Work with profession to identify how best to improve early diagnosis of dementia through improvements in awareness, education and training and through potential improvements to the GP contract.
- Ask NICE to consider ways of improving the dementia indicators in the Quality and Outcomes Framework.
- Call on the Royal Colleges to respond to the challenge of dementia by bringing forward plans to ensure that all their members are capable and competent in dementia care. The Royal Colleges have committed to driving this forward.
- Ensure that memory clinics are established in all parts of the country, and work with the Royal College of Psychiatrists to drive up the proportion of memory services that are accredited, through publication of their national Memory Services Accreditation Programme, so that individual organisations can benchmark and report their own performance to drive improvement The NHS will guarantee a written integrated personalised care plan to people with dementia.
- Better support for carers with the NHS required to work closer than ever before with local carers' organisations and councils to agree plans, pool their resources, and make sure that carers get the support and break they deserve and that young carers do not take on excessive or inappropriate caring roles
- Carers have the right to be assessed and their needs met carers can take their support as a personal budget and should be encouraged so to do. The NHS should also ensure that a range of psychological therapies are commissioned and made available to carers of people with dementia in line with NICE/SCIE guidelines, as well as ensuring services are made available to support the couple relationship where one person is caring for a partner with dementia.
- Launch pilots of dementia clinical networks aimed at spreading clinical expertise by September 2012
- Create dementia friendly communities across the country

- Support from leading businesses for the PM's Challenge on Dementia Leading national organisations have already pledged to look at how they and others can play a part in creating a more dementia-friendly society and raising awareness of dementia.
- Awareness-raising campaign From autumn 2012, there will be a nationwide campaign to raise awareness of dementia, to be sustained to 2015. This will build on lessons learned from previous pilot campaigns and will inform future investment.
- A major event over the summer, bringing together UK leaders from industry, academia and the public sector, to take forward the PM's Challenge on Dementia.
- Work with the Alzheimer's Society to develop local Dementia Action Alliances to bring together people with dementia, their carers and key organisations, funded by £537,000 from the Department of Health over three years.
- Make sure that people with dementia and carers on diagnosis have an information pack about dementia produced in conjunction with the Alzheimer's Society. The Dementia-friendly Communities Programme working in partnership with the Dementia Action Alliance will develop evidence on what a dementia-friendly community is.

Better research

With a number of initiatives, including:

- The PM's Challenge includes a commitment to more than double overall funding for dementia research to over £66m by 2015.
- Major investment in brain scanning
- £13m funding for social science research on dementia (NIHR/ESRC) including £3m for public health research.
- £36m funding over 5 years for a new NIHR dementia translational research collaboration to pull discoveries into real benefits for patients. F
- The MRC will spend over £3m in supporting the UK brain bank network, which connects all the UK brain banks for the benefit of donors, researchers and future patients This includes £500k a year to improve the process for donation of brain tissue by meeting the costs of collecting brain tissue through the NHS, so smoothing the pathway to donation.
- A major event will be staged for pharmaceutical and biotech companies to showcase the benefits of conducting dementia research in the UK, and to assess how best to remove barriers.
- Up to £9m of DH funding will be made available for research into 'living well with dementia' and the delivery of dementia care. The DH will increase its support for capacity-building in dementia research, focusing on nurses as well as doctors.

14.12 Appendix 12: The Common Core Principles for Supporting People with Dementia

- Principle 1: Know the early signs of dementia.
- Principle 2: Early diagnosis of dementia helps people receive information, support and treatment at the earliest possible stage.
- Principle 3: Communicate sensitively to support meaningful interaction.
- Principle 4: Promote independence and encourage activity.
- Principle 5: Recognise the signs of distress resulting from confusion and respond by diffusing a person's anxiety and supporting their understanding of the events they experience.
- Principle 6: Family members and other carers are valued, respected and supported just like those they care for and are helped to gain access to dementia care advice.
- Principle 7: Managers need to take responsibility to ensure members of their team are trained and well supported to meet the needs of people with dementia.
- Principle 8: Work as part of a multi-agency team to support the person with dementia.

14.13 Appendix 13: Cost of medications for Alzheimer's disease

Donepezil is initially given at 5 mg once daily at night. After 1 month the treatment should be assessed, and the dose can be increased to a maximum of 10 mg once daily if necessary. Common undesirable effects include diarrhoea, muscle cramps, fatigue, nausea, vomiting and insomnia. Donepezil is available as tablets and orodispersible tablets. Net prices are stated. The cost of tablets is £59.85 (5 mg, 28-tablet pack) and £83.89 (10 mg, 28-tablet pack). The cost of orodispersible tablets is £59.85 (5 mg, 28-tablet pack) and £83.89 (10 mg, 28-tablet pack)¹⁵⁵. As the patent for Donepezil will expire on February 13th 2012¹⁵⁶, the price structure for Donepezil is due to change.

The formulation of Galantamine which is most frequently prescribed is a capsule given initially at 8 mg once daily for 4 weeks and then increased to 16 mg once daily for at least 4 weeks. Maintenance treatment is 16–24 mg once daily depending on assessment of clinical benefit and tolerability. An older tablet formulation and a liquid preparation are also available to be given twice a day, see the summaries of product characteristics for more information. Common undesirable effects include nausea and vomiting. The cost of tablets is £68.32 (8 mg, 56-tablet pack) and £84.00 (12 mg, 56-tablet pack). Oral solution (4 mg/ml, 100 ml) costs £120.00. Modified release capsules cost £51.88 (8 mg, 28-capsule pack), £64.90 (16 mg, 28-capsule pack) and £79.80 (24 mg, 28-capsule pack).

Rivastigmine is initially prescribed at 1.5 mg twice daily and may be increased in steps of 1.5 mg twice daily at intervals of at least 2 weeks according to tolerance up to a maximum dose of 6 mg twice daily. Alternatively rivastigmine patches are available, initially using a 4.6-mg patch per day. This can be increased to a 9.5-mg

patch per day for at least 4 weeks. Common undesirable effects are mainly gastrointestinal including nausea and vomiting. Rivastigmine is available as capsules, oral solution and patches. The cost of 1.5 mg rivastigmine capsules is £33.25 (28-capsule pack) and £66.51 (56-capsule pack); 3 mg capsules cost £33.25 (28-capsule pack) and £66.51 (56-capsule pack); 4.5 mg capsules cost £33.25 (28-capsule pack) and £66.51 (56-capsule pack); 6 mg capsules cost £33.25 (28-capsule pack) and £66.51 (56-capsule pack). Oral solution costs £99.14 (2 mg/ml, 120 ml). Patches cost £77.97 (4.6 mg/24 hours, 30 patches) and £77.97 (9.5 mg/24 hours, 30 patches).

Memantine is initially given as 5 mg once daily and then increased in steps of 5 mg at weekly intervals to a maximum of 20 mg daily. Common undesirable effects are dizziness, headache, constipation, somnolence and hypertension. For full details of side effects and contraindications, see the summaries of product characteristics. Memantine is available as tablets and oral drops. 10 mg memantine tablets cost £34.50 (28-tablet pack), £69.01 (56-tablet pack) and £138.01 (112-tablet pack). 20 mg tablets cost £69.01 (28-tablet pack). A treatment initiation pack (7 × 5 mg, 7 × 10 mg, 7 × 15 mg, and 7 × 20 mg tablets) costs £43.13. Oral drops (10 mg/g) cost £61.61 for 50 g and £123.23 for 100 g.

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Appendix C



Leicester City Council Scrutiny Review

'Domiciliary Care'

Scoping Document for completion by Members

Background to scrutiny reviews

Getting the right topics for scrutiny reviews is the first step in making sure scrutiny provides benefits to the Council and the community.

This scoping template has been designed to assist in thinking through the purpose of a review and the means of carrying out the review. This scoping document needs to be completed by the member proposing the review but advice can be sought from a Scrutiny Officer (contact details below).

In order to be effective, every scrutiny review must be properly project managed. This is to make sure that the review achieves its aims and has measurable outcomes. One of the most important ways to make sure that a review goes well is to ensure that it is well defined at the outset. This way the review is less likely to get side-tracked or be overambitious in what it hopes to tackle. The Commission's objectives should, therefore, be as SMART (Specific, Measurable, Achievable, Realistic & Time-bound) as possible.

This template includes a section for the Department to complete to allow the Scrutiny Commission and OSC to consider any additional factors that may influence the proposed review. It also includes a section on public and media interest in the review which should be completed in conjunction with the Council's Communications Team. This will allow the Commission to be properly prepared for any media interest and to plan the release of any press statements.

Scrutiny reviews will be facilitated by a Scrutiny Officer.

Evaluation

Reviewing changes that have been made as a result of a scrutiny review is the most common way of assessing effectiveness. Any scrutiny review should consider whether an on-going monitoring role for the Commission is appropriate to the topic under review.

For further information please contact the Scrutiny Team on (0116) 229 8898

1. Title of Proposed Scrutiny Review

A review to look into the quality of domiciliary care provision in the independent sector; and to consider whether there is a link between conditions of service and levels of pay, staff morale and the quality of care given.

Also to understand what can be specified in the commissioning process ie terms and conditions, qualifications and experience of carers etc.

Proposed by - Councillor Dr Lynn Moore

2. Rationale

Members should outline the background to this review and why it is an area worthy of in-depth investigation.

The commission is aware that domiciliary care staff working for the private sector seem to be paid considerably less than council staff. Also having had sight of some contracts of domiciliary care workers it is felt that the contracts offer poorer terms and conditions to staff.

The commission is keen to examine the Council's commissioning process and contracts with care providers to understand approach to conditions and pay for staff. The commission want to ascertain whether the level of wages in the private sector have an effect on morale, management of time and care given; if there is a fair, equitable and comparable approach to council terms and conditions; and whether this has an impact on contract performance.

The commission are concerned to understand what the weekly wage pattern is for care workers, not just hourly pay. Also what expenses are paid and what counts as work time. This is in the context of the council's commitment to introducing a living wage.

The commission would also like to assess the frequency of inspections of providers and establish if there is an adequate system that gathers feedback from staff regarding the changing needs of service users.

3. Purpose and Objectives of Review

Members should consider what the objectives of the review are

To assess the quality of domiciliary care services in the independent sector by considering the following:-

- 1) To determine how the Council, Regulators and Providers measures the compliance and quality of domiciliary care services
- 2) What do domiciliary care staff in the private sector actually earn in comparison to council counterparts i.e. per week or per year?
- 3) Do the level of wages in the private sector have any impact on staff morale?
- 4) Is there an adequate system to collect feedback from care staff as to the changing needs of service users?
- 5) If appropriate, the scope for amendments of contracts with providers to encourage better pay and conditions for staff.
- 6) The frequency with which the quality of provision is assessed and how this compares other local authorities?
- 7) What do we specify in our contracts as commissioners?
- 8) What recommendations should be made for immediate and longer term consideration and also for future commissioning of domiciliary care services.

4. Methodology/Approach

Members should consider how the objectives of the review will best be achieved and what evidence will need to be gathered from officers and stakeholders, including outside organisations and experts.

- Review literature on the subject
- Take evidence from officers and stakeholders as to current contractual agreements with providers
- Examine examples of contracts
- Consider reported conditions of domiciliary care from service users and their carers
- Consider information gathered from Providers and their staff
- Look into best practice examples (national)
- Invite evidence from the Commissioning and Contract team
- Invite input from Trade unions
- Consider Regulatory inspection reports of commissioned providers

5. Expected length of the review

Members should anticipate the likely length of the review being proposed.

It is anticipated that the review should be completed in 3 months.

6. Additional resource/staffing requirements

All scrutiny reviews are facilitated by Members Support/Scrutiny Support Officers. Members should anticipate whether any further resource is required, be this for site visits or independent technical advice.

This review will require officer time from Care Services and from Service Contracting and Procurement.

The review will be supported by Member Support Officer time.

7. Risks

Members should consider whether there are any additional risks to undertaking this scrutiny review, for example whether there is a similar review being undertaken by the Executive or whether a national or local change in policy or service may supersede the need for this review.

Insufficient time to complete the review.

Availability of people from whom to take evidence.

8. Further Supporting Evidence

Members should consider whether they would like to add further information to support the case for a scrutiny review.

Before approving this scoping document the Scrutiny Commission should ensure the following boxes should be completed in conjunction with the relevant officers:

9. Likely publicity arising from the review

Members will wish to anticipate whether the topic being reviewed is high profile and whether it will attract media interest. If so, this box should be completed with help from the relevant officer in the Council's PR and Media Team.

Publicity will be through all Adult Social Care & Housing Scrutiny Commission Meetings as they are public meetings.

Stakeholders of interest will be kept informed.

10. Divisional Comments

Scrutiny's role is to influence others to take action. It is, therefore, important for the Scrutiny Commission and OSC to understand the Division's view of the proposed review. The following box should be completed in sufficient time for the Commission to consider as part of its deliberations whether to proceed with the review.

It is not possible to regulate the level of monies paid to independent domiciliary care workers through the Council's contract for services. What we do require are the contractors to perform the services (i.e. to the specification for providing personal care and support) in compliance with statutory requirements, including employment law. The issue with going beyond this is that under European Union Law contract conditions have to relate to the performance of the contract.

The better means of enforcement of the national minimum wage (NMW) is for the worker (or someone on their behalf) to complain to Her Majesty's Revenue and Customs (HMRC) who have the job of enforcing the NMW. If someone has been convicted or suffers a penalty we could perhaps exclude them from tendering or terminate their contract under regulation 23.

A good summary of who is eligible and the rules on NMW can be read by accessing information on the following website; <https://www.gov.uk/minimum-wage-different-types-work>

There is some very recent debate on the subject of the living wage as a result of Scottish Government Activity, but they have not got a very good response from the European Commission (i.e. they are saying it could amount to breach of treaty on Functioning of European Union) also attached below as a PDF.

In the current procurement exercise for a range of domiciliary care providers, Legal Services have been considering a payment mechanism approach to payment of travel costs and using project trust account. However there is no doubt that this will increase the cost of the service

to the Council, which is likely to be unaffordable. Nor will it attach to the direct provision service user who contracts direct with the agencies.

The procurement exercise to secure a new domiciliary care providers is currently underway, and Scrutiny should be aware that this is the case when considering the scope, timing and recommendations from any review. For example, providers may change after procurement, so any issues identified might not be relevant into the future. The current procurement exercise includes a focus on quality of care, staffing policies and monitoring arrangements.

Therefore, it would be helpful for Scrutiny to further clarify the scope of the review, to ensure this is focussed on what the Council (Adult Social Care) can influence or determine.

The Department agrees to assist in the proposed review.

Departmental Comments Completed by __ Tracie Rees _____

Job Title __ Director Care Services and Commissioning – Adult Social Care ___

Report to the Adult Social Care Scrutiny Commission

Date: 5th December 2013

Outline Timetable for the future of the Council's Elderly Persons Homes

Lead Director: Tracie Rees

Useful Information:

- Ward(s) affected: New Parks, Western Park, Latimer, Eyres Monsell
- Author: Tracie Rees
- Author contact details Ext 2301

1. Summary

- 1.1 This report provides an indicative timetable for the actions needed to support existing residents living in the Council's Elderly Persons Homes that are due to be closed.
- 1.2 It should be noted that it is not possible to be specific about some of the timings until residents have been assessed and their needs and preferred alternative homes are known.

2. Background Information

2.1 Following the decision on 15th October 2013 to close 4 and sell 4 of the Council's Elderly Persons homes a Programme Board has been set up to oversee the implementation of the phased approach.

2.2 Within the programme, there are three work streams that have been created to progress the sales and closure of the homes as follows:

- 1) To move residents out of Elizabeth House, Herrick Lodge and Nuffield House
- 2) To give consideration to the disposal of the above properties once all residents have moved to alternative residential care homes
- 3) To sell Abbey House and Cooper House as going concerns.

2.3 In the first instance the work streams will concentrate on implementing phase 1 and Appendix 1 provides an indicative timetable for supporting existing residents to move to alternative homes. As the assessment process is individual and can vary in length depending on complexity timescales are indicative at this time.

2.4 The sales work stream has recently been established and is currently undertaking preparatory work prior to designing the procurement process for this exercise.

2.5 It is not possible to confirm the dates for disposal of the homes to close until the existing residents have been moved out.

Activity	Task Owner	Due Date
Set up dedicated reassessment team to provide specific support to the residents and families affected by change	JH	Complete
Produce information for residents and families on how we will support them through change	AH	Complete
Produce template for registered managers to use to develop a moving plan for each resident and guidance for registered managers and social work staff on how to approach each stage of the moving plan	AH/RR	Complete
Hold staff workshop to enable all staff to fully understand the above	TR/AH/RR/ JH	Complete
Allocate cases to social workers so that officers can start to build relationships with residents and their families	JH	Complete
Identify if there are any residents who have been placed in our homes by the County Council. (We would need to liaise with the County Council about the process)	JH	30 th November
Identify residents who have told home managers that they prefer to move as soon as possible. (There are only a small number but their reassessments will be prioritised)	RR	30 th November
Develop a practical checklist that managers can use to ensure that all arrangements are in place to make sure that each move runs smoothly.	AH	30 th November
Complete stages 1 and 2 of moving plans	Home	30 th

<p>Stage 1 is identifying the people each resident wants to be involved in their moving plan. This can include keyworkers in the home who know the resident well.</p> <p>Stage 2 is developing an outline moving plan which is passed to the social worker so that the resident's wishes are fully taken into account as part of the reassessment process.</p>	Managers	November
Develop resident tracking plan for updating progress to Adult Social Care Scrutiny Commission once the process is underway.	RR/JH/AH	30 th November
Complete stage 3 of all moving plan (reassessments and support plans) (Assessments will be staggered and start at different times, assessments will vary in timescale depending on complexity)	JH	30 th November onwards -
<p>Review of moving plans planning the move day, and completing a moving checklist</p> <p>Following the reassessment residents will review and choose a new home. They can be supported by key workers from the home who know them well, if they wish</p> <p>We will then start to plan with each resident and their families, what needs to happen before and on the day of the move. We will set up a moving checklist so that we can keep a check that everything is on track.</p>	Home Managers	January 2014 – the end date will be determined on individual circumstances
<p>Check that resident's new accommodation has been prepared with appropriate equipment /furniture etc. prior to move and everything is in place to make the move successful.</p> <p>(The date people move will be individually determined)</p>	JH	The end date will be determined on individual circumstances
Day of Move: Ensure all actions on checklist have been implemented and safe transport of resident to new accommodation is organised. People can be supported by key workers from the home who know them well, if they wish.	Registered Manager/ Social	The end date will be determined

	worker	on individual circumstances
We will put in place follow up checks in line with the residents' wishes to check how they are settling in. This will include members of staff from the social work team as well as informal networks such as family and friends.	Social worker	Weeks 1-4 after move
Four weeks after each resident has moved there will be a formal review of the resident's needs and this will be recorded. Residents and their families/ representatives are fully involved in this.	Social worker	4 weeks after the move
Six months after each resident has moved there will be a formal review of the resident's needs and this will be recorded. Residents and their families/ representatives are fully involved in this.	Social worker	6 months after the move

Executive Briefing

Proposal for the future of mobile meals provision

Lead Director: Tracie Rees
Briefing Date: 31st October 2013

Useful information

- Ward(s) affected: City-wide
- Report author: Mercy Lett-Charnock
- Author contact details: 37 2377

1. Summary

- 1.1 On 4th October 2012 the Executive gave approval to consult on the future of the Council's mobile meals provision.
- 1.2 The service comprises three elements:
 - All meals are delivered by City Transport
 - Some meals are purchased from an external provider and re-heated by City Catering
 - Some meals are cooked fresh and delivered by two external providers
 - East West Community Project (EWCP) and
 - West Indian Senior Citizen's Project (WISCP)
- 1.3 A formal consultation exercise has been completed and the Executive is requested to make a decision about the future of the service taking into consideration the findings from the consultation and the Council's strategic and financial priorities.
- 1.4 The statutory consultation ran from 9th July to 7th October 2013 on the following proposal:
 - Stopping the Council's current mobile meals service and helping people to prepare or obtain meals in alternative and more flexible ways

It should be noted that the Council does not cook any meals and its role is limited to re-heating and delivering some of the meals.
- 1.5 The numbers of people using the service has been reducing significantly as the eligibility criteria is being robustly applied and people are choosing to use their personal budget to buy alternative services. There are currently 236 people using the service, reflecting a 34% drop in numbers since April 2012. Consequently the unit cost of providing the service has increased by 43% over the period from 2010/11 to 2012/13.
- 1.6 The consultation has found that users would like to continue to receive a hot meal and those involved in the provision and delivery of the current service are concerned about the quality of alternative options. These issues are addressed in the report.
- 1.7 Information relating to the consultation process and key findings are detailed in the report. However, the overall recommendation is to cease the service as it is no longer financially viable and people's needs can be met in more flexible ways, especially as there are suitable alternative providers and options available.

2. Recommendation

- 2.1 The Executive is recommended to approve ceasing the current mobile meal service with individuals being supported to prepare or obtain meals in an alternative way, as detailed in Option 4.
- 2.2 In order to ensure both the nutritional and social needs of service users are met there will be a number of service options available to people who need support with obtaining or preparing a meal in future. These will be:
 - Direct payments, so people can make their own arrangements
 - Domiciliary care to heat or prepare a meal
 - Support to order meals provision
 - A managed service via the Council from a Framework Agreement (this would meet nutritional and quality standards)

3. Background

- 3.1 The number of people using the service has dropped significantly over the last few years and as demand reduces, the costs have increased for City Transport, City Catering and Adult Social Care (ASC). The Council subsidised the service by £396k in 2012/13 and the service is becoming financially unviable.
- 3.2 As part of the ASC Transformation Programme, the move to personal budgets has meant more service users are choosing alternative meal provision. Demand for the current service has fallen and it is forecast to continue falling, resulting in an increasing average cost.
- 3.3 For 2012/13 the average gross cost to the Council per meal was £7.76, representing a total annual gross cost of £607k. If this situation continues the average cost to the Council per meal could rise by 50% to around £12.00 over the next 3 years.
- 3.4 There are currently 236 service users in receipt of a mobile meal, but the number of people using the service has been declining year on year. The decline in the number of meals has been evident for some time, as follows:

2009/10 = 168,000
2010/11 = 159,000
2011/12 = 112,000
2012/13 = 78,000

- 3.5 National policy, such as the Putting People Concordat (2007), promotes independence and gives people greater choice and control over the services they receive.
- 3.6 Therefore, it is necessary to ensure that people have choice and control, which enables people to live independently and delivers value for money.

Consultation Process

- 3.7 Statutory consultation was carried out between 9 July and 7 October 2013. The following proposal was based on the falling demand and increasing level of subsidy paid by the Council.

Stopping the Council's current mobile meals service and helping people to prepare or obtain meals in alternative and more flexible ways.

Information relating to the consultation process can be found at Appendix 1.

Summary of Findings

3.8 Service Users

In general, service users either appreciate or rely on the service and wish to continue receiving a hot meal. 56% of those that responded receive a meal every day. The majority of those who responded (80%) still want a hot meal delivered to them and comments highlight they would prefer this to be via the Council as it is now. However, a few comments indicate that some people recognise the current financial pressures on the Council and the availability of alternatives that weren't possible until recently means that the service needs to change.

- Officer Response: There will still be a hot meal service if required through alternative options

38% of those who responded feel the full cost would not offer value for money. 33% felt that the full cost would be good or very good value for money, if they were asked to pay the full amount. Comments made on the questionnaires indicate that there would be some people who would be willing to pay more if it meant a good quality nutritious meal, whereas others could not afford any increase.

- Officer Response: Costs will be considered when planning future options

A notable proportion (32%) of respondents felt they would miss someone calling on a daily basis and therefore the need for a meal was not the only benefit from the service. Some comments show this is linked to concerns about what would happen if they no longer received a daily visit. 30% felt that they would need help and support to find alternatives if the service was stopped.

- Officer Response: When people are assessed for social care support, the assessment considers all their needs including social interaction and community involvement.

A large number of service users (46%) stated that they need appropriate meals for religious or cultural reasons and 62% have one or more specific dietary needs, the most common being vegetarian or diabetic. Some people have also commented that they are concerned that any new arrangements may not provide the nutrition they need.

- Officer Response: The Council has a duty to ensure people's cultural, dietary and nutritional needs are met and will take this into account when making any service changes and as part of the assessment process for

individuals.

3.9 Trade Unions, staff and stakeholder groups

The main concern from staff and unions was the suggestion that the Council had deliberately run the service down. It was also suggested that the reasons why the number had declined were not fully understood.

- Officer Response: Information relating to one case has been put forward by Unison, which was not substantiated and an explanation has been provided. Social work staff are required to offer people choice as part of the personalisation agenda, as well as offering the existing mobile meal service and since July 2013 15 new service users are now in receipt of the service. However, despite 15 new people using the service, overall the numbers continue to decline.

A suggestion was made by the unions that the service should be promoted to increase usage and make it more cost effective.

- Officer Response: As explained in the previous point, social work staff do offer the service, which is demonstrated by the number of new service users who are now in receipt of the service.

It was felt that there were risks if people went directly to providers who had not been vigorously quality-checked.

- Officer Response: Concerns over commissioned services could be mitigated by a robust contracting process which includes health and safety as well as nutritional requirements. The Council contracted providers will be required to meet the National Association of Care Caterers guidelines. Those who take a direct payment will be monitored to ensure their needs are being met.

Concerns were raised about isolation and welfare (including nutrition), particularly the benefits of a daily check.

- Officer Response: Where people are eligible and require support other than the meal itself (e.g. support to avoid social isolation), these needs will be taken to account in individual assessments. People's nutritional requirements will be considered and a hot meal from a provider meeting required standards could be organised. However, where service users have capacity they can make their own food choices.

Concerns were raised about the direct payment amount being sufficient.

- Officer Response: People receiving a mobile meal currently contribute £3.05 for the cost of the food, if they continue to do this in future and spend the £2.28 direct payment amount (this is the amount given to prepare a meal) they will have £5.33 to spend on every meal. Soft market testing suggests that meals can be purchased from between £1.48 and £5.95 for frozen meals and £3.60 and £7.71 for a hot meal, including delivery.

Appendix 2 and 3 contain detailed union and staff feedback.

3.10 Current providers

Current providers had concerns about the potential for any change to impact on their business (viability) and as a result other work that they do. A reduction in the numbers using services has already begun to have an impact.

- Officer Response: Consideration will be given to the impact on current providers and any mitigating actions that may be required. However, the Council cannot guarantee future business for specific organisations. Information will be provided to prospective users in future and the current organisations could be included on that information.

They felt that information could be given to self-funders about providers which would help them develop their business, but that there could be risks if people chose cheaper options from places without such rigorous checks than they currently go through.

- Officer Response: Information for self funders is being considered as part of the Information, Advice and Guidance strategy and providers can currently market their own services to self-funders and via ChooseMySupport or in future an e-directory. People taking a direct payment are able to choose from providers not regulated by the Council, but any Council appointed provision via a Framework Agreement would meet quality standards.

They stressed the need for culturally-appropriate meals, and that some types of food, such as Caribbean, cost more due to the higher cost of ingredients.

- Officer Response: The Council recognises that some meals may be more expensive for customers to purchase, however the food element of a meal is the responsibility of the customer and the Council is responsible only for ensuring a customer is able to obtain or prepare that meal. Soft market testing shows there are providers of culturally appropriate meals available for service users to purchase directly and where the Council is commissioning services, it will ensure that value for money and appropriate options are available.

3.11 A detailed discussion of the financial, legal, equalities and workforce implications of the proposals can be found in section 6 of the report. The Equality Impact Assessment (EIA) in Appendix 6 of this report describes in detail how the Council might mitigate against negative customer impacts.

Specific alternative proposals made by those consulted

3.12 Promote and increase take up of the in house service to improve economies of scale (this may include consideration of increasing cost to service users).

3.13 Joining with the County mobile meals provision to improve economies of scale.

The consultation summary can be found at appendix 4.

Soft market testing

- 3.14 At the same time the consultation was underway, a soft market testing exercise was undertaken to establish what provision was available for service users who wanted to use their direct payment to purchase meals as well as what providers are potentially willing and able to contract with the Council if it was required. The findings are included at Appendix 5.
- 3.15 In summary, it suggests there are appropriate providers in the market but that in some areas such as providers of Caribbean meals there may be limited choice/availability. However, a procurement exercise would be more likely to receive a response than soft market testing, where there is little incentive for providers to respond. Desk top work and information known informally via lunch clubs and other contracting contacts suggests there are other providers who may be interested in providing meals, that did not respond via this process.

4. Options and impacts

4.1 Options - These include alternative proposals put forward as part of the Consultation process.

4.1.1 Option 1. Do nothing.

The advantage of this option:

- The service would continue to be provided in the same way

The disadvantages of this option:

- The number of service users are declining and the level of subsidy paid by the Council will continue to increase

4.1.2 Option 2. Expand the in house service by actively marketing and attracting people into the service.

The advantage of the this option:

- An increase in numbers would improve the economies of scale and overall viability

The disadvantages of this option:

- The service is only available to people eligible for ASC support and they are already given the choice of using the service and therefore numbers are unlikely to rise further

4.1.3 Option 3. Merge the service with Leicestershire County provision (shared services).

The advantages of this option:

- An increase in overall numbers would improve economies of scale and overall viability

The disadvantages of this option:

- The County purchases its service from an external provider, so a shared service option is not possible
- Consideration could be given to a joint contract, but the County costs are likely to be higher due to transport costs associated with a rural locality and a separate City contract is likely to be cheaper

4.1.4 **Option 4.** Cease the current provision. Service users would be supported to choose alternative meal support options through the support planning process. There would be 4 options for service users:

- Direct payments, so people can make their own arrangements
- Domiciliary care to heat or prepare a meal
- Support to order meals provision
- A managed service via the Council from a Framework Agreement (this would meet nutritional and quality standards)

The Council would undertake a procurement exercise to ensure it has providers of culturally appropriate, high quality meals that meet dietary and nutritional requirements for all those who may need this service.

The advantages of this option:

- It offers customers choice and control
- It enables the Council to retain some control/responsibility for quality of provision (nutritionally and hygienically)
- It makes savings of approximately £213k
- It has limited financial or qualitative impacts on customers

The disadvantages of this option:

- A contract for these small numbers still requires procuring and monitoring
- Contracted services don't always offer sufficient flexibility e.g. in delivery times
- Potential for TUPE may limit the number of providers coming forward or increase the cost
- Costs may increase due to reduced numbers using the service

Option 4 is the recommended option.

4.1.5 **Option 5.** Cease the current provision. Service users would be supported to choose alternative meal support options through the support planning process. There would be 4 commissioning options. Service users could:

- use a direct payment to take maximum control for their service
- use a managed direct payment to enable choice and flexibility without the responsibility for organising and managing the process
- receive domiciliary care to heat or prepare a meal
- receive support to order meals provision

This option is similar to option 4 but instead of the Council purchasing meals via a contract for those who cannot have their needs met appropriately using other options,

customers would be able to use a managed personal budget.

The advantages of this option:

- It offers customers choice and control
- It enables the Council to fully implement the personalisation agenda by withdrawing from formalised contacting arrangements
- It requires less Council resource procuring and monitoring
- It makes savings of approximately £206k

The disadvantages of this option:

- Some customers may still not want a direct payment even if managed on their behalf
- The Council relinquishes control over quality and nutritional standards
- Costs for customers are likely to increase in “like for like” options as the Council will no longer be subsidising the service – however their needs can be met in other ways for a lower cost if they chose this
- Slightly lower estimated savings than option 4

4.2 Impacts

4.2.1 **Customer financial impacts.** The preferred option (option 4) will have different financial implications depending on people’s circumstances and what option they require going forward. The following assumptions have been made in order to estimate the likely impact of changes to services:

- For the customers who are expected to receive a replacement delivered meal, the assumption is that the charge from the Council will be at the current rate (£3.05 per meal). There will be no financial impact for these customers.
- For those customers who are expected to receive extended home care calls, 17% are likely make a contribution towards the service. The financial assessments undertaken for these customers show that the remaining 83% can either not afford to make a contribution or are already paying their maximum amount.
- For those customers who are expected to receive support to order food, this is assumed to be chargeable at the current home care rate of £12.45 per hour. Financial assessments undertaken for these customers indicate that around 42% of these customers are likely to make a contribution; the remaining 58% can either not afford to make a contribution or are already paying their maximum amount.

4.2.2 It is estimated that out of the 236 current mobile meals recipients 220 (93%) will pay no more than they do currently; 16 people (7%) are expected to pay more. This is based on applying assumptions about the future services that people will receive, along with information from financial assessments for the 70% who have had them.

4.2.3 Using information about the expected services that people will receive, and the outcomes of financial assessments already undertaken, it has been possible to estimate the additional future contributions as ranging from zero to £15.

Appendix 7 reflects this in further detail.

4.2.4 It should be noted that it is possible some people could pay more than £15 extra per week but this would be as a consequence of people who currently do not require home care receiving a half an hour home care call as a replacement service for each meal. In practice, this is an unlikely commissioning decision (unless someone's needs had increased in which case that isn't the impact of the review implementation but of changed personal circumstances) and it is more likely that a customer would request an alternative service to avoid such a charge.

4.2.5 It is also possible that some people may no longer require a meal following a reassessment. This could be due to them having only required the meal for a time limited period, or due to improved circumstances meaning they are no longer eligible for services. This will be subject to individual assessment.

4.2.6 In addition, there are people who may be better off as result of the change if option 4 was implemented, by purchasing the actual food themselves for less than £3.05 they currently pay towards a meal. This could apply if a person:

- Received no replacement service and instead sourced ready meals from a supermarket, then there is the possibility they could get these for less than the £3.05 they currently pay.
- Had frozen meals delivered by a supermarket (or a family member) and then received a home care call to reheat these, then they could save money by paying less than £3.05 for the frozen meal itself. (Any contribution towards the home care call would offset any savings for the individual, but based on current information we know most will not pay for the home care).

4.2.7 Where people take a direct payment they would effectively have £5.33 to purchase a meal (£2.28 direct payment amount plus £3.05 contribution). If they are able to arrange a delivered meal for less than this then they could free up money to meet other eligible needs. Appendix 8 shows case study impacts for service users.

4.3 Customer "other" impacts.

4.3.1 There is the potential for qualitative impacts for some customers. For those who currently get a fresh meal delivered (Gujarati or African/Caribbean meals) and also get domiciliary care a likely alternative option, would be for the care visit to be extended so that meal support can also be provided. In these cases, service users are likely to have a chilled or frozen meal reheated which they may perceive more negatively than when they had fresh provision. However, service users could choose a direct payment in order to continue the same meal type if it was preferable.

4.3.2 All customers will be reassessed and supported to find alternative options. It is possible that some will no longer be eligible and in this case people will be signposted to alternative options that people can organise themselves or with the support of family. Reassessments will also include an assessment of people's need for social interaction and ensure that need is met with appropriate

support planning.

- 4.3.3 **Workforce impacts.** This will be dependent on the option chosen, if the decision is to close the service then all posts would be deleted and post holders would be redundant. If it is one of the other options, there may be TUPE implications. See further information below on TUPE. These changes are likely to have an impact on employee relations and staff morale. See section 6.4 below for further detail.
- 4.3.4 **Provider impacts.** For both external providers, loss of a contract would have an impact on their viability and provision of other services. However, both responded to the soft market testing exercise and are potentially willing to continue to provide services privately or as part of a contracted service with the Council. Both currently have private customers and would also be looking to develop this area further. Internal provider impacts are covered in the workforce impacts above.
- 4.3.5 **Council financial impacts.** See section 6.1 below. In summary Option 4 will enable the Council to achieve approximately £213k savings per year based on current projections (please note these are only an estimate and final savings will be based on individual choices and options).
- 4.3.6 **Winter Pressures.** It has been suggested that the loss of the mobile meal service we currently commission will cut people off from contact with people who can check on wellbeing / raise an alarm. However, as every person who is requiring assistance will continue to receive it, this is not felt to be a risk. As this is a targeted service, like other ASC provision, it cannot substitute for citizenship, neighbourliness or family care and oversight of our older population.
- 4.3.7 **Equalities impacts.** See section 6.3 below. In summary, some service users may pay more in future, which impacts on older people and those with disabilities. Depending on meal type chosen, there may also be a disproportionate effect on those using a direct payment to purchase a fresh African/Caribbean meal or Kosher meal as these appear to be more expensive. At present this only affects a small number of people (twelve). If these users continued to have a meal from the Council framework this would be charged at a flat rate and the impact would be removed.
- 4.8 **Other impacts.**
- 4.8.1 The Council will need to ensure robust project planning so that during the transition no one “slips through the net”, that is to say that we ensure current customers are tracked and that a suitable alternative is in place before existing provision ceases. This will be part of the reassessment work stream. Where service users fall out of eligibility the Council needs to provide good reasons for the withdrawal and ensure an individual’s needs are not worsened by that withdrawal. Workers should also ensure they have information on appropriate alternatives.
- 4.8.2 There is a need to undertake a procurement exercise to ensure we have alternative hot meals provision. This will only be for a relatively small number of people. Therefore it is possible that economies of scale mean providers will not

be able to offer competitive pricing. However, indicative findings suggest this will not be the case. See the soft market testing at appendix 5 for more detailed information. Linked to this procurement is potential TUPE risk – highlighted in section 6.2.

5. Tell us how this issue has been externally scrutinised as well as internally?

5.1 ASC Leadership Team and the Assistant Mayor for ASC

5.2 The following stakeholders were also informed of the consultation with the opportunity to provide their views and those of the people they represent:

- Elected Members and Local Members of Parliament
- Trade Unions and staff at the in house service (transport and catering)
- The two external providers
- The general public via the Council website
- Forum for Older People
- The Carers Reference Group
- The 50+ Network
- Discuss (Disabled Customers Group)
- Leicester Centre for Integrated Living (LCIL)
- Age UK
- Alzheimer's Society
- Healthwatch

6. Financial, legal and other implications

6.1 Financial implications

6.1.1 The budgeted saving for the mobile meals service is £158k in 13/14, rising to £248k from 14/15 onwards.

6.1.2 Based on the forecast cost and number of meals, the average gross cost per meal for 13/14 is expected to be in the region of £8.70. Over the last 3 years the unit cost has increased by an average of 17% per annum. It is forecast that the unit cost could rise to around £12 over the next 3 years. Department of Health guidance (Fairer Charging) restricts the extent to which the charge to eligible customers could be raised to cover this increasing cost, since the charge can only 'substitute for ordinary living costs'.

6.1.3 Option 1 of doing nothing is not financially viable since it would lead to rising costs and not deliver against the savings target. It does not represent good value in meeting customer needs.

6.1.4 Under Option 2, if the number of meals being delivered could increase through selling to self-funders then the unit cost would fall. PSSRU (Personal Social Services Research Unit) has estimated that self-funders number around a third of the eligible customers supported by Local Authorities. Financial information in relation to Option 2 has been requested from Education and Children's Services

to establish the likely fall in unit costs, but at this stage it is considered unlikely to reduce significantly. This is because it would be necessary to charge self-funders a much higher rate (perhaps the full cost), which would be prohibitively expensive for many.

- 6.1.5 Under Option 3, the contractual arrangements of the County would need to be explored further to establish whether joint contracts could significantly reduce costs. Transport costs would likely be much higher in the County and the types of meal being delivered be less varied. This could increase the complexity of such a contractual arrangement, and reduce the potential savings.
- 6.1.6 Option 4 of contracting out the mobile meals service would lead to annual savings in the region of £213k. There would be additional costs incurred in terms of staff time spent on the procurement process and the on-going monitoring of contracts. The actual savings would be determined by the outcome of each assessment and the selection of any replacement services.
- 6.1.7 Option 5, involving an increased use of managed direct payments to meet people's needs would lead to annual savings in the region of £206k. As with Option 4, the actual savings would be determined by the outcome of each assessment and the selection of replacement services by each customer.
- 6.1.8 The savings for all options shown above are against the full current cost of providing the service, including van leasing costs. Edward Street Kitchens, where some meals are currently re-heated, had a cleared-site valuation of £130k in 2011. Those options which would lead to the closure of these kitchens (options 3, 4 and 5) could therefore result in an additional one-off capital receipt of this amount.

Stuart McAvoy - Adult Social Care Accountant

6.2 Legal implications

6.2.1 Community Care Law

Legal advice has been sought on the implications for service users from a Community Care Law perspective and consideration needs to be given to the Council's public law duties under section 149 of the Equality Act 2010 when undertaking assessments of need and considering suitable alternative provisions for service users subject to their individual needs. The Local Authority also must bear in mind its legal obligations as prescribed under section 117 of the Mental Health Act 1983 which provides for provisions without charge to the service user, Sections 2 (1) (a), 2 (1) € and 2 (1)(g) under the Chronically Sick and Disabled Act 1970 in respect of the provision of meals for disabled persons and the Health Service and Public Health Act 1968 section 45 (DHSS circular 19/71) which makes provision for meals and recreation in the home or elsewhere for elderly persons. A failure to adhere to these duties could result in a legal challenge by way of judicial review.

Legal advice should continue to be obtained as and when necessary.

Pretty Patel - Principal Lawyer, Social Care and Safeguarding

6.2.2 TUPE Implications

All five options proposed are likely to result in employment law implications either by way of changes to terms and conditions, redundancy and/ or transfers of staff either in or out of the Council under the transfer of Undertakings (Protection of Employment) (“TUPE”) Regulations 2006.

It is advised that Legal Services are consulted throughout to ensure that the Council complies with its legal obligations and to ensure that the risk of claims is minimised.

Hayley McDade, City Barrister

6.2.3 Contracts Law

The conflicting consideration with public procurement law is in respect of the statutory Best Value Guidance 2011 and the public law duties in accordance with S149 as mentioned by my work colleague above. This impacts upon the reduction or cessation of services as per the recommended Option 4. Not complying with these obligations will place the Council at a high risk of a public law challenge. I understand the first part of the consultation process has already been concluded.

If it is agreed to implement Option 4 then, the client must serve 12 weeks’ written notice to terminate the Service, to continue with the application of the Best Value Statutory Guidance. This notice period is not aligned in the original contracts signed back in 2009.

Nimisha Ruparelia - Commercial Contracts Solicitor

6.3 Equalities Implications

6.3.1 the current 236 users of the mobile meals service, the main relevant protected characteristics influencing their needs are age, disability, race, religion and belief, and gender. Over the past few years users of the service have increasingly chosen to leave the service and source their meal requirements in other ways. The remaining users have expressed a range of concerns about potentially negative impacts that ending the current service will have: loss of social contact; concern about continuing to have their nutritional and cultural/religious food needs met to the same level; and continued provision of a hot meal. The recommended proposal aims to address these negative impacts through a range of mitigating actions that will enable the service user to choose the most appropriate options for themselves which best meets their meal needs and suits their practical arrangements.

Irene Kszyk - Corporate Equalities Lead

6.4 HR Implications

- 6.4.1 If the proposal is approved there will be 19 staff (8.93 FTE) that would be affected. There will be no requirement for redundancy selection as it is proposed that all City Council posts involved in the mobile meals service are to be deleted and therefore the post holders would be compulsorily redundant.
- 6.4.2 It is envisaged that there may be a possibility to offer the catering staff suitable alternative employment within the schools catering service. Similarly there may be suitable vacancies in PATS which may be offered as suitable alternative employment. It is also proposed that voluntary redundancy will be offered within the PATS service area that could be considered as a release for “bump-on” if there are no vacancies available.
- 6.4.3 If the proposal is approved and failing the above strategies, qualifying affected employees will be placed on the redeployment list. This will afford them the support of a redeployment officer who will assist them to apply for suitable alternative employment and offer guidance around redundancy payments and rights if applicable. They will also be offered support through the Council’s outplacement service and AMICA.
- 6.4.4 Following the consultation process, if the proposal is approved, staff that do not secure alternative employment either in the same service or through redeployment will be identified as redundant. Any subsequent dismissals would be on the grounds of redundancy with the required notice period.
- 6.4.5 Any dismissals will be effected by the issue of notice of termination giving the relevant statutory or contractual notice period, whichever is greater.

Jagruti Barai – HR Advisor

7. Background information and other papers:

4th October 2012 Future of Mobile Meals executive report

8. Summary of appendices:

Appendix 1 Consultation approach

Appendix 2 Staff feedback

Appendix 3 Union feedback

Appendix 4 Consultation findings

Appendix 5 Soft Market Testing

Appendix 6 Equality Impact Assessment

Appendix 7 Financial analysis

Appendix 8 Customer Scenarios

9. Is this a confidential report (If so, please indicated the reasons and state why it is not in the public interest to be dealt with publicly)?

No

10. Is this a “key decision”?

Yes

Appendix 1 - Consultation Approach

Statutory consultation was carried out between 9 July and 7 October 2013 on the future of Leicester's Mobile Meals service. The proposal that we consulted on was:

Stopping the Council's current mobile meals service and helping people to prepare or obtain meals in alternative and more flexible ways.

Comments were invited on the proposals from people who receive mobile meals, their families and interested parties. The following methods were used.

Letters and questionnaires to service users

Letters and questionnaires were sent to everyone who was using the mobile meals service on 9 July 2013. An information booklet and a frequently asked questions booklet were also included. All of these were made available in different formats or languages where requested. A prepaid envelope was supplied to allow people to respond as easily as possible. If anyone felt that they would have difficulty in filling in the questionnaire, an officer was available to visit them and assist.

A reminder letter and another copy of the questionnaire were sent out on 23 September 2013 to give people a further opportunity to respond if they hadn't already done so.

On line questionnaire

The questionnaire was made available on the Council's website for anyone to fill in.

Focus groups

Two focus groups were held for service users or their relatives/carers. There is nothing to report back on these as only one person took up this opportunity. A one-to-one meeting was held with this person to discuss the issues and take the person's views through a questionnaire.

One-to-One interviews and additional support

The documentation was provided in different languages on request and, where appropriate, the information was converted to Easy Read and/or support workers assisted customers to understand the proposal so that they could contribute if they wished. Officers visited customers in exceptional circumstances to help them fill in the questionnaires. There were two such visits.

Key stakeholders, councillors and MPs

Letters were sent to various groups representing the wider interests of older people, including Healthwatch and Age UK, inviting them to take part in the consultation. Various forums were also consulted, such as the 50+ Network, Carers Reference Group, Discuss (Customer User group) and Forum for Older People. Each Leicester City councillor and MP was also written to about the proposal. Cllr Lynne Moore was also written to in her role as chairperson of the Adult Social Care & Housing Scrutiny Commission Chairperson.

Helpline

A dedicated helpline was available for people to discuss any issues between 8.30am and 5pm Monday to Thursday (4.30 on Friday).
All calls to this number were logged and responded to appropriately.

Email

A dedicated email address was set up for people to contact the Council via this means if they wished.

Letters to and meetings with current providers

The two current external providers of meals on behalf of Leicester City Council were sent a letter informing them of the proposal. Individual meetings were held for each provider to discuss their views and concerns. Notes were taken of the comments raised at these meetings and they were invited to submit further responses if other issues came up as a result of the meeting.

Staff and trade unions

Meetings were held with staff of the internal services (catering and transport) and trade unions and their views gathered.

Appendix 2 – Staff Feedback

MEETING WITH STAFF

Notes of meeting on 17 September 2013

Management attendees:

Jan Dudgeon, Jane Faulks, Mercy Lett-Charnock, Jagruti Barai

Unions Representatives:

Minesh Patel – Unite, Dave Taylor – Unite, Billy Baksh – GMB, Christine Reader – GMB, Steve Barney – GMB, Gaynor Garner – UNISON

JF opened the meeting and explained the background and reason for the meeting. JF confirmed that the consultation on the proposals to close the service started on the 7 July 2013. This meeting was to provide a further opportunity for staff to feedback any comments verbally in addition to the other methods i.e. via the trade unions, e-mail or telephone to the project team.

The following comments were received.

1. Staff will be losing jobs
2. Service users will not be getting a meal

MLC commented that the proposal was about ceasing this service, not meals support as the Council still had a duty to ensure people can obtain or prepare a meal.

3. The unions added that the consultation on the proposals with service users was not good enough, particularly those that cannot read or are not mobile enough to attend the focus groups

MLC confirmed that there was a help-line number and the option of a 1:1 meeting had been offered to users. Interest groups such as the Forum for Older People had also been attended as these groups represent the interests of mobile meals users.

JB confirmed that further consultation on redundancy would take place if the decision is to close the service, but stated that attempts would be made to redeploy staff into other roles wherever possible.

4. BB queried why consultation did not take place when there were more service users.
5. Some users had stated that Social Workers are not promoting the service and telling clients that the service is closing, this issue goes back 2 years.

6. In the 2009/2010 budget the proposal was to cut the service, if this process had started then, then there would have been wider consultation.
7. A concern was raised about giving out personal data of clients i.e. key code numbers to a third party and compliance with the Data Protection Act.
8. It was also raised that all budget cuts of late are affecting the old and vulnerable.
9. Staff understood the service to be closing in December.

MLC confirmed that the service was not closing in December, no decision has been made and the earliest would be in June 2014.

10. The number of meals delivered had been declining over a 2 – 3 year period; this had been raised with management with no action taken to improve.
11. Concern was raised about the service users, as when the meals are delivered this is the only contact they have with anybody in the day.

MLC confirmed that alternatives would be in place so all clients that have been assessed as requiring a meal would get a meal, this could be provided through a carer if required and therefore reduce their isolation.

12. Concern was raised about warming meals in a microwave, potentially they are not cooked properly, and concern was also raised that the meals could end up being sandwiches and soup.
13. It was felt that the service was required in the community and that there was a demand for it but it wasn't being offered any more e.g. to those leaving hospital. More advertising should be done.
14. It was also felt that this situation could be turned around and referrals increased. Money was being spent elsewhere on unnecessary projects such as the Market redevelopment. It was seen that Council staff were too expensive and a cheaper option was being sought.
15. Concern was also raised about Health & Safety and hygiene of any alternative providers.
16. Questions were raised about alternative employment options. JB confirmed that if a decision to cease the service was made, further consultation would be undertaken around redundancies.

JF thanked all for their comments and re-iterated that further comments could be made either via e-mail or telephone or through the unions to the project team. The closing date for the consultation was 7 October 2013.

JF confirmed that these comments would be fed into the report for the Executive.

Additional member questions put forward (in writing) to the staff meeting:

1. Even though there has to be money cut backs why does it have to be in the old and vulnerable?
2. Meals has been going down for well ever two and a half years, all meals on wheels staff have been concerned and regularly brought it to the attention of the office staff and of course Jan, Sheila and Anisha.
3. We were told social services were going round and telling service users they no longer could have meals, in fact to the old. One could say it was bullying tactics.
4. All our service users are old and most of them only see the meals/staff each day have you thought you are taking that safe/care line, away from them do you really care!
5. To issue microwaves, I have witnessed what carers do yes put meal in, blast away ding - done, put on service user's lap say goodbye and away we go – service user got hot meal on outside – COLD in the middle, they don't have time.
6. Family of service users don't think very highly of Leicester City Council and what they are proposing, it is a service that is required in our community. We are all caring and work to the best standard it's not just delivering a meal, it's being the 1st person if there is an emergency, even fatal we report, ring emergency services, wait with them, surely it's a service that is required?
7. This is on your behalf about the money, we could turn this around and go back to getting referrals, there are a lot of elderly out there that need this service. Surely you can cut back elsewhere office staff – spending money in e.g. Leicester market – that wasn't all that long ago all that money spend councillors pay rise etc

50+ NETWORK

Extract from the minutes of a meeting on 29 July 2013

Mercy Lett-Charnock, Lead Commissioner for Early Intervention and Prevention at LCC, gave a presentation about “Mobile Meals” and took questions from the floor afterwards. Mercy invited those present to participate in the consultation that runs until 7th October. Further information can be found at:
<http://consultations.leicester.gov.uk> or by telephoning 0116 252 8301.

CARERS REFERENCE GROUP

Extract from the minutes of a meeting on 29 July 2013

Mobile Meals Consultation

Mercy-Current consultation. Numbers of people having meals is dropping. Only 264 have the service. Flexibility and quality an issue. The proposal is to stop the meals but to find a good replacement that people want.

Ranjit- Asian people she has spoken to, don't like them.

One person has an agreement with a shop to supply his meals.

Mercy is going to the 50 plus network this pm and there will be focus groups on the proposals.

Gill raised the issue of isolation as a big problem. Mercy- This should be picked up on an assessment of need. Feedback welcome.

FORUM FOR OLDER PEOPLE

Extract from the minutes of a meeting on 29 July 2013

The Chair introduced the item commenting that a review of the current mobile meals arrangements had begun. She asked Forum Members to note that customers currently in need of the service would still be provided for but that the existing arrangements of the service were likely to be altered given the current cost implications.

The Director of Care Services and Commissioning gave a presentation on the existing arrangements, together with the scope of the consultation and the current cost implications to the Council. The presentation focussed on the proposal to stop the Council's current mobile meals service and to help people to prepare or obtain meals in alternative and more flexible ways.

Forum Members were encouraged to take away and complete questionnaires provided. Other consultation material was made available including guidance on completing the questionnaire and information on frequently asked questions. It was noted that Focus Groups had also been arranged for customers and carers in order for views on the proposals to be submitted.

In reply to questions it was confirmed that the consultation would involve a wide range of stakeholder groups and external organisations. Officers also agreed to report back to the Forum on the result of the consultation and on future changes to the service.

DISCUSS

Extract from the minutes of a meeting on 10 September 2013

Mercy Lett-Charnock talked about the mobile meals consultation taking place at the moment.

People have more choice and control over the services they receive. People are given a personal budget, so they can buy the services they need from a range of providers. This is having an impact on traditional services, such as mobile meals.

For every meal it costs the council additional £4.76 on top of £3.05 paid by the customer. The cost to the council is going up for mobile meals. Number of people using mobile meals is dropping. People are choosing other options such as ready meals.

Alternative options include:

- Having a personal assistant to help with meal preparation
- Having a domiciliary care worker reheat a ready meal delivered by Tesco for example
- Having local or national organisation deliver a mobile meal

The Council is looking at how to meet people's needs more effectively to support them to live in the community using services that meet their needs.

City transport delivers the meals between 11am and 2pm. Some people would prefer an evening meal but this cannot be provided by the current service. The figures show that number of mobile meals customers are dropping. Some service users are using their personal budget to have meals delivered and reheated by a personal assistant.

The proposal is to stop providing the mobile meals service by May 2014 and to help people prepare or obtain meals in more flexible ways. Service users will be supported to organise suitable alternative support that meets their need for food preparation.

If the proposal is agreed reassessments will start next year. All service users will also be reassessed to ensure they are not socially isolated and see how they can best be supported. The consultation runs from 9th July to 7th October 2013.

xx asked about what the council is doing to promote mobile meals.

Mercy said people were choosing other options such as talked about supermarket home delivery and people getting personal assistant to reheat meals but the Council service was still being offered.

xx said that people will feel lonely and isolated. There should be more activities in community like lunch club where people can go once a week. Elderly people might not want people coming in their home to heat meals.

Yasmin talked about a lady who is blind, as part of her package somebody takes her out for lunch once a week.

xx said that it could be that people are not happy with the quality of mobile meals. Elderly people will be worried if mobile meals service stops.

Mercy said that everybody who is eligible will get a meal in different ways that suits them and whether people might be lonely or isolated is considered as part of the assessment.

Mercy asked people to feed their views into the consultation if they had anything further to add and left copies of questionnaires.

Appendix 3 – Trade union feedback

MEETINGS WITH TRADE UNIONS

Below are the minutes from three meetings held with trade union representatives:

9th July 2013

Present: Ty Denton (Unite), Jan Dudgeon (Head of Service Passenger and Transport Services), Jane Faulks (Head of Service City Catering), Jagruti Barai (HR advisor), Tracie Rees (Director Care Services and Commissioning), Mercy Lett-Charnock Lead Commissioner Early Intervention and Prevention

Tracie Rees welcomed the group and explained members of the other unions had been invited. Ty suggested there may have been a clash with another meeting. Tracie confirmed no apologies had been received.

The purpose of the meeting was to outline the issues in relation to the provision of mobile meals. She outlined the issues for the service as follows:

The service was for Adult Social Care users who were unable to prepare or obtain a meal. This is not about food but about preparation and delivery. There has been a rapid decline in numbers using the service. Personalisation means that people can choose from a range of providers not just Council services and people are increasingly choosing other options such as home deliveries from supermarkets or personal assistants to support with meal preparation. In addition there is some variation in quality and satisfaction with meals – some being reheated from frozen and some prepared freshly. The Council subsidises the service – each meal costing the Council £4.76 at present and will increase.

Ty asked how much this was due to increase by. Tracie said that we do not have exact figures at this time but forecasts indicate this cost will continue to rise and are becoming unviable.

The Council is starting a public consultation today which runs until 7th October. The proposal is “Stopping the Council’s current mobile meals service and helping people to prepare or obtain meals in alternative and more flexible ways”. Letters are going out today to service users.

There will be staffing implications and potential redundancies for both City Catering and Transport. This is not the start of collective consultation, just a “heads up” about the consultation. It is likely collective consultation will start in September so that views of staff and Unions can be fed into the report to executive, so that they can make an informed final decision which is likely to be in November. Labour Group letters were given out to members last night.

Staff support will come from managers and Amica counselling service is also available. The Heads of Service will brief staff at 1.30pm today and letters will be given to each staff member.

Tracie stressed no decision has been made but the consultation is about closure of the current service.

Ty said this was not good. Tracie said that it was recognised how difficult this will be for staff but evidence is suggesting this is a service people are no longer wanting and other options are meeting their needs.

Ty asked if reducing costs had been looked at. Tracie said that as numbers are going down so fast it's hard to reduce costs as last year the Council subsidised the service by £396k.

Ty asked if the usual provisions were being made for staff. Tracie confirmed the redeployment policy would be applied. There would be possible options for Catering staff within schools and maybe options for Transport staff but compulsory redundancy couldn't be ruled out.

A briefing note was handed out to attendees.

Tracie confirmed the minutes from this meeting and the briefing note would be emailed to union representatives that had been unable to attend.

19 August 2013

Present: Ty Denton (Unite), Gaynor Garner (Unison), Steve Barney (GMB), Jagruti Barai (HR advisor), Tracie Rees (Director Care Services and Commissioning), Mercy Lett-Charnock (Lead Commissioner Early Intervention and Prevention)

Tracie Rees welcomed the group and explained it was being held at the request of the unions. Tracie had held a briefing for unions on 9th July, outlining the rationale for change. We are now in the middle of formal consultation. The issues are around declining numbers and the fact that the Council subsidy of approx. £400k is financially unviable. The proposal is to support people to access alternative services.

Steve asked how the consultation with staff had occurred. Staff were informed via a briefing after the trade union meeting on 9th July. Ty Denton and local reps were in attendance.

Jagruti explained that collective consultation regarding redundancies would not commence until after a decision had been made in November as service closure may not be the outcome. However, we do want staff and unions to feedback on the service proposal – including offering alternative proposals for consideration. This will feed into the executive decision making process.

Jan Dudgeon met with staff on 10th after they had had time to consider the information. Staff have been told how to bring issues forward to feed into the consultation.

There will be a meeting in September for unions again to feed in comments, queries and alternative proposals. Unions are requested to give their availability for week commencing 9th September so this can be arranged.

Gaynor asked about the business case stating that there were alternative posts for redeployment – were there enough? Jagruti said there were. However, some staff have two jobs and therefore the hours may not suit them. This will need considering individually.

Ty asked why the numbers had dropped so dramatically – he did not think this was all due to personalisation alone.

Tracie responded that eligibility criteria are for substantial and critical needs and these are being applied strictly. In addition, people are now being offered direct payments and people are using these to choose options such as personal assistants and this has contributed to the drop.

Steve said that the Council isn't promoting its' own services and this is being used as a way of cutting staff.

Tracie responded that we cannot make service users use Council services, we have to give choice. Steve re-iterated that this should be a balanced choice, not just promoting non-Council services. There should be a balance on promoting Council and non-council services. Tracie confirmed that staff are offering both to service users. The current service is somewhat restrictive in what it can deliver and when. Some people don't like the food and some people don't want a lunchtime meal. Chilled supermarket meals that can be warmed up are a good option for some people. Other people are getting someone in to support them to cook for them.

Steve asked about people with no family who may become malnourished. Tracie explained that the Council has a duty of care and this would not change.

Gaynor asked about other options. Mercy explained this could be a direct payment which would mean people can chose whatever they want. Other options could include an alternative hot meal provider, supermarket meals, a personal assistant or homecare. It would depend on individual need and social isolation would be considered as part of the assessment.

Steve said we would know if people were eating the meal when empty plates were collected but Tracie said the current service does not provide this, empty plates are not collected. Home care is a good option if people need this level of support.

If the proposal is agreed, people will need to be assessed and supported to find an alternative. If people need support they will still get it, it could just be from another provider.

Steve asked if we were using the Council service as a second class option and again asked whether services were being offered equally. Tracie said she had no evidence to the contrary and would like Steve to share this with her if he had any.

Ty requested a full breakdown of the decline in numbers and details of the assessment criteria.

Gaynor asked if unions were present when managers met with staff. They were on the day of the briefing.

Gaynor has requested that when Jan and Jane meet with staff again to invite unions to attend.

Jagruti requested availability for the union meeting in September.

Tracie thanked everyone for their attendance.

16 September 2013

Present: Ty Denton (Unite), Janet McKenna (Unison), Steve Barney (GMB), Jagruti Barai (HR advisor), Jane Faulks (City Catering), Anisha Mistry (City Transport), Mercy Lett-Charnock (Lead Commissioner ASC)

Mercy welcomed the group and explained it was a further opportunity to put forward views or raise questions in relation to the consultation proposal. Tracie Rees had held a briefing for unions on 9th July, outlining the rationale for change and a further meeting had been held on 19th August. Consultation runs until 7th October and there will be a meeting with Catering and Transport staff tomorrow which union representatives are also attending.

Ty said that his concerns were the same as those raised at the last meeting, namely that it wasn't fair as it is felt to not be an even playing field as there is a view that the current service is not being promoted by staff. There is a belief that personalisation is not the only reason for numbers dropping.

Janet asked if we knew why people stopped using the service – did we canvas people's views. Mercy responded that whilst people weren't asked why they stopped using a service, some information was available from their assessment and reassessment information. This was not qualitative as it was as a result of some tick box options but some information could be gathered. Mercy will provide this information as it was gathered for a FOIA request but recalls there was a variety of reasons. Ty asked if any stood out - from memory, Mercy said none did but would provide the information.

As per the last meeting a tighter application of eligibility criteria was also discussed.

Janet asked if Scrutiny had called this in. Mercy said Cllr Moore was informed on 9th July but it hasn't yet been called in but could be at any time.

It was said that there was a rumour the service would be finishing at Christmas. Confirmed an outcome would be known after the report goes to the executive – planned for November. However, implementation would take time so even if the decision was to close the service December would be too early.

Jane said that some of the catering staff expressed an interest in going on to escorting duties, there was also likely to be posts available in catering – short hours particularly. Jagruti confirmed that if a decision was taken to close, consultation on alternatives would start after the executive decision.

Anisha said that some of the transport staff were concerned about the people who get meals as they have a connection with customers due to the delivery. The consultation is about this service ceasing not meals support. The Council will still have a duty to support people who have an assessed need.

Janet asked about the costings as staffing is usually the most expensive element of the service. Mercy confirmed this. The £3.05 contribution from clients was for food, the remainder was other costs.

Janet also queried whether the Direct Payment amount would be sufficient to meet people's need as she couldn't see how the alternative would be cheaper than the current service. Mercy said that there may be several possible alternatives but one of those could be that customers have to pay more.

It was commented that day centres and EPH's as well as mobile meals are political issues and vulnerable people are getting hit.

Steve also raised that there are ways of promoting the service. The council could have carried out a trial of how promoting the service could impact on numbers using the service. Raising the charges could also be considered – if numbers increased the service would be more viable. Had the Council considered increasing the charge?

Jane asked how this would be done as drivers etc. couldn't do this. Steve said it would be assessors (care management staff) that would need to do that.

Steve commented that some service users have good relationships with the people that deliver and without a meal they may deteriorate and could end up costing more. Need to understand the unintended consequences of making the change. Mercy responded as before the Council would still have to provide a service to those that need it. However, Steve was concerned about those who don't meet the criteria now the bar (or eligibility) is perceived to have been set higher. Steve asked if we could

guarantee everyone would get a suitable alternative and no one would fall through the gap. Mercy said the Council has a duty to do this and it would be individually assessed and if they were eligible would get an alternative to meet their need. Steve raised a concern about lack of confidence in the assessment process.

Janet asked how service users were consulted and what the response was. Mercy said she thought it was about 30% last time she had been informed and there had been service user focus groups offered as well as 1-1 meetings if people requested it. In addition representative groups such as the 50+ forum, older people's network, disabled customers group and carers reference group were attended. Concern was raised that those attending wouldn't be the vulnerable people who can't get out of the house. However, Mercy said that these groups are there to represent others and we have had a good response to the survey (numbers wise) and the phone line and questionnaire has given people an opportunity to contact us without having to attend meetings.

Jagruti asked whether the unions would be submitting a written response or whether the minutes of the meetings would suffice. This may vary from union to union so the minutes will be used to feed into the process, along with anything else received.

Mercy thanked everyone for their attendance and confirmed the information requested and notes would be circulated.



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UNISON'S RESPONSE TO THE PROPOSAL TO STOP RUNNING THE COUNCIL'S MEALS-ON-WHEELS SERVICE

There are some concerns from UNISON that there has been a significant decline from 2010 where there was 1,252 people using the service to May 2013 where there are now 269 people using the service. We are convinced that this reduction in service-users is not just down to numbers using the service dropping and personal budgets.

We believe there has been a deliberate attempt not to refer service-users from 2010; this was echoed in the meeting held with the staff on 17 September 2013 affected by the proposals where a number of them expressed concern that social services were telling service-users the meals-on-wheels service had stopped running and that social workers have not been referring service-users to the meals-on-wheels service. There was also an example of a service-user of 18 years told to stop using the meals-on-wheels service.

UNISON have asked why over the last 2/3 years we have not canvassed people's views on why they have stopped using the service. An opportunity has been missed where a marketing campaign could have been launched to promote the in-house service.

UNISON also questions whether the direct payment amount would be sufficient to meet people's needs.

There are concerns over the quality of meals provided in the private sector and the health and safety implications attached to that.

Our in-house meals-on-wheels service goes that "extra mile" with service-users. They observe service-users and in some cases have even stayed with a service-user who needed medical attention. They have often passed concerns on to social services. Can we see the private sector doing that! Nutrition is a big part of the service-users well-being.

It is common for older people to be particularly vulnerable to malnutrition resulting in the prevention or recovery from illness and an increased likelihood of developing more health problems.

Gaynor Garner
(UNISON Social Care and Health Convenor).

CONSULTATION ON THE FUTURE OF MOBILE MEALS PROVISION IN LEICESTER

JULY – OCTOBER 2013

Findings report

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How to use this report

This report collates the responses from a statutory consultation exercise. The main body of the report summarises the responses from a variety of sources. Appendices 1 and 2 provide more detailed responses and comments. Any information that would allow for a customer or provider to be identified has been removed.

PART 1 - INTRODUCTION

Statutory consultation was carried out between 9 July and 7 October 2013 on the future of Leicester's mobile meals service.

The proposal:

Stopping the Council's current mobile meals service and helping people to prepare or obtain meals in alternative and more flexible ways.

The consultation was led by a small team of staff within adult social care.

PART 2 - METHODOLOGY FOR THE CONSULTATION EXERCISE

We invited comments on the proposals from people who receive mobile meals, their families and interested parties.

Letters and questionnaires to service users

Letters and questionnaires were sent to everyone who was using the mobile meals service on 9 July 2013. An information booklet and a frequently asked questions booklet were also included. All of these were made available in different formats or languages where requested. A prepaid envelope was supplied to allow people to respond as easily as possible. If anyone felt that they would have difficulty in filling in the questionnaire, an officer was available to visit them and assist.

A reminder letter and another copy of the questionnaire were sent out on 23 September 2013 to give people a further opportunity to respond if they hadn't already done so.

On line questionnaire

The questionnaire was made available on the Council's website for anyone to fill in.

Focus groups

Two focus groups were held for service users or their relatives/carers. There is nothing to report back on these. One person attended. A one-to-one meeting was held with this person to discuss the issues and take the person's views through a questionnaire.

One-to-One interviews and additional support

We provided the documentation in different languages on request and where appropriate, the information was converted to Easy Read and/or support workers assisted customers to understand the proposal so that they could contribute if they wished. Officers visited customers in exceptional circumstances to help them fill in the questionnaires. There were two such visits.

Key stakeholders, councillors and MPs

Letters were sent to various groups representing the wider interests of older people, inviting them to take part in a meeting and/or respond to the consultation in another way. Various forums were also consulted, such as the 50+ Network, Carers Reference Group, Discuss and Forum for Older People. Each Leicester City councillor and MP was also written to about the proposal.

Helpline

A dedicated helpline was available for people to discuss any issues between 8.30am and 5pm Monday to Thursday (4.30 on Friday).

All calls to this number were logged and responded to appropriately.

Email

A dedicated email address was set up for people to contact us this way if they wished.

Letters to, and meetings with, current providers

The two current providers of meals on behalf of Leicester City Council were sent a letter informing them of the proposal. Individual meetings were held for each provider to discuss their views and concerns. Notes were taken of the comments raised at these meetings.

Staff and trade unions

Meetings were held with staff and trade unions and their views gathered.

PART 3 – SUMMARY

The key findings from the consultation are as follows (a more detailed analysis can be found in Part 4 of this report):

Customers:

In general, customers either appreciate, or feel they rely on, the current mobile meals service and wish to continue receiving a hot meal. 56% of respondents receive a meal every day. The majority of those who responded (80%) still want a hot meal delivered to them and comments that several of them made show that they would prefer this to be through the Council as it is now. However, a few of the comments indicate that some people recognise that current financial pressures on the council and the availability of alternatives that weren't possible until recently, mean that the service needs to change.

38% of those who responded felt that the full cost would not be value for money. 33% felt that the full cost would be good or very good value for money if they were asked to pay the full amount. Comments made on the questionnaires indicate that there would be some people who would be willing to pay more for quality food, whereas others could not afford any increase.

A notable proportion (32%) of respondents felt that they would miss someone calling in on them daily and therefore the need for a meal was not their only benefit from the service. Some comments show that this is linked to concern about what would happen to them if they no longer received a daily visit. 30% felt that they would need help and support to find alternatives if the service was stopped.

A large amount of customers (46%) stated that they need appropriate meals for religious or cultural reasons and 62% have one or more specific dietary needs, the most common being vegetarian or diabetic. Some people have also commented that they are concerned that any new arrangements may not provide the nutrition they need.

Trade Unions, staff and stakeholder groups

The main concern was about isolation and welfare, particularly the benefits of a daily check. There was also a feeling that the Council had been deliberately running the service down. A suggestion was made that the service should be promoted to increase usage and make it more cost effective. It was also suggested that the reasons why the number had declined were not fully understood. They felt that there were risks if people went directly to providers who had not been vigorously quality-checked.

Current providers

Current providers had concerns about the potential for any change to impact on their business and other work that they do as a result. They felt that information could be

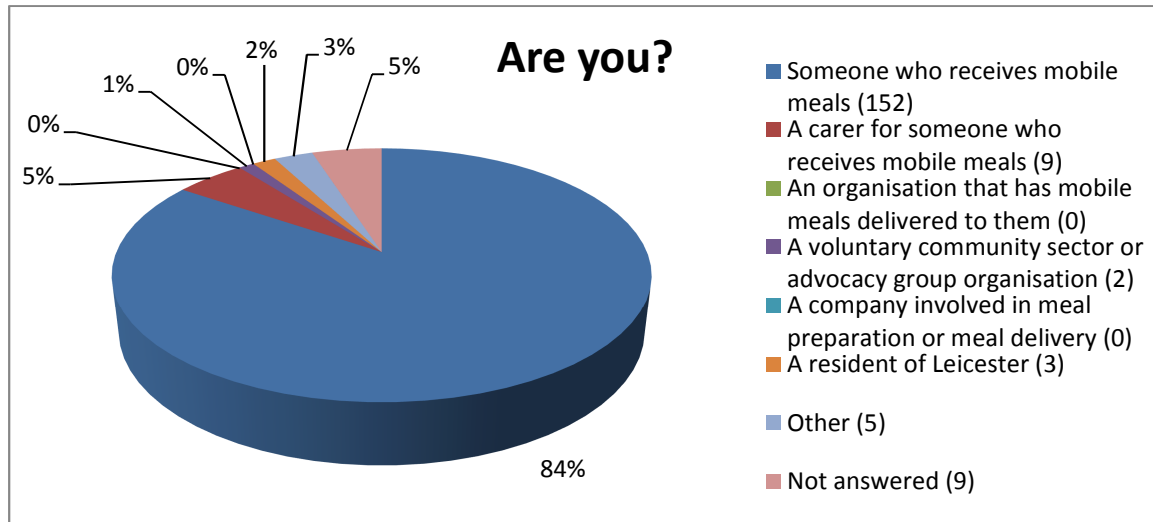
given to self-funders about providers, but that there could be risks if people chose cheaper options from places without such rigorous checks that they currently go through. They stressed the need for culturally-appropriate meals and that some types of food, such as Caribbean, cost more due to the higher cost of ingredients.

PART 4 - CONSULTATION FINDINGS

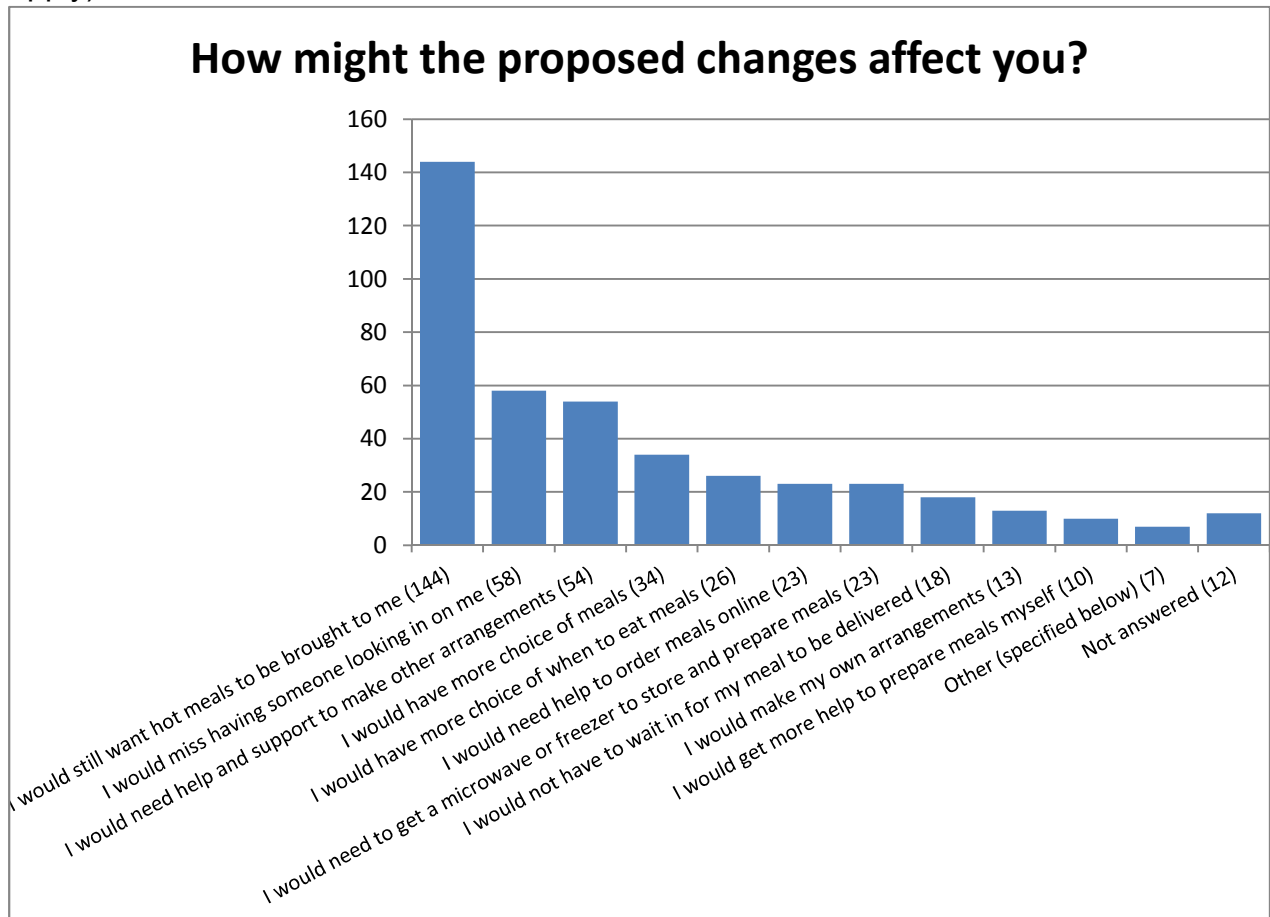
Questionnaires

- Number of questionnaires sent out: **261**
- Number of questionnaires returned: **177**
- Percentage return rate: **63%**
- Number of questionnaires filled in on the consultation website: **3**

Question 1 – Are you...?



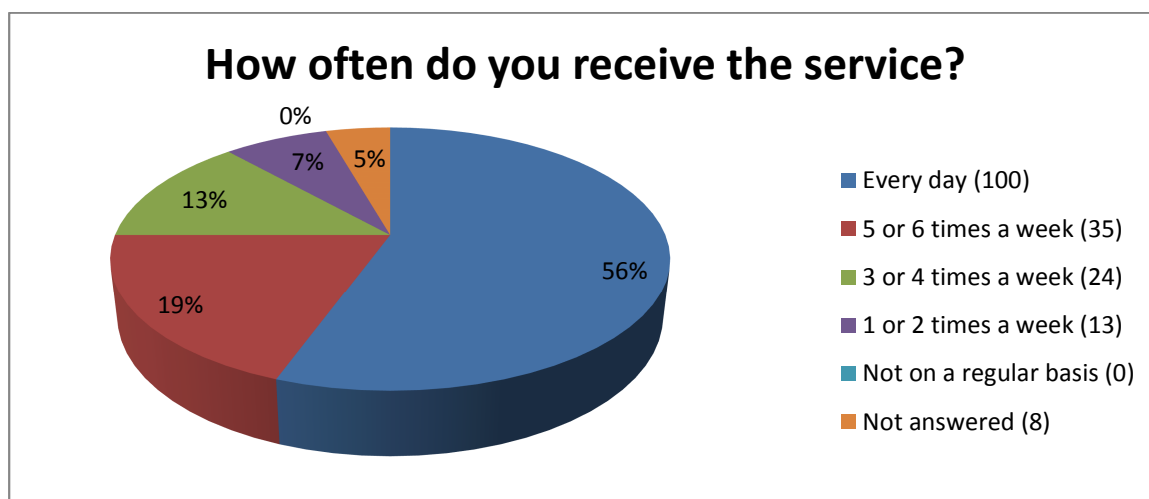
Question 2 – How might the proposed changes affect you? (please tick all that apply)



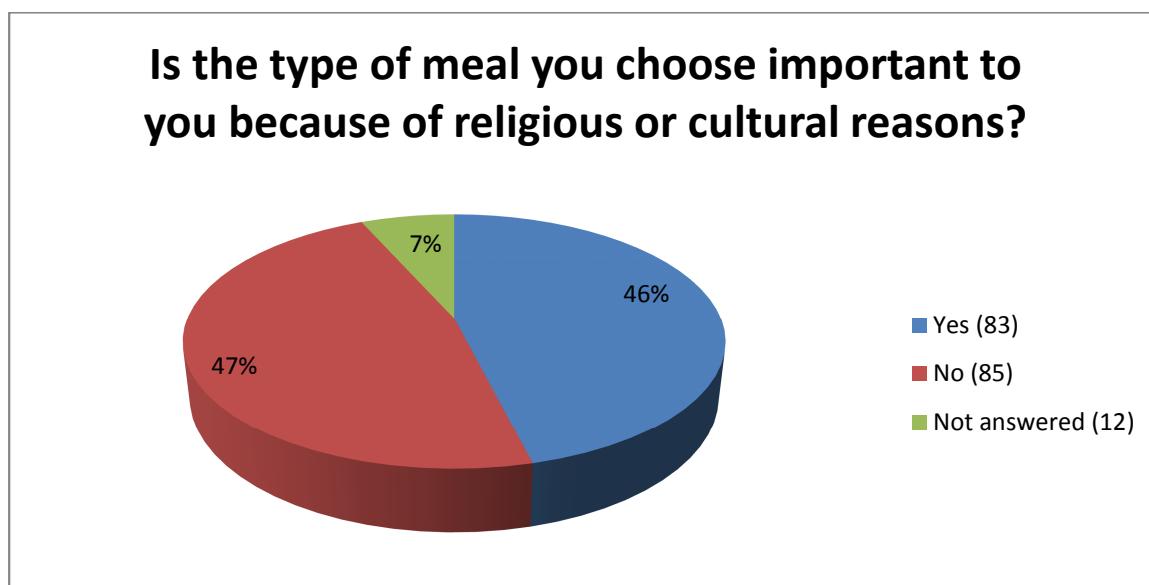
“Other:”

- My body is feeble. My mouth cannot chew hard crispy food. The meals I get currently are nourishing. I do not want change.
- Son lives outside Leicestershire. He would have to bring food in.
- No internet access
- Unable to do food myself safely
- Extra pressure on family to get meals in. Family members are already under immense pressure to care for family member at home.
- Community Centre running luncheon club
- Person would have no means of eating a main meal as intolerant of strangers except for MOW driver with whom he has built relationship over a number of years

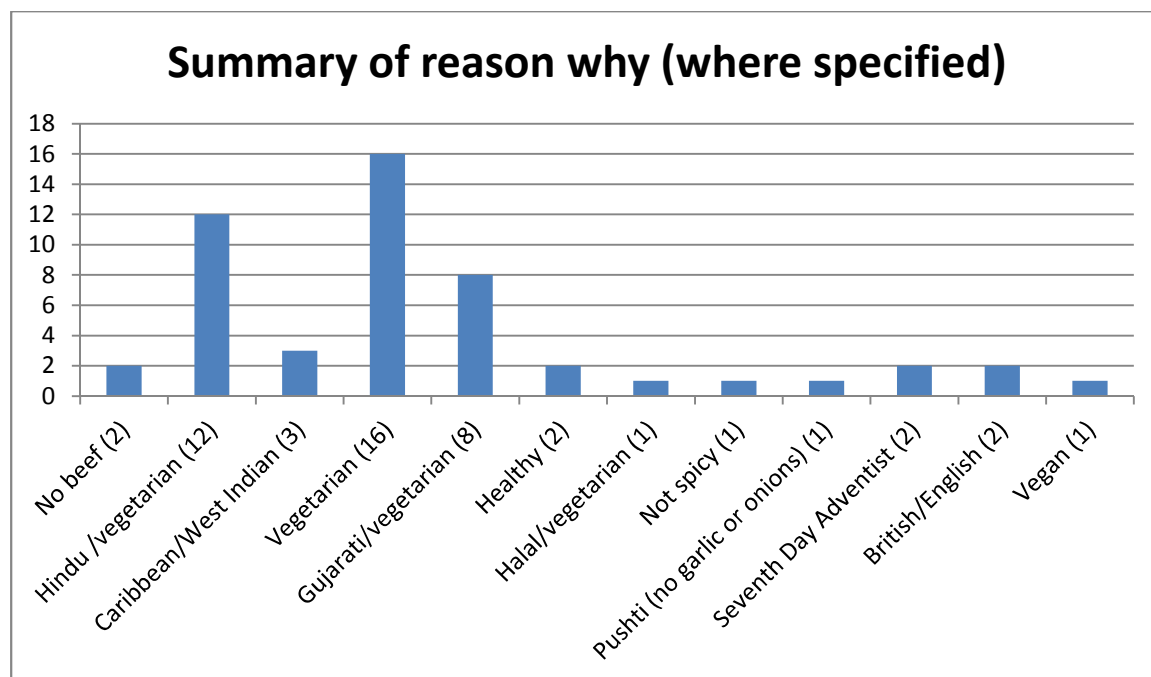
Question 3 – How often do you receive the service?



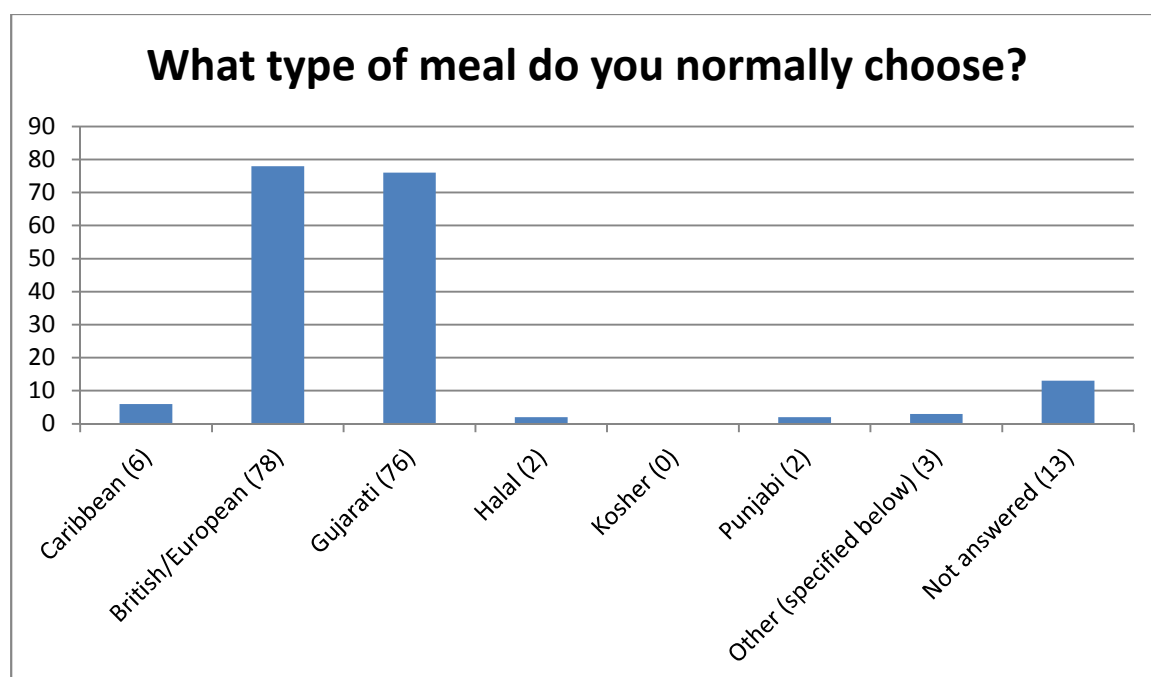
Question 4 – Is the type of meal you choose important to you because of religious or cultural reasons?



Summary of reasons given for why the type of meal is important:



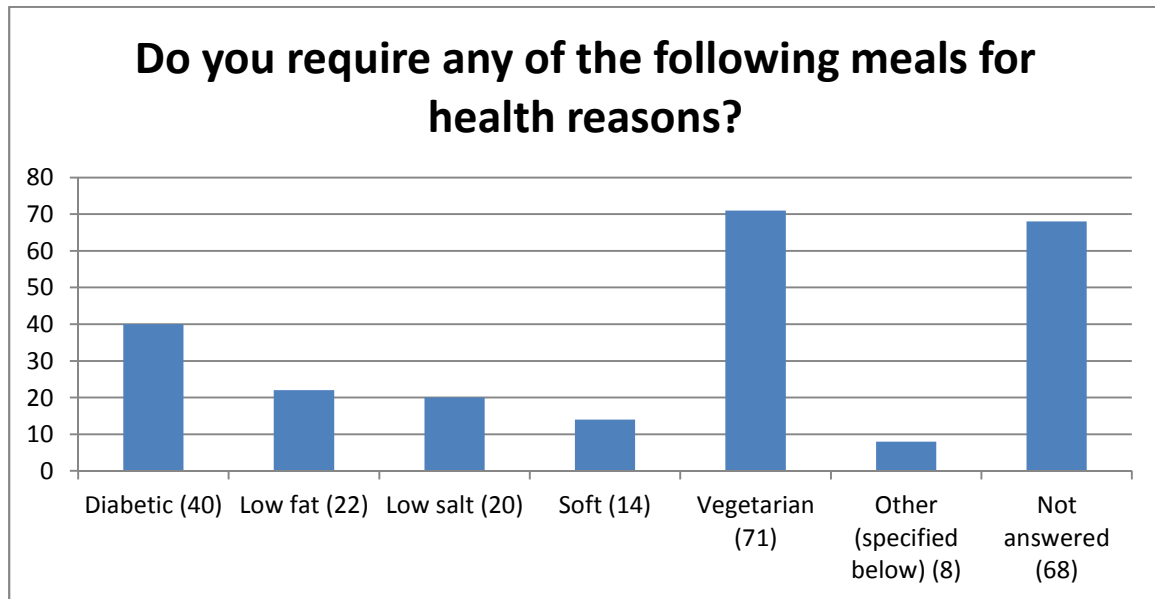
Question 5 – What type of meal do you normally choose? (please tick all that apply)



Other types of meal:

- Hindu
- English cooked meals (specific request for English, not British)
- Extra specially mild
- Chinese (amongst other choices)

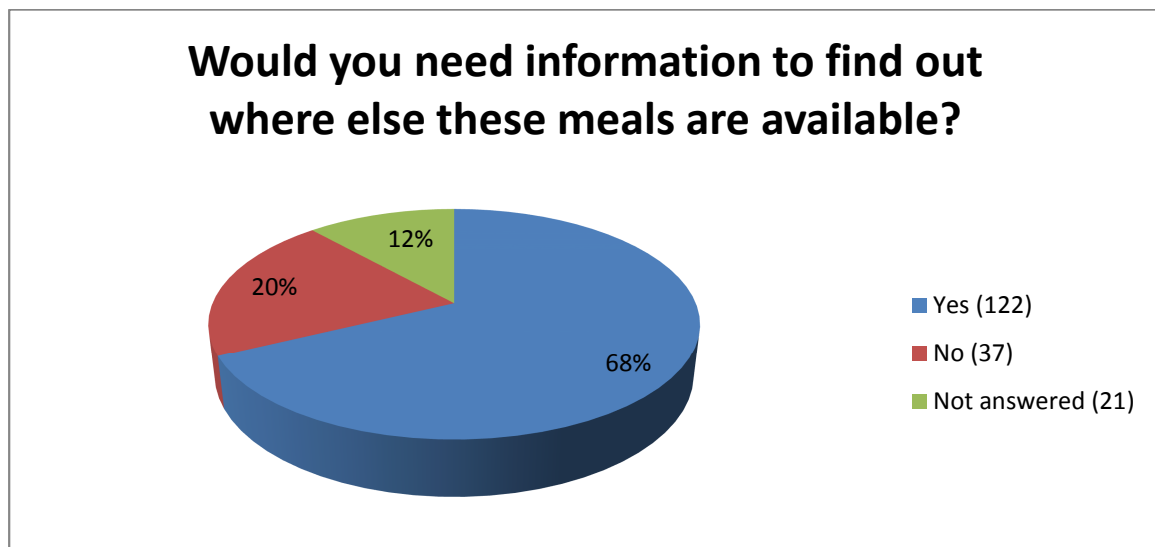
Question 6 – Do you require any of the following meals for health reasons?
(please tick all that apply)



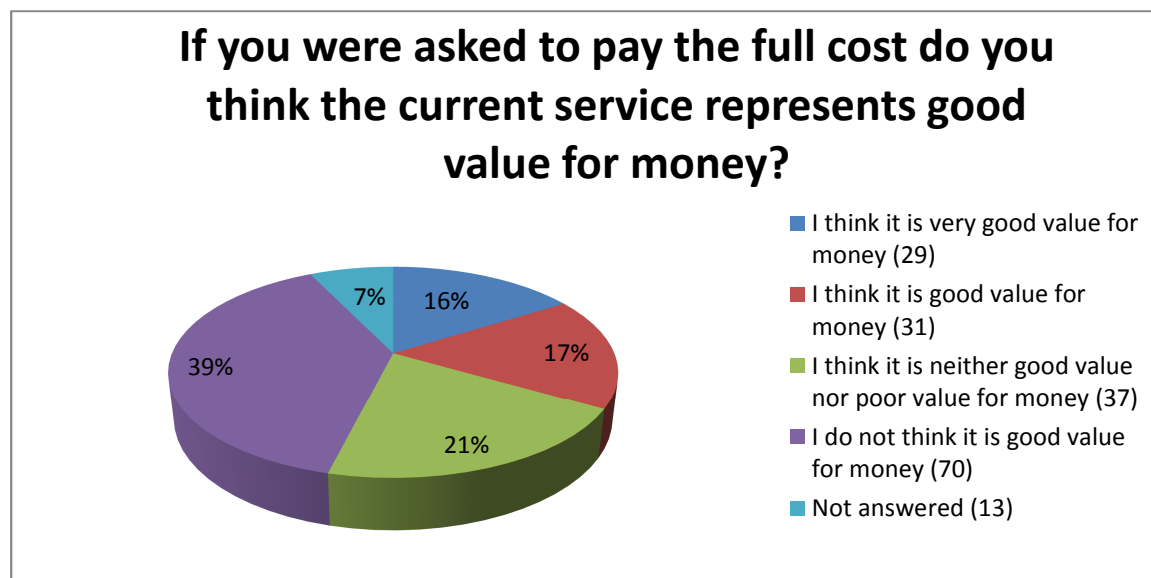
Other meals specified:

- Less oily, not spicy, chilli and not rich. I have simple meals as my stomach gets upset easily
- Specially extra mild
- Pureed
- Mild meals with no chilli
- Asthmatic, underweight
- Vegan

Question 7 – Would you need information to find out where else these meals are available?



Question 8 – The full cost of a meal from the mobile meals service is currently £7.76 (customers pay £3.05 and we pay the rest.) **If you were asked to pay the full cost, do you think the current service represents good value for money?**



Question 9 – We believe that the proposed changes to mobile meals services are fair because help will still be given to those who need it. They will also help the council to spend its limited resources more equally. **Do you have any views about this and any comments on how the council can best support people who need help with meals?**

Main issues raised:

- Daily visit is important
- Keep service the same
- Not safe to have someone heat a meal in my home
- Home care would be more expensive
- Willing to pay a little more if council can help with the rest
- Can't afford to pay more
- More choice needed
- People need routine
- Need help/advice if there is a change
- Agree that there are better options
- Nutrition concerns
- Appreciate current service
- Worry about health and wellbeing without the service

Other responses

MEETINGS

The proposals were discussed at meetings and responses recorded as follows (full minute extracts are in Appendix 2):

Trade Unions	<p>Three meetings were held. Key issues raised were:</p> <ul style="list-style-type: none"> • Concerns about availability of suitable alternatives for staff. • Feel that the service has intentionally been run down and that a balanced choice not being given. • Propose that the Council should trial promotion of the service to increase take-up and reduce unit cost. • Concerns from drivers that customers will lose human contact, which could lead to isolation and risk to their welfare. • Concerns about the quality of assessments and the risk of someone without “critical” or “substantial” needs eventually needing more support. • Queries about why the numbers had dropped so dramatically – don’t believe it’s due to personalisation alone. • Will direct payments be sufficient to meet people’s needs? • Concerns about nutrition.
50+ Network	Received briefing, but no comments made.
DISCUSS	<ul style="list-style-type: none"> • Asked what the council was doing to promote mobile meals. • Isolation – should be more lunch clubs. • People may not be happy with the quality of the meals.
Carers Reference Group	<ul style="list-style-type: none"> • Isolation is a big problem.
Forum for Older People	Received briefing, questions were asked but no comments were made.
Staff	<p>Meeting held with the unions present. Key issues were:</p> <ul style="list-style-type: none"> • Why didn’t we consult in 2010/11 when there were more customers? • Believe social workers are not promoting the service and are telling people it is closing. • Concerns about giving customers’ personal data to a third party. • Effects of budget cuts on old and vulnerable. • No action has been taken to increase numbers. • Microwave meals may not be cooked properly. • Could end up with sandwiches and soup. • Should advertise the service more.

	<ul style="list-style-type: none"> • Council staff are seen as too expensive. • Concerns of health, safety and hygiene of other providers. • What are the alternative employment options? • This is the only contact some customers have with people all day. We check on them. • Cut back elsewhere in the Council.
Providers	<p>Invited to attend a meeting individually and discuss issues and concerns. Key issues were:</p> <ul style="list-style-type: none"> • Still a need for culturally appropriate meals • Potential impact on their service if changes are agreed. • Give provider information to self funders. • Important to have the right checks – if customers buy cheaply, they may be risking their health and wellbeing.

HELPLINE, LETTERS, EMAILS

Helpline	<p>23 calls. Most to do with current service queries, which were dealt with appropriately. Calls about the consultation:</p> <ul style="list-style-type: none"> • 3 wanted to discuss in Gujarati or Hindi and 2 requests for home visits. • How soon will meals stop? • Want more food.
Letters	<p>2 letters received with the following points:</p> <ul style="list-style-type: none"> • Council is deliberately saying people can't have mobile meals. • Need for daily checks. • Suggest combine with the County or school meals service. • Questions from Liz Kendall MP about impacts on customers in her constituency, including what support there would be and what assessments have been made of needs.
Emails	<p>4 emails were received, mostly about operational issues. Points raised specific to the consultation:</p> <ul style="list-style-type: none"> • Mobile meals are needed for vulnerable people who don't want to engage, with no initiative and will accept only the minimum help. They don't want to manage alternatives. • Most private suppliers don't report non-access. • What about food safety issues for private suppliers. • Changes could lead to increased risk and blame on the council.
Freedom of Information request	<p>A FOIA request was received asking how many people in 2011/12 and 2012/13 were told that they could no longer have mobile meals. The response given was that there were four people no longer eligible for services.</p>

PART 13 – FURTHER INFORMATION

This report can be viewed electronically at:

http://consultations.leicester.gov.uk/adult-social-care-health-and-housing/mobile-meals/consult_view An equality impact assessment is available at the same link.

Contact details for further enquiries:

By post:

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8th Floor, B Block
New Walk Centre
Welford Place
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LE1 6ZG

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Telephone: 0116 252 8301

APPENDIX 1 – FULL COMMENTS FROM QUESTIONNAIRES

Question 9 – We believe that the proposed changes to mobile meals services are fair because help will still be given to those who need it. They will also help the council to spend its limited resources more equally. **Do you have any views about this and any comments on how the council can best support people who need help with meals?**

- I am 88 and immobile. I have had a stroke and so can only use one hand therefore I cannot open frozen or packaged meals. I have found meals on wheels to be a god send as my daughter cannot come everyday to give me a hot meal. Also when she goes on holiday I am able to extend the amount of meals to every day and I would want to continue this and I am sad to think it is changing.
- As I can't walk very well and am almost housebound and at age of 83 yrs mobile meals are vitally important to me.
- Continue with the option of giving people like me a cultural Caribbean meal daily.
- As I am severely disabled and housebound I wouldn't like the meals on wheels service to stop. The council could try and get the local MP's to seek help from the Government for the sick & elderly who really need this service with possibly an extra allowance on benefits for people who could not afford the full amount for the meals.
- Unfortunately my mother has dementia. Prior to her being recommended for mobile meals by her social worker she was able to heat meals in a microwave. As her condition deteriorated she was no longer able to use the microwave and on several occasions she heated meals for 40 minutes causing the food to virtually ignite. We had to remove the microwave for safety reasons. Regarding question 8, ' I think it is unfair. The proposal is to go from £3.05 customer share, to £7.76 full cost. Why isn't there a proposal for customers to pay an increased share of the cost e.g. £4? My mother's current arrangement with mobile meals works very well. She has carers morning & evening and a hot meal at lunchtime. Please keep the mobile meals service running.
- Thank you so much for the best you are doing to those who need it, I appreciate. You are the best.
- I am happy with the current service and cost.
- Please carry on providing hot meals and I am happy with you.
- Yes, but will the council ensure help is given to the extent that good value meals can be found at affordable prices? What if they do not meet our needs, what would we eat? Surely, getting home care assistance will be more costly for us?
- Generally MOW are good. I don't think they ought to stop.

- Alternative meal provision needs to make sure that someone visits the client's home every day. Sometimes this is the only contact the person has with a human that day to make sure that they are o.k.
- I am currently housebound. It is not safe for me to prepare my own meals. I am not able to go out to get meals from outside. My eyesight is very restricted and I am hard of hearing. I enjoy independent living which is possible only because of the meal service. I rather fear that I may have no alternative other than to seek move to a residential home. My age is 80+.
- Services of 'home care assistances' surely would prove more expensive?? Receiving hot meal from another company. How would this save money? Or does it make any difference to service user? Earlier mobile meals service insisted on healthy food, labels indicated not to re-heat food, emphasis was on Balanced Diet. Surely now a strong contradiction is proposed?
- I am very grateful to council for delivery meals. I am disabled and got fracture on my right arm. Thank you.
- I realise that money is tight and you need to check only people in need receive the meals but they are important to my husband & myself. I am registered blind, crippled with arthritis and have recently suffered several small strokes making mobility very difficult. I rely on my disabled husband for my care and the fact that a cheerful lady brings hot meals to us is such a big help to us and gives my husband a bit of respite on those days.
- The current service is very good & meets my requirements. I do not feel the change would improve the service and I would find it difficult for future.
- When mobile meals were first introduced to Asian people at B. N. Centre. They were done with "not for profit". The food supplied was good quality and lots of green vegetables. Now, it is a case of cheap products, mostly potatoes and pulses. Food is not as a high standard. All this change does not necessarily mean progress -.
- We do need more help by council. To support concession payee for old people meal do not want any changes.
- I would like my meal deliver to me as it is now
- I am a widower living alone. Age 79 years. I am not able to cook as I suffer from Dementia and balancing my movement. It is not possible to cook. Only I hope city council deliver my mobile meals as I getting at present. I do not mind if I am charged for meal about under £5.00. Full cost £7.76 is too much over. Council should give some concession.
- I would prefer that the meals on wheels meals service continue as it is. I am happy to receive a different meal (hot) every day and would continue to pay for the meals once a month.
- I hope that 'help still be given to those who need it' will include continuing mobile meals for those who need it. I would be willing to pay extra towards this service. I cannot cook or prepare meals more than once a week, I am 99 years old.
- Although I have a cooker and microwave, I am unable to operate my microwave. As my sight is limited reading instructions is difficult and I no

longer have the reasoning skills to operate even the simplest appliances.

Stopping this service would affect my daily life. This form was completed by my son on my behalf.

- My mother 91 has to have a soft meal every day, due to Oesophagus stretch. (Not able to eat other type of food). Also not able to use a microwave due to pacemaker and does not have a freezer. The meals and service you provide is " excellent ". All the girls who deliver the meals are very polite and very helpful with taking film off meals. As my mother cannot open meals due to arthritis. The meal service and care that we have in place for our mother means she is able to be in her own home. It would be very sad if this was taken away from her, due to the loss of this meal service.
- I can understand that money is tight and meals should only be given to those who really need them. I can only say that the meals are a complete god-send to my wife and myself. We are both 93 years old and I am my wife's sole carer. I am confined to a wheelchair, having had a leg amputated. I am also diabetic, suffering from prostate cancer, have had triple bypass surgery and been diagnosed with low vision. It would make my already very difficult life even worse if we were to lose the meals. They don't only cut down on shopping/preparing & cooking they provide us with a cheerful friendly face when they are delivered. Please don't stop them.
- To Deb Watson. I have read your proposal and feel sure you have not taken into account all disabled people and in view of my son's care I cannot agree with the proposal to completely stop all mobile meals. (Although in your letter you do say people who are eligible will still receive them.) *[My son's]* disability keeps him full time in a wheelchair, he cannot stand and has carers during the day, to get him up in the morning, dress, wash or shower, toilet and put him to bed in the evening. I am sure Health and Safety would not allow him to try to prepare meals or even put them in or out of a microwave or cooker. The carer only prepare meals that can be microwaved, (a cooker is not available) and really it is just preparing sandwiches. *[My son's]* disabilities do not really allow him to assist and he relies on the mobile meals for his hot meal during the day. Before it is suggested I help with his meals, I am 87 and not able to assist. Thank you for your comments and reply.
- I am 94 years old. The meals I get are suitable for my age, health related problems in eating. They do not upset my system, and are varied and serve the purpose of providing one nutritional hot meal a day delivered at home. I am not capable of going through your proposed changes to the current Meals on Wheels service. I find that in my old age I am locked in the four walls of my flat. I am too feeble even to open windows of my flat and as for going out of flat it's impossible as I don't have strength to open my flat entrance door. The only thing left is to enjoy my meal - one hot meal daily and you want to take that away from me. You might as well take my life because I find this too problematic and traumatic. Please kindly provide reply to this.

- Only concern regarding changes is that my mum - already very old and frail - changes to what she is used to, might have to change. Consulting her (I am her son who is looking after her) she says I will have to accept the changes.
- Please provide me with more choice. For I time hot meal.
- Having meals delivered has been a huge help as she has confidence issue shopping in the town, having to put up with the hustle & bustle of people. I do not think she will accept a stranger to do her shopping for her. She tells me that she can cope and cook for herself if I bring her food. I am not convinced, if you view her kitchen, Microwave, Oven are almost in brand new condition & yet must be 10 years old. I will be able to buy the food for her not sure how travelling thru the winter might affect my frequency of visit.
- I am 95 years old. I really need these dinners. As I am unable to get my own. As I can't stand for too long and would be dangerous for me to try.
- I need my Gujarati meal provided to me as it now. I would prefer more choices from other Gujarati organisation.
- My 95 year old Aunt, who uses and relies on this service suffers from Dementia. She would not be able mentally or physically cope with preparing her own meals. We already have 3 carers a day to help cope with day to day activities like washing, dressing and preparation of breakfast and tea. Losing this service would be a nightmare for us. She has no freezer/microwave to prepare meals, and she wouldn't be safe to try. Please reconsider your plans to take away this service on which many housebound people rely on. At 95 my Aunt would not cope with the fast food options you are suggesting - Pizza/Chinese? no thank you. She deserves a good wholesome meal like she is getting now.
- I was really shocked to receive this letter & questionnaire as I am 81 yrs old with diabetes & other health complications. Whereas I can fully understand that council wants to save money but in my opinion, the savings will not help people of my age with a lot of health concerns. I think it is the duty of council to look after the old & infirm people and support them with the best services in general. And food is the main one which help me to survive and keep in good health. I must emphasise that I will get the same quality of food & service from any other provider and hence this note.
- I am happy with the current service of receiving a mobile meal twice a week. I think the amount I contribute is fair too. Would I have to pay extra for a carer to come in and re-heat my meal if this goes ahead?
- I think council should continue with service. Private company will not be any good for providing service as LCC and disable persons will suffer as a result.
- I do not want to complain about anything. Normally the meals I receive for seven days are satisfactory. I have no objection, if you want to make any alteration about the service delivery. Thanks.
- We are satisfied and happy with your meals and service so far.
- Without the M.O.W service I will be struggling as I don't have any other means to get food. I don't mind paying extra charge if your (L.C.C.) service could continue.

- I am 90, house bound and unable to stand unaided. Meals on wheels is an important part of my day. I look forward to the contact with the delivery lady. I would struggle to provide hot food for myself, as I find making breakfast and tea a challenge. Please don't stop my only chance of hot food during the day.
- I am concerned that I may not be able to have a hot meal Mon- Fri as I am diabetic and need my meal at a certain time each day. I would like to continue with my current arrangements I have, as I do not like change, I like continuity.
- I am totally confused and not sure how I would need help, but to respect my time & privacy I prefer to eat out as it gives me an outing & choice in summer but winter time I am not sure with my health. A personal budget to fulfil my requirements is a good idea, as I could choose when & what to eat. Would a home care assistant be able to cook according to my needs? Who would do the shopping? Would I be able to adjust according to the carer's times? My ex is acting as my carer now, would he be able to carry on?
- I have mental health difficulties and am registered blind. I rely on Mobile Wheels as I can't cook independently. I would require hot meals to be delivered by another service or someone to help me prepare a meal. Cost is important as I am on benefits. The current cost is expensive but a good price given the service. Any more would be hard to find however. I understand the need for the change, but in many people's cases the Meals on Wheels service is very important and vibrant to enable independent living.
- I would like the meals to continue, it would be very difficult for me if they stopped as I am on my own. This is being written by my daughter who lives overseas, and is here on a visit. I am 95 this year and I am satisfied with the present arrangement. My freezer would not hold 7 days of frozen dinners.
- The current mobile meal service is already in place, does the job it was put in place for so why change it for such a few people that need it. Surely a new system will cost more. I do not want any change to my meal procedures and I am sure other OAP's will feel the same. This way we get a hot meal of good nutritional value and a pudding with safety and a visit from someone even if for a few minutes.
- Like mobile meal service, it is good but my aunty needs vegetarian Gujarati meals and it should be more tasty and there should be more variety of vegetables.
- Profit over services!! That sounds like our caring Leicester City Council. Particularly when picking on the old the infirm and the most vulnerable. Leave well enough alone. To change or finish meals on wheels I can only see it creating problems for the elderly. They don't need changes they need routine. By cancelling the meals they will need more shopping, (on line won't work) someone to prepare and/or cook the meal, or micro wave a meal. All of this takes more time than having it served as it is now. Changes NO NO NO.
- I think there are many outlets where meals are bought more economically. As such we have to close down the service.

- I would be very upset if the service was closed. I would be extremely grateful if you would continue this service. Many thanks.
- I do think the mobile meals should stay in place for people who really need help as it would benefit. Those don't need help and can manage the food from freezer.
- The quality of the food has improved over the last year or so. The Sunday Roast is probably the worse - the meat is very stringy. I look forward to having a smiling face at the door & a few cheery words each day. It can be very lonely all alone each day. My daughter lives in another part of the city & so only come twice a week to do my shopping. I cannot walk far & it's impossible for me to do the shopping. The most important thing is to have a smiling face each day - it makes no end of difference to welcome someone like xx with a cheerful face and a comment on the weather or some such. It seems at the present time the ladies can't be bothered to have a word with me - it's all in such a rush. My hands are not 'safe' enough after my stroke to take hot food out of my oven as it opens down to the floor & I have difficulty in bending down. On the other hand it would be nice not to have lunch at 11.30 am. I really need meals on wheels to continue.
- I accept these changes are coming. I would need/appreciate help in changing from delivered hot meals to getting in frozen meals. I would like to help to get a freezer and a microwave & help with how to use these. (On the question of value for money of the existing mobile meal, I would judge it's value at about £5.00.)
- I would still prefer to have a hot meal delivered to me each day and would like further information regarding this.
- Without the mobile meals service when I was discharged from hospital following hip surgery, I could not have stayed in my own home. It has been a godsend to me. But now I am better able to care for myself and will probably order direct from Apetito and heat them up myself. I will miss the daily visit of the staff who call however.
- I feel that I should be given the choice to purchase my meals from places that I choose so I can have a varied diet & not the same meals everyday. I also think that I could purchase better value for money meals elsewhere.
- I am disabled and housebound so I need someone to bring me a hot meal Tuesdays & Thursdays.
- Nutrition - Wants food provided to keep him healthy, Nutritional standards, Council to oversee that - we'd go through council, want good standard as they pay, keep people healthy, stomach delicate - balanced - can't digest bad food, not old food etc. - fresh, £3.05 is ok. but lives on pension- don't want to pay too much more, very good from East West, his meal comes quite early but he likes that time, has sore teeth & speech issue, so needs help, want some standard in future, he wants council to organise it, 7 days a week, no other services, his wife is sick, People have been and not offered anything, poor English so hard to speak on phone - people write things down and then do

nothing, - stopped his meals after Indian visit, long time to get started again, said he wasn't eligible, different people "pass the buck".

- It should be possible to pay for the meal only (and not the pudding). Currently it is not possible to pay for the main meal only and the pudding is wasted, as I do not eat the pudding. This is a waste of food and money.
- I can understand that in the modern day meals on wheels is outdated. I never believed it the perfect answer but at least the old and vulnerable were in contact with people and that was the main benefit. As long as good alternative provision is made and users are not just abandoned then the decision is justified. I can't imagine how this support can be ensured so we are very reliant on the authorities to do the right thing.
- Hope the changes won't effect to much because I am not able to walk far only in the house and does not speak English. She would be restricted of food by ordering from restaurant. Can't see or use the telephone is partially blind.
- Need more variety at meals to choose from. I need the right food amount for the money I spend. I do not want less food for the money I pay.
- I am from xxxxx. About 3/4 used to get but now only one/two are getting. Here there are food suppliers with £2.50 and person can take both the times - Noon - Evening. Still left. Hot & fresh. This opinion is mine and only xxx. Thanks.
- Please leave it as it is.
- I need somebody at least 2 times between 12.00 pm & 2pm & 6 to 7 pm to open and serve my meal and help with dish washing & evening meal etc. Can you send a home care assistant for helping me.
- Just that the times of meal, when, come don't change and can come on time. Just keep doing job that council do. Thank U all you hard work.
- I like seeing Sandra my wheels on meals lady during the week, the meals are nice & tasty. I don't know the names of the weekend people. I would miss my meals on wheels service a lot. P.S. Thank you for the Freepost envelope.
- I am of the opinion that the current system of delivering mobile meals is very good and does not need changing.
- If the council want to stop the mobile meals that's it.
- I am happy with the daily meals I get and would prefer the meals to carry on.
- My mother needs this service. She is old and not capable of even putting a meal in a microwave as she is not steady on her feet and has arthritis in her hands also she has serious health problems. If she doesn't get this service she will not have a hot meal.
- I have already replied you earlier in detail of my concerns. I again emphasise that the changes will effect the elderly people badly and as a result unless an alternative is found their health will be effected and deteriorated. I would only suggest that you could cut down fruit and poppadum and yogurt and increased the price by 50p or so. This will indeed help everyone.
- I am elderly and I am happy with the current service. I am unable to prepare meals myself as I have poor eyesight and arthritis this prevents me from

preparing my own meals. I am happy with the current service and it is good value for money.

- xxx is 93-94 next month and these meals are vital for her.
- Written by carer. I believe that the alternative methods (Q2 a) would cost more. From speaking to people who would benefit from Meals on Wheels, some of them do not know it exists. This could well be the reason that you say that fewer meals are being served. Note Green Booklet Page 4 Para 1 & 2 "receive a visit" Much more expensive than present. Page 5 Para 2 "Providing services in a new way....." At a higher cost.
- I have already returned this form once. I cancelled Meals on Wheels some Months ago. I have Wiltshire Farm Foods because it means my carer can heat me a meal when she arrives and I have some choice of the meal on that day. With mobile meals the carer often found it had come but I wasn't eating.
- Think if the MOW service ends an alternative should be available.
- I would like to continue with hot meals every day. If I have to pay the full cost I would expect better value and quality and taste of meals provided. I would prefer to continue with the current service as I am very happy with this.
- Social worker decided xx was not capable of making meals and recommended taking away cooker and so he is reliant on meals being delivered. 7 days a week.
- Continue with home delivery of meals would be better, more choices would be nice, Reduced amount of cooking oil used better.
- The proposed changes would have a devastating effect on my health and well being. I am 94 years old and cannot operate a stove cooker anymore, therefore the proposals would force me to starve. I am very satisfied with the current service and I am sure a lot of us in the community receiving such a service are very grateful.
- I think that in many ways the proposed changes will be a positive step in people's lives. They will have more choice and flexibility in their diets.
- Providing a pick up service for the elderly to transport them to our community centre for their meal has proved a viable and essential support service. Our regular attendance often exceeds 70 senior citizens. The cost of meals has been £3.00 and a £1.00 contribution towards diesel. The service not only provides a nutritious lunch but also serves as a social event combatting loneliness and isolation.
- I have got used to a routine of receiving the meal delivered to me. At my age any disruption or major change will cause unnecessary stress and worry which will impact on my health. My request is to keep your process simple to enable me to continue to get hot meals delivered. Will appreciate your help & support to make this arrangements.
- My father gets his meals delivered on a day when I am able to be there - (I am his carer). By not having someone bringing a meal in would mean I would not be able to work on that day. I rely on someone popping in - if there was something wrong or he didn't open the door I would get a call. Not to happy with proposed changes.

- As an elderly disabled person with family who cannot provide me with support with meals, this service is essential for me to have a good healthy hot meal. The food is balanced, nutritious and healthy. It is also vegetarian and suitable for my religion. The food is as I cooked at home when I was able to. I feel that if the service were to stop it would be detrimental for my health (and that of other service users). I am aware of other sources of Gujarati vegetarian foods like restaurants. Unfortunately this food is not suitable to be consumed on a daily basis as it is over spiced and very oily and therefore bad for health. Receiving this service means that someone pops in on me as well. I would strongly urge you to please keep this service for the older people of Leicester and not to put monetary concerns over their health & wellbeing. Thank you.
- My uncle has no choice but to have meals on wheels. He may be just has good to have meals brought in by another company in the area as he may get more choice.
- I wish current service will continue. We need help from council we need support from council.
- The cost of £3.05 per meal is reasonable and good value for money. I would not be prepared to pay £7.76 for a single meal as it is too expensive and not value for money.
- This is only fair to the people who are able to cook for themselves or prepare their own meals with assistance. For those without this ability the mobile meals service is a lifeline. This minority is likely to be left with no hot meal each day or a poor substitute in the form of a ready meal. In this case if not heated correctly can cause serious illness. It is hard enough to get carers to make a sandwich so would not trust them to heat a ready meal correctly.
- I would like the current system to carry on as I am looking after my mum as I work myself and look after an elderly.
- I think Council meals services are fair. People who need regular meals would still get meals on time. Council meals are taking care to supply meals according to there sickness and health.
- The Council has a big budget of millions of pounds and have started cutting services of older people ie meals and care services. You as a council worker are reading this and your later years (old age) you might need this service yourself. Are this the only way council can save money by targeting the most vulnerable in our society? Every other week we get a letter about some sort of cut's in services from the council. You hardly hear about the cut's to your council tax bills and other rates. For a change lets have a consultation of how Leicester City Council can save money within itself ask yourself are there no other way the city Adult Social Care can save money than troubling our old & sick people. You will be a older person one day and you will be deprived of the very services you want to cut.
- Please keep current service for those who want to use it.
- We assume that he will continue to get the equivalent of meals on wheels in the future as he has a severe mental impairment and cannot cope with any ordering or preparation of a meal.

- I would like a supermarket voucher to stock up on frozen meals. I already have a microwave.
- I would like the hot meal service I receive at present to continue at the cost I am currently paying. It is a reliable service. These meals are delivered by more or else same staff. They know me due to my disability. I have a carer who comes to feed me. It is not easy to time everything.
- I am happy with present meal. I would miss your meals. Good balance for my diet. Other provider do you think would provide good balance meal ??.
- I am filling this form in for xx. I use a Frozen Meal delivery myself so would include xx - unless my condition changes would include xx - also.

MEETINGS WITH TRADE UNIONS

Below are the minutes from three meetings held with trade union representatives:

9th July 2013

Present: Ty Denton (Unite), Jan Dudgeon (Head of Service Passenger and Transport Services), Jane Faulks (Head of Service City Catering), Jagruti Barai (HR advisor), Tracie Rees (Director Care Services and Commissioning), Mercy Lett-Charnock Lead Commissioner Early Intervention and Prevention

Tracie Rees welcomed the group and explained members of the other unions had been invited. Ty suggested there may have been a clash with another meeting. Tracie confirmed no apologies had been received.

The purpose of the meeting was to outline the issues in relation to the provision of mobile meals. She outlined the issues for the service as follows:

The service was for Adult Social Care users who were unable to prepare or obtain a meal. This is not about food but about preparation and delivery. There has been a rapid decline in numbers using the service. Personalisation means that people can choose from a range of providers not just Council services and people are increasingly choosing other options such as home deliveries from supermarkets or personal assistants to support with meal preparation. In addition there is some variation in quality and satisfaction with meals – some being reheated from frozen and some prepared freshly. The Council subsidises the service – each meal costing the Council £4.76 at present and will increase.

Ty asked how much this was due to increase by. Tracie said that we do not have exact figures at this time but forecasts indicate this cost will continue to rise and are becoming unviable.

The Council is starting a public consultation today which runs until 7th October. The proposal is “Stopping the Council’s current mobile meals service and helping people to prepare or obtain meals in alternative and more flexible ways”. Letters are going out today to service users.

There will be staffing implications and potential redundancies for both City Catering and Transport. This is not the start of collective consultation, just a “heads up” about the consultation. It is likely collective consultation will start in September so that views of staff and Unions can be fed into the report to executive, so that they can make an informed final decision which is likely to be in November. Labour Group letters were given out to members last night.

Staff support will come from managers and Amica counselling service is also available. The Heads of Service will brief staff at 1.30pm today and letters will be given to each staff member.

Tracie stressed no decision has been made but the consultation is about closure of the current service.

Ty said this was not good. Tracie said that it was recognised how difficult this will be for staff but evidence is suggesting this is a service people are no longer wanting and other options are meeting their needs.

Ty asked if reducing costs had been looked at. Tracie said that as numbers are going down so fast it's hard to reduce costs as last year the Council subsidised the service by £396k.

Ty asked if the usual provisions were being made for staff. Tracie confirmed the redeployment policy would be applied. There would be possible options for Catering staff within schools and maybe options for Transport staff but compulsory redundancy couldn't be ruled out.

A briefing note was handed out to attendees.

Tracie confirmed the minutes from this meeting and the briefing note would be emailed to union representatives that had been unable to attend.

19 August 2013

Present: Ty Denton (Unite), Gaynor Garner (Unison), Steve Barney (GMB), Jagruti Barai (HR advisor), Tracie Rees (Director Care Services and Commissioning), Mercy Lett-Charnock (Lead Commissioner Early Intervention and Prevention)

Tracie Rees welcomed the group and explained it was being held at the request of the unions. Tracie had held a briefing for unions on 9th July, outlining the rationale for change. We are now in the middle of formal consultation. The issues are around declining numbers and the fact that the Council subsidy of approx. £400k is financially unviable. The proposal is to support people to access alternative services.

Steve asked how the consultation with staff had occurred. Staff were informed via a briefing after the trade union meeting on 9th July. Ty Denton and local reps were in attendance.

Jagruti explained that collective consultation regarding redundancies would not commence until after a decision had been made in November as service closure may not be the outcome. However, we do want staff and unions to feedback on the service proposal – including offering alternative proposals for consideration. This will feed into the executive decision making process.

Jan Dudgeon met with staff on 10th after they had had time to consider the information. Staff have been told how to bring issues forward to feed into the consultation.

There will be a meeting in September for unions again to feed in comments, queries and alternative proposals. Unions are requested to give their availability for week commencing 9th September so this can be arranged.

Gaynor asked about the business case stating that there were alternative posts for redeployment – were there enough? Jagruti said there were. However, some staff have two jobs and therefore the hours may not suit them. This will need considering individually.

Ty asked why the numbers had dropped so dramatically – he did not think this was all due to personalisation alone.

Tracie responded that eligibility criteria are for substantial and critical needs and these are being applied strictly. In addition, people are now being offered direct payments and people are using these to choose options such as personal assistants and this has contributed to the drop.

Steve said that the Council isn't promoting its' own services and this is being used as a way of cutting staff.

Tracie responded that we cannot make service users use Council services, we have to give choice. Steve re-iterated that this should be a balanced choice, not just promoting non-Council services. There should be a balance on promoting Council and non-council services. Tracie confirmed that staff are offering both to service users. The current service is somewhat restrictive in what it can deliver and when. Some people don't like the food and some people don't want a lunchtime meal. Chilled supermarket meals that can be warmed up are a good option for some people. Other people are getting someone in to support them to cook for them.

Steve asked about people with no family who may become malnourished. Tracie explained that the Council has a duty of care and this would not change.

Gaynor asked about other options. Mercy explained this could be a direct payment which would mean people can chose whatever they want. Other options could include an alternative hot meal provider, supermarket meals, a personal assistant or homecare. It would depend on individual need and social isolation would be considered as part of the assessment.

Steve said we would know if people were eating the meal when empty plates were collected but Tracie said the current service does not provide this, empty plates are not collected. Home care is a good option if people need this level of support.

If the proposal is agreed, people will need to be assessed and supported to find an alternative. If people need support they will still get it, it could just be from another provider.

Steve asked if we were using the Council service as a second class option and again asked whether services were being offered equally. Tracie said she had no evidence to the contrary and would like Steve to share this with her if he had any.

Ty requested a full breakdown of the decline in numbers and details of the assessment criteria.

Gaynor asked if unions were present when managers met with staff. They were on the day of the briefing.

Gaynor has requested that when Jan and Jane meet with staff again to invite unions to attend.

Jagruti requested availability for the union meeting in September.

Tracie thanked everyone for their attendance.

16 September 2013

Present: Ty Denton (Unite), Janet McKenna (Unison), Steve Barney (GMB), Jagruti Barai (HR advisor), Jane Faulks (City Catering), Anisha Mistry (City Transport), Mercy Lett-Charnock (Lead Commissioner ASC)

Mercy welcomed the group and explained it was a further opportunity to put forward views or raise questions in relation to the consultation proposal. Tracie Rees had held a briefing for unions on 9th July, outlining the rationale for change and a further meeting had been held on 19th August. Consultation runs until 7th October and there will be a meeting with Catering and Transport staff tomorrow which union representatives are also attending.

Ty said that his concerns were the same as those raised at the last meeting, namely that it wasn't fair as it is felt to not be an even playing field as there is a view that the current service is not being promoted by staff. There is a belief that personalisation is not the only reason for numbers dropping.

Janet asked if we knew why people stopped using the service – did we canvas people's views. Mercy responded that whilst people weren't asked why they stopped using a service, some information was available from their assessment and reassessment information. This was not qualitative as it was as a result of some tick box options but some information could be gathered. Mercy will provide this information as it was gathered for a FOIA request but recalls there was a variety of reasons. Ty asked if any stood out - from memory, Mercy said none did but would provide the information.

As per the last meeting a tighter application of eligibility criteria was also discussed.

Janet asked if Scrutiny had called this in. Mercy said Cllr Moore was informed on 9th July but it hasn't yet been called in but could be at any time.

It was said that there was a rumour the service would be finishing at Christmas. Confirmed an outcome would be known after the report goes to the executive – planned for November. However, implementation would take time so even if the decision was to close the service December would be too early.

Jane said that some of the catering staff expressed an interest in going on to escorting duties, there was also likely to be posts available in catering – short hours particularly. Jagruti confirmed that if a decision was taken to close, consultation on alternatives would start after the executive decision.

Anisha said that some of the transport staff were concerned about the people who get meals as they have a connection with customers due to the delivery. The consultation is about this service ceasing not meals support. The Council will still have a duty to support people who have an assessed need.

Janet asked about the costings as staffing is usually the most expensive element of the service. Mercy confirmed this. The £3.05 contribution from clients was for food, the remainder was other costs.

Janet also queried whether the Direct Payment amount would be sufficient to meet people's need as she couldn't see how the alternative would be cheaper than the current service. Mercy said that there may be several possible alternatives but one of those could be that customers have to pay more.

It was commented that day centres and EPH's as well as mobile meals are political issues and vulnerable people are getting hit.

Steve also raised that there are ways of promoting the service. The council could have carried out a trial of how promoting the service could impact on numbers using the service. Raising the charges could also be considered – if numbers increased the service would be more viable. Had the Council considered increasing the charge?

Jane asked how this would be done as drivers etc. couldn't do this. Steve said it would be assessors (care management staff) that would need to do that.

Steve commented that some service users have good relationships with the people that deliver and without a meal they may deteriorate and could end up costing more. Need to understand the unintended consequences of making the change. Mercy responded as before the Council would still have to provide a service to those that need it. However, Steve was concerned about those who don't meet the criteria now the bar (or eligibility) is perceived to have been set higher. Steve asked if we could guarantee everyone would get a suitable alternative and no one would fall through the gap. Mercy said the Council has a duty to do this and it would be individually assessed and if they were eligible would get an alternative to meet their need. Steve raised a concern about lack of confidence in the assessment process.

Janet asked how service users were consulted and what the response was. Mercy said she thought it was about 30% last time she had been informed and there had been service user focus groups offered as well as 1-1 meetings if people requested it. In addition representative groups such as the 50+ forum, older people's network, disabled customers group and carers reference group were attended. Concern was raised that those attending wouldn't be the vulnerable people who can't get out of the house. However, Mercy said that these groups are there to represent others and we

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have had a good response to the survey (numbers wise) and the phone line and questionnaire has given people an opportunity to contact us without having to attend meetings.

Jagruti asked whether the unions would be submitting a written response or whether the minutes of the meetings would suffice. This may vary from union to union so the minutes will be used to feed into the process, along with anything else received.

Mercy thanked everyone for their attendance and confirmed the information requested and notes would be circulated.



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UNISON'S RESPONSE TO THE PROPOSAL TO STOP RUNNING THE COUNCIL'S MEALS-ON-WHEELS SERVICE

There are some concerns from UNISON that there has been a significant decline from 2010 where there was 1,252 people using the service to May 2013 where there are now 269 people using the service. We are convinced that this reduction in service-users is not just down to numbers using the service dropping and personal budgets.

We believe there has been a deliberate attempt not to refer service-users from 2010; this was echoed in the meeting held with the staff on 17 September 2013 affected by the proposals where a number of them expressed concern that social services were telling service-users the meals-on-wheels service had stopped running and that social workers have not been referring service-users to the meals-on-wheels service. There was also an example of a service-user of 18 years told to stop using the meals-on-wheels service.

UNISON have asked why over the last 2/3 years we have not canvassed people's views on why they have stopped using the service. An opportunity has been missed where a marketing campaign could have been launched to promote the in-house service.

UNISON also questions whether the direct payment amount would be sufficient to meet people's needs.

There are concerns over the quality of meals provided in the private sector and the health and safety implications attached to that.

Our in-house meals-on-wheels service goes that "extra mile" with service-users. They observe service-users and in some cases have even stayed with a service-user who needed medical attention. They have often passed concerns on to social services. Can we see the private sector doing that! Nutrition is a big part of the service-users well-being.

It is common for older people to be particularly vulnerable to malnutrition resulting in the prevention or recovery from illness and an increased likelihood of developing more health problems.

Gaynor Garner

(UNISON Social Care and Health Convenor).

MEETINGS WITH STAFF

Notes of meeting on 17 September 2013

Management attendees:

Jan Dudgeon, Jane Faulks, Mercy Lett-Charnock, Jagruti Barai

Unions Representatives:

Minesh Patel – Unite, Dave Taylor – Unite, Billy Baksh – GMB, Christine Reader – GMB, Steve Barney – GMB, Gaynor Garner – UNISON

JF opened the meeting and explained the background and reason for the meeting. JF confirmed that the consultation on the proposals to close the service started on the 7 July 2013. This meeting was to provide a further opportunity for staff to feedback any comments verbally in addition to the other methods i.e. via the trade unions, e-mail or telephone to the project team.

The following comments were received.

1. Staff will be losing jobs
2. Service users will not be getting a meal

MLC commented that the proposal was about ceasing this service, not meals support as the Council still had a duty to ensure people can obtain or prepare a meal.

3. The unions added that the consultation on the proposals with service users was not good enough, particularly those that cannot read or are not mobile enough to attend the focus groups

MLC confirmed that there was a help-line number and the option of a 1:1 meeting had been offered to users. Interest groups such as the Forum for Older People had also been attended as these groups represent the interests of mobile meals users.

JB confirmed that further consultation on redundancy would take place if the decision is to close the service, but stated that attempts would be made to redeploy staff into other roles wherever possible.

4. BB queried why consultation did not take place when there were more service users.
5. Some users had stated that Social Workers are not promoting the service and telling clients that the service is closing, this issue goes back 2 years.
6. In the 2009/2010 budget the proposal was to cut the service, if this process had started then, then there would have been wider consultation.

7. A concern was raised about giving out personal data of clients i.e. key code numbers to a third party and compliance with the Data Protection Act.
8. It was also raised that all budget cuts of late are affecting the old and vulnerable.
9. Staff understood the service to be closing in December.

MLC confirmed that the service was not closing in December, no decision has been made and the earliest would be in June 2014.

10. The number of meals delivered had been declining over a 2 – 3 year period; this had been raised with management with no action taken to improve.
11. Concern was raised about the service users, as when the meals are delivered this is the only contact they have with anybody in the day.

MLC confirmed that alternatives would be in place so all clients that have been assessed as requiring a meal would get a meal, this could be provided through a carer if required and therefore reduce their isolation.

12. Concern was raised about warming meals in a microwave, potentially they are not cooked properly, and concern was also raised that the meals could end up being sandwiches and soup.
13. It was felt that the service was required in the community and that there was a demand for it but it wasn't being offered any more e.g. to those leaving hospital. More advertising should be done.
14. It was also felt that this situation could be turned around and referrals increased. Money was being spent elsewhere on unnecessary projects such as the Market redevelopment. It was seen that Council staff were too expensive and a cheaper option was being sought.
15. Concern was also raised about Health & Safety and hygiene of any alternative providers.
16. Questions were raised about alternative employment options. JB confirmed that if a decision to cease the service was made, further consultation would be undertaken around redundancies.

JF thanked all for their comments and re-iterated that further comments could be made either via e-mail or telephone or through the unions to the project team. The closing date for the consultation was 7 October 2013.

JF confirmed that these comments would be fed into the report for the Executive.

Additional member questions put forward (in writing) to the staff meeting:

1. Even though there has to be money cut backs why does it have to be in the old and vulnerable?

2. Meals has been going down for well ever two and a half years, all meals on wheels staff have been concerned and regularly brought it to the attention of the office staff and of course Jan, Sheila and Anisha.
3. We were told social services were going round and telling service users they no longer could have meals, in fact to the old. One could say it was bullying tactics.
4. All our service users are old and most of them only see the meals/staff each day have you thought you are taking that safe/care line, away from them do you really care!
5. To issue microwaves, I have witnessed what carers do yes put meal in, blast away ding - done, put on service user's lap say goodbye and away we go – service user got hot meal on outside – COLD in the middle, they don't have time.
6. Family of service users don't think very highly of Leicester City Council and what they are proposing, it is a service that is required in our community. We are all caring and work to the best standard it's not just delivering a meal, it's being the 1st person if there is an emergency, even fatal we report, ring emergency services, wait with them, surely it's a service that is required?
7. This is on your behalf about the money, we could turn this around and go back to getting referrals, there are a lot of elderly out there that need this service. Surely you can cut back elsewhere office staff – spending money in e.g. Leicester market – that wasn't all that long ago all that money spend councillors pay rise etc

50+ NETWORK

Extract from the minutes of a meeting on 29 July 2013

Mercy Lett-Charnock, Lead Commissioner for Early Intervention and Prevention at LCC, gave a presentation about “Mobile Meals” and took questions from the floor afterwards. Mercy invited those present to participate in the consultation that runs until 7th October. Further information can be found at:
<http://consultations.leicester.gov.uk> or by telephoning 0116 252 8301.

CARERS REFERENCE GROUP

Extract from the minutes of a meeting on 29 July 2013

Mobile Meals Consultation

Mercy-Current consultation. Numbers of people having meals is dropping. Only 264 have the service. Flexibility and quality an issue. The proposal is to stop the meals but to find a good replacement that people want.

xx- Asian people she has spoken to, don't like them.

One person has an agreement with a shop to supply his meals.

Mercy is going to the 50 plus network this pm and there will be focus groups on the proposals.

xx raised the issue of isolation as a big problem. Mercy- This should be picked up on an assessment of need. Feedback welcome.

FORUM FOR OLDER PEOPLE

Extract from the minutes of a meeting on 29 July 2013

The Chair introduced the item commenting that a review of the current mobile meals arrangements had begun. She asked Forum Members to note that customers currently in need of the service would still be provided for but that the existing arrangements of the service were likely to be altered given the current cost implications.

The Director of Care Services and Commissioning gave a presentation on the existing arrangements, together with the scope of the consultation and the current cost implications to the Council. The presentation focussed on the proposal to stop the Council's current mobile meals service and to help people to prepare or obtain meals in alternative and more flexible ways.

Forum Members were encouraged to take away and complete questionnaires provided. Other consultation material was made available including guidance on completing the questionnaire and information on frequently asked questions. It was noted that Focus Groups had also been arranged for customers and carers in order for views on the proposals to be submitted.

In reply to questions it was confirmed that the consultation would involve a wide range of stakeholder groups and external organisations. Officers also agreed to report back to the Forum on the result of the consultation and on future changes to the service.

DISCUSS

Extract from the minutes of a meeting on 10 September 2013

Mercy Lett-Charnock talked about the mobile meals consultation taking place at the moment.

People have more choice and control over the services they receive. People are given a personal budget, so they can buy the services they need from a range of providers. This is having an impact on traditional services, such as mobile meals.

For every meal it costs the council additional £4.76 on top of £3.05 paid by the customer. The cost to the council is going up for mobile meals. Number of people using mobile meals is dropping. People are choosing other options such as ready meals.

Alternative options include:

- Having a personal assistant to help with meal preparation
- Having a domiciliary care worker reheat a ready meal delivered by Tesco for example
- Having local or national organisation deliver a mobile meal

The Council is looking at how to meet people's needs more effectively to support them to live in the community using services that meet their needs.

City transport delivers the meals between 11am and 2pm. Some people would prefer an evening meal but this cannot be provided by the current service. The figures show that number of mobile meals customers are dropping. Some service users are using their personal budget to have meals delivered and reheated by a personal assistant.

The proposal is to stop providing the mobile meals service by May 2014 and to help people prepare or obtain meals in more flexible ways. Service users will be supported to organise suitable alternative support that meets their need for food preparation.

If the proposal is agreed reassessments will start next year. All service users will also be reassessed to ensure they are not socially isolated and see how they can best be supported. The consultation runs from 9th July to 7th October 2013.

xx asked about what the council is doing to promote mobile meals.

Mercy said people were choosing other options such as talked about supermarket home delivery and people getting personal assistant to reheat meals but the Council service was still being offered.

xx said that people will feel lonely and isolated. There should be more activities in community like lunch club where people can go once a week. Elderly people might not want people coming in their home to heat meals.

Yasmin talked about a lady who is blind, as part of her package somebody takes her out for lunch once a week.

xx said that it could be that people are not happy with the quality of mobile meals. Elderly people will be worried if mobile meals service stops.

Mercy said that everybody who is eligible will get a meal in different ways that suits them and whether people might be lonely or isolated is considered as part of the assessment.

Mercy asked people to feed their views into the consultation if they had anything further to add and left copies of questionnaires.

PROVIDER MEETINGS

Meetings were held with current providers. The notes have not been included here, as they contain information relating to the providers' business. Potential impacts of any change were discussed plus business options and concerns the providers may have.

Executive Briefing

September 2013

Soft Market Testing - Community Meals

Lead director: Tracie Rees



City Mayor

Useful information

- Ward(s) affected: All
- Report author: Adult Social Care Procurement
- Author contact details: 37 2319
- Report version number: v2

1. Summary

Soft Market Testing (SMT) exercise – Community Meals (aka Mobile Meals, Meals on Wheels)

- 1.1 To report findings of the Soft Market Testing (SMT) for Community Meals.
- 1.2 Assessing the range of respondents it could be summarised that the prospects for the Council of encouraging operators to express an interest through the procurement/tendering process are good.
- 1.3 All those that responded could demonstrate a positive track record of providing meals service and can deliver all type of meals including African, Asian, European and Kosher, 365 days a year.
- 1.4 It is to note that some providers are able to provide more additional services including general checking on customers' well-being, serving meals, take out rubbish and prepare hot drinks.
- 1.5 Following the SMT, the Project Board may wish to take up the opportunity to invite respondents to further dialogue to assist future decision on procurement of the service. The procurement exercise can incorporate views of SMEs, voluntary sector and others respondents of the SME exercise.

2. Background:

2.1 In line with the principles of Self Directed Support, the Council implemented fundamental changes to its ways of working in April 2010. The new way of working requires that following an assessment of need and subsequent establishment of eligibility a customer is advised of their indicative allocated resource through the use of the Resource Allocation System (RAS). The customers then should have a choice in how they wish to choose meals provision in accordance with their own choice and assessed needs.

2.2 The Council's aspiration is that a customer will have a range of choices available to

them and will be supported to support plan either by themselves or with support from another party including Care Management in Adult Social Care (ASC).

2.3 The service currently delivers to approximately 260 people providing culturally-appropriate, nutritious meals 365 days a year.

2.4 Existing providers prepare meals that reflect the origins of the service user and their cultural needs. All meals are produced under strict hygiene conditions and practices as laid down by law, enforceable by the local Environmental Health Department. All meals meet nutritional standards established by local or national recognised bodies.

2.5 There are currently two external providers based in the community and voluntary sector and one in-house provider. Currently, all meals are transported by an in-house provider.

2.6 The future of the current mobile meals service is being consulted on and the department is seeking to establish whether suitable alternative provision is available in the market.

3. Purpose of Soft Market Testing

3.1 The overall objectives of the exercise were to assess whether there is potential in the market from suitably qualified and experienced providers to achieve Council's outcomes, which are:

- a) To help Customers maximise their options
- b) To determine if there is market interest in providers delivering meals to those in receipt of a managed personal budget
- c) To determine what barriers there are to doing this (e.g. transport, meal types, charges, location, frequency, volume)
- d) To determine level of interest in different contract types including framework contracts with no guarantee of hours
- e) To establish what providers can do – meal types, frequency, delivery times, locations, food only, prices etc.
- f) To identify any gaps in market provision
- g) To determine what is available for people in receipt of a Direct Payment

4. Process

4.1 The SMT was advertised on 26th July 2013 via Source Leicestershire. It was made clear to the market that it was not a call for competition.

4.2 All current providers for variety of Adult Social Care services had been notified (Voluntary Sector including current Mobile Meals providers; Care Homes, Domiciliary Support Services; Independent Living). Notifications were also sent to providers who expressed interest previously. Members of Federation for Small Businesses and

Voluntary Action Leicestershire had also been notified.

4.3 The closing date for submission of responses was 9th September 2013. A total of seven responses to the SMT were received.

4.4 Type of Operators:

The legal status of the organisations who submitted responses is as follows:

- a) Public Limited Company / Registered Charity: 2
- b) Charity with Trustees: 1
- c) Charitable Organisation limited by Guarantee: 1
- d) Private Limited Company: 2
- e) Partnership: 1

4.5 Experience / Suitability of Providers:

All Providers have given details of their current activities including additional well-being services, capacity of providing community various type of meals, current take up, price and ability to deliver meals.

5. Analysis of Responses

5.1 Type of Meal

Four providers cater for clients from a variety of cultural backgrounds (European, Asian, African-Caribbean, Halal etc.), whereas three of the have stated provision of meals for a specific client group only. In terms of special diets, all respondents are able to provide meals for Diabetic clients, Vegetarians and Pureed/Soft or other form of Texture modified meal. Some are also able to supply the following: Milk Free; Gluten Free; Low/ No Added Salt; Egg Free; Low Fat; Energy Dense.

It must be noted that two of the respondents are only currently able to provide frozen meals.

5.2 Premises and Food Hygiene Rating

All but one respondent have confirmed that their premises are approved and inspected. One organisation did not provide the answer.

Three respondents have confirmed food hygiene rating of 5, two – 4 and two have not provided a response.

5.3 Meals Availability

Five respondents have confirmed that they can deliver meals 365 days a year. One, who provides frozen meals, can supply them to a transport provider's facility every week. Another respondent does not provide services during weekends and Christmas, however, can provide alternative frozen meals for these periods.

5.4 Price

The SMT questionnaire asked respondents to provide price for their meals and applicable delivery charge.

Two providers who only supply frozen meals quoted prices ranging from £1.48 to £2.65 for standard meals and up to £5.95 for cultural meals.

Prices provided by the remaining five respondents were as follows:

- Standard meal from £3.60 to £7.56
- Asian Vegetarian from £5.25 to £7.71
- African-Caribbean from £6.71 to £7.71
- Halal from £6.71 to £7.71
- Kosher £12.09 (frozen option available from £6.45)
- Other special diets (diabetic, low salt, texture modified etc.) from £5.25 to £7.56 (frozen options available from £1.60)

All prices include delivery.

5.5 Additional Services

The respondents have listed a number of additional services provider whilst delivering the meal, including:

	Organisation A	Organisation B	Organisation C	Organisation D	Organisation E	Organisation F	Organization G
General checking on customer's wellbeing/cause for concern	✓	✓	✓	✓	□	✓	✓
Offer a drink of water	✓	□	✓	□	□	□	✓
Remove lids from meals	✓	□	✓	□	□	✓	✓
Plate up meals	✓	□	✓	□	✓	□	✓
Cut up meals	✓	□	✓	□	□	□	✓
Bring in items from the doorstep	✓	□	✓	✓	□	□	□
Take out rubbish	□	□	✓	□	□	□	□
Dispose of container or lid	□	□	✓	□	□	□	□
Help with menu planning	□	□	✓	□	□	□	□
Get seasonings, cutely, clean tea towel	□	□	✓	□	□	□	✓
Smell gas	□	□	✓	□	□	□	□
Heating working	□	□	✓	□	□	□	□
Make hot dink	□	□	✓	✓	□	□	□
Best before' dates checked	□	□	✓	□	□	□	□
Tripping hazard	□	□	✓	□	□	□	□
Post letters	□	□	□	✓	□	□	□
Place meal in the freezer or microwave	□	□	□	✓	□	□	□
Safe, Warm and Well checks'	□	□	□	□	□	□	✓

✓ additional charge

Organisation B and E provided very limited responses, it is possible that they provide more additional services, but failed to include these in the SMT response. Organisation C provides wide range of services, beyond the above listed, however, these attract additional charge.

5.6 Capacity and Current Take Up

Most providers are able to provide from 50 meals per day to 1000+meals. Providers are providing meals from 30 to 125 per day. Frozen meals are provided in bulk as required by the customers.

6. Options

The SMT questionnaire asked respondents their views on the most effective option for the delivery of the service. They were presented with 3 examples, but there was an opportunity to present the Council with a completely new solution. The 3 options were:

- A. A single service provider to prepare and deliver all types of Community Meals (Mobile Meals). Provision covering all Customer Groups across Adult Social Care (single provider undertakes service delivery).
- B. A framework of multiple specialist providers to prepare and deliver Community Meals (Mobile Meals) covering all customer groups of ASC (potential providers could undertake this for one or more of the type of meals provision).
- C. A framework of multiple specialist providers to prepare only Meals covering all customer groups of ASC (potential providers could undertake this for one or more of the type of meals provision).

One of respondents, who currently provide frozen meals, opted for proposing an option not listed above. Their suggestion was for them to deliver frozen meals to in-house or external transport provider for distribution.

Out of the remaining 6 respondents, those able to provide a wide range of cultural meals stated preference for option A. above, i.e. single provider service. The organisations specialising in only one culturally appropriate type of meal (Gujarati, African-Caribbean, European) expressed preference in having a framework of multiple specialist providers, who both prepare and deliver meals (option B).

7. Issues for Consideration

- The current mobile meals provider (that is the organisation who provides the meals for the in-house provider to reheat) would not be in position to deliver hot meals direct to customers in Leicester City, due to not having facilities in the area and an inadequate volume of meals indicated.

- There are alternative providers who can prepare and deliver nutritionally well balanced and culturally appropriate hot meals if frozen meals are discontinued in future.
- Limited providers came forward to provide African- Caribbean and Kosher type of meals.
- Higher unit costs for African – Caribbean and Kosher meals provision.
- One of the Charity organisations is able to provide Customers breakfast and tea packs and can also explore delivery times offering service in the late afternoon or early evening (offering choice to Customers).
- There is a potential risk around TUPE – although this is low and advice from the legal team has been sought.

3. Details of Scrutiny

One of the objectives of the SMT was to establish what providers can do to provide various types of meals, frequency and price of meals. The SMT has been external scrutiny by providers who have responded and internally the Mobile Meals Project Board, Transformation Team including Contracts and Quality Assurance Section scrutinised to achieve the Council's outcomes.

5. Financial, legal and other implications

5.1 Financial implications

The financial allocation for mobile meals provision is yet to be determined.

5.2 Legal implications

Not arising from this report.

5.3 Climate Change and Carbon Reduction implications

This report does not contain any significant climate change implication. However, the proposed tendering of the mobile meals must consider it to ensure the meals service provision must not have a detrimental effect on the Council's climate change targets. Issues to consider are packaging and transporting of meals.

5.4 Equality Impact Assessment

The Mobile Meals Service provision must considers issues as stated below:

- Ensuring culturally appropriate meals are available.
- Ensuring customer choice.
- Ensuring meals reflect any dietary requirements.
- Ensuring vegetarian meals are being prepared in appropriate facilities where no meat and being handled and they are stored and transported appropriately,
- Ensuring meals are fresh and nutritious and ingredients used are responsibly sourced.

5.5 Other Implications

Impact on customers currently in receipt of the service.

6. Background information and other papers:

None.

7. Summary of appendices:

- (i) Soft Market Testing Questionnaire – Community Meals



SMT MoW final.doc

Equality Impact Assessment for Service changes / Budget proposals

An EIA is a tool which will help you assess whether there are any positive or negative equality impacts on people affected by proposed changes requiring formal decision.

Service change involves redesigning or reshaping, (and in some cases the removal of) current service provision – whether directly provided by Council officers or commissioned by the Council for provision by an external provider.

Budget proposals should arise from service changes that you are considering throughout the year in light of the current financial climate. The EIA for budget proposals should cover the same issues as considered for service changes.

Our public sector equality duty requires us to ensure that we do not discriminate against any protected group or person with protected characteristics (see below) covered by the Equality Act 2010 when taking decisions that affect them. Potential negative impacts that we disregard or ignore could mean discrimination. We also have a duty to actively promote positive impacts that advance equality of opportunity. The protected characteristics covered by the Equality Act 2010 are:

- Age
- Disability
- Gender reassignment
- Pregnancy and maternity
- Race
- Religion or belief
- Sex
- Sexual orientation.

What to do: The service change / budget proposal EIA contains 3 steps:

Step 1 The proposal

This part of the EIA examines the proposed change to the service and potential equality impacts takes place at the start of the planning process.

Step 2 Consultation

This part of the EIA covers the outcome of the consultation with service stakeholders about service change proposals.

Step 3 The recommendation

The final part of the EIA presents the recommendation for decision along with potential positive and negative equality impacts of the recommended action.

Any issues identified in the above EIA process requiring action should be addressed in a SMART EIA action plan.

Remember to keep your supporting information and analysis as your evidence base (including any needs assessments informing the start of the planning process) in case of challenge to the contents of your EIA, your interpretation of the evidence used to support the EIA, or your interpretation of protected groups affected.

Equality Impact Assessment for service changes / budget proposals

Name of service	Mobile Meals – review implementation
------------------------	---

Date of assessment:

Start date	Completion date
01-10-2013	23-10-2013

Lead officer and Contact details	Mercy Lett-Charnock Contact: 37 2377
List of other(s) involved	Jagruti Barai – HR Advisor Irene Kszyk – Corporate Equalities Lead

What is this EIA about?

(Please tick✓)

Budget proposal for existing service or service contract to achieve savings	<input type="checkbox"/>
Budget proposal for new or additional service expenditure	<input type="checkbox"/>
Budget proposal for capital expenditure	<input type="checkbox"/>
Commissioning a new service or service contract	<input type="checkbox"/>
Changing or removing an existing service or service contract	<input checked="" type="checkbox"/>

Step 1: The proposal (how you propose to change the service)

Question 1:

What is the proposal/proposed change?
<p>The proposal is to cease the current mobile meals service and provide meals in more flexible ways. The current mobile meal service has two components, meal preparation and a delivery service. The delivery service is provided by the Council's Passenger & Transport Service (PATs), via a Service Level Agreement (SLA) with Adult Social Care. In terms of the meal preparation, City Catering re-heats re-generated frozen food for the European, Punjabi, Halal and Kosher meals, which are supplied by Appetito. Caribbean style and Gujarati vegetarian meals are freshly prepared by the West Indian Senior Citizens Project and the East West Community Project respectively through a block/spot contract arrangement. If change is supported, service users currently in receipt of mobile meals will receive individual reassessments of their needs to enable an appropriate alternative to be planned. Where needed, appropriate support will be given to set up alternative options chosen by the service user. The alternatives will be dependent on individual needs and will therefore vary but may include options such as direct payments, domiciliary (home) care, alternatives hot meal provision or support to order meals which the service user can reheat themselves for example.</p> <p>As well as service users, the change will impact on staff at City Transport and City Catering</p>

involved in the mobile meals preparation and delivery as well as the two external food suppliers currently under contract to prepare mobile meals.

Who will it affect and how will they likely be affected?

It will affect 236 existing service users as well as 19 staff, 16 from City Transport and 3 from City Catering (8.93 FTE). It will also affect two external support/meal providers.

Service users will be reassessed and where they have eligible needs will be supported to organise alternative provision. This will mean they continue to get their needs met but in many cases will get their meal from a different source. Those receiving meals from external providers may choose to continue to purchase their meals from there so there may be a lesser impact. Assessments are holistic and diet and health needs will be included in a support plan and will be taken into account when services are organised on behalf of a service user.

For staff at City Catering and City Transport redundancy is a possibility, however staff may be able to be redeployed within school kitchens or within Passenger and Transport services where vacancies exist.

A change from a block contracting arrangement to the use of personal budgets and a lower value contract (likely to be a framework) would cause some financial uncertainty for both providers as there is less security of knowing what income will be received.

Question 2:

Will the proposal have an impact on people because of their protected characteristic? Tick the anticipated impact for those likely to be affected by protected characteristic.

	No impact	Positive impact	Negative impact	Impact not known
Age		✓	✓	
Disability		✓	✓	
Gender reassignment				✓
Pregnancy and maternity				✓
Race		✓	✓	
Religion or belief				✓
Sex (gender)		✓	✓	
Sexual orientation				✓

Question 3:

For those likely to receive a positive impact, describe the likely positive impact for each group sharing a protected characteristic. How many people are likely to be affected?

Age, disability, race, religion and gender have been highlighted as areas likely to be impacted on through this project/proposal. The majority of people in receipt of meals are older people or disabled people and more women receive meals than men and these groups will therefore be disproportionately affected compared to other groups. Meals are delivered to people in all communities and their race, religion or belief may impact on their meal choice and current meal provider. People in some communities may be more affected than others therefore.

The positive impact is likely to be the same for each group affected, in that the change proposed would mean that people get reassessed and those eligible for services will receive support to choose a suitable alternative to mobile meals which they will then purchase with their personal budget (either directly through a Direct Payment or indirectly through a managed budget). This should result in people choosing options that meet their needs and suit their practical arrangements. With the current mobile meals provision many thousands of meals are wasted each year because meals can only be delivered at certain times so people are often out and miss them. If people can choose from a variety of places they should be able to arrange more flexible options that meet their needs both in terms of any cultural or dietary requirements but also in terms of preparation and delivery. In addition people currently receiving a home care call may have their meal support needs met by home care support and again – this can be more closely tailored to chosen meal times.

It is possible those currently receiving frozen regenerated European, Halal, Punjabi and Kosher meals may experience a particularly positive impact as these meals have come under some criticism in terms of quality and portion size.

Service users - profile

Race

Leicester City Council estimates (which are based on the census 2011 and local information) suggest that across the Council as a whole 51% of the population is white, 37% is Asian and 6% is Black. The data from current mobile meals service users shows us that 45% of users are Asian, 45% white and 6% African Caribbean. This shows that Asian service users will be

disproportionately affected by the proposed recommendations.

Gender

There is a significantly higher number (60%) of female recipients as compared to male (40%). The gender profile of Leicester city as a whole has a higher proportion of females compared to males running across all age groups. However within the 65+ age group across the city, the difference is 56% female and 44% male. Therefore females will be disproportionately affected by these recommendations.

Age

Perhaps unsurprisingly the largest group affected are older people (77% of the total customers in receipt of Mobile Meals are over the age of 70 years) and this may indicate that many of those affected will be looking for a managed personal budget in future.

Disability

Across Leicester 8.4% of the population are disabled people claiming invalidity benefits. Unsurprisingly, the percentage of people currently receiving the mobile meals service is much higher than that with 43% having a physical disability rising to 64% if physical/age related frailty or temporary illness is included.

Religion

We do not know the religion of all the current users. However meal choices are often dictated or influenced by people's religion and we know the current meal provision is as follows:

	Number of Customers	Percentage Customers
European Style Meals	120	51%
Gujarati Style Meals	92	39%
Caribbean Style Meals	12	5%
Punjabi Style Meals	12	5%
	236	100%

Question 4:

For those likely to receive a negative impact, describe the likely negative impact for each group sharing a protected characteristic. How many people are likely to be affected?

Age, disability, race, religion and gender have been highlighted as areas likely to be impacted on through this project/proposal. The majority of people in receipt of meals are older people or disabled people and more women receive meals than men and these groups will therefore be disproportionately affected compared to other groups. Meals are delivered to people in all communities and their race, religion or belief may impact on their meal choice and current meal provider. People in some communities may be more affected than others therefore. The service user profile is as listed in Question 3.

For all groups affected the impact will be similar – that is they will cease to receive the mobile meals service they currently get but they will each have an individual needs assessment that will identify an appropriate personalised alternative. Therefore although receiving a different service, it will still meet their needs and those affected should not be impacted on adversely. However, it is recognised that many people do not like change and may experience a negative impact from experiencing change itself as much as from the change of meal/provider. It is possible some people may have regular drivers delivering meals and may experience a negative impact as a result of the change.

As EWCP and WISCP already provide meals to customers through private arrangements it

is possible that these users will continue to get their meals from the same source going forward (if they choose) but just under a different arrangement. It will not be an option for those receiving European, Halal, Punjabi and Kosher meals regenerated by City Catering and delivered by City Transport to continue to get this service as it will not be available to purchase on a private/individual basis going forward. It is therefore possible to suggest that those receiving European, Halal, Punjabi and Kosher meals may notice a bigger change therefore.

Impacts will vary depending on individual options chosen but one of the likely alternative options is or those who receive home care to have a meal prepared or reheated by a home care worker. In this case, for those who have meals delivered freshly currently – i.e. those who get Gujarati or African/Caribbean meals, a reheated replacement may provide a perceived lower quality option.

However, it must be noted all service users can take the opportunity to take a Direct Payment and therefore could continue to purchase the meal type they wish.

Providers can set their own pricing arrangements and although we would anticipate they price themselves competitively it is possible that because the meals have been subsidised to date, when service users get to choose their own options they may not want to pay the “going rate” that is being set by the current providers and will therefore not continue to receive meals from EWCP or WISCP.

How can these negative impacts be reduced or removed?

Service users will be supported on a 1-1 basis to choose appropriate options that meet their needs and as part of the project management service users will be communicated with to explain the changes and reassure them. People who are currently in receipt of a mobile meals service have differing needs for example with some unable to prepare a meal but other simply unable to obtain the shopping/food/meal. Any future services will be designed to meet the specific area of need and different options will be made available to ensure this can happen.

Question 5:

Is there other alternative or comparable provision available in the city? Who provides it and where is it provided?

Some external providers already undertake some of the functions of the mobile meals service – WISCP and EWCP provide to specific cultural groups. When looking at alternative meal options, soft market testing established that there are providers across the city who can deliver hot meals. Providers also exist who will deliver frozen meals but heating of these needs to be arranged separately. The Council wouldn't commission frozen meal provision but this may be an option people choose independently. Other home care providers exist who can support people to prepare or warm a meal and a mixture of these options will be the replacement service for some of the people affected. Soft market testing showed there were examples of all meals types being provided for however there is more choice for some groups than others and prices vary.

Can this alternative or comparable provision reduce or remove the negative impacts identified in Question 5? If not, why not?

As service users will receive a personal budget going forward there is no longer a remit for the Council to hold block contracts as people will make their own choices and purchases.

Therefore getting another provider to deliver the mobile meals service en masse is not appropriate but the Council will need to ensure there are options available for people to purchase with their personal budget.

Would service users negatively affected by the proposal be eligible to use this alternative or comparable provision, and would it meet the service users' identified needs?

Although it is believed service users will not experience a significant negative impact, service users assessed as eligible for continued provision will be able to receive a service from wherever they choose including existing providers if they take a Direct Payment. The cost factor may be an issue in deciding where meals are purchased.

Question 6:

Will any particular area of the city be positively or negatively affected by the proposal, compared to other parts of the city? Describe where this is likely to take place, and why.

This impacts across the city however, we know from the profile of service users that in Latimer and Spinney Hills there are a larger proportion of mobile meals recipients than elsewhere. Within these 2 wards, approximately 39% of the mobile meal customers receive Gujarati style meals.

The user profile across the city is as follows:

	Number of Customers	Percentage of Customers
Abbey	10	4%
Aylestone	5	2%
Beaumont Leys	6	3%
Belgrave	20	8%
Braunstone Park Rowley Fields	7	3%
Castle	7	3%
Charnwood	19	8%
Coleman	7	3%
Evington	8	3%
Eyres Monsell	5	2%
Fosse	6	3%
Freemen	2	1%
Humberstone & Hamilton	13	6%
Knighton	7	3%
Latimer	30	13%
New Parks	8	3%
Rushey Mead	17	7%
Spinney Hills	22	9%
Stoneygate	11	5%
Thurncourt	11	5%
Westcotes	8	3%
Western Park	7	3%
	236	100%

Question 7:

Is it likely that there may be additional negative impacts arising over the next three years that need to be considered? Describe any additional negative impacts over time that could realistically occur.

Some people using the mobile meals service may also be in receipt of other social care services such as day care which may change over the next 3 years. Although changes to service are in order to personalise provision and should not have a negative impact, for some people the cumulative effect of change can be important.

Question 8:

What data/information/analysis have you used to inform your equality impact findings?

Staff profiles for City Catering and City Transport, population data for the city and profile data for the current mobile meals users.

Date completed10th October 2013.....

Step 2: Consultation on the final proposal

Question 1:

What consultation on the final proposal has taken place? When, where and who with?

Statutory consultation was carried out between 9 July and 7 October 2013 on the future of Leicester's Mobile Meals service

The proposal:

Stopping the Council's current mobile meals service and helping people to prepare or obtain meals in alternative and more flexible ways

The consultation was led by a small team of staff within adult social care and a variety of methods were made available for customers and stakeholders to feed back including information in alternative formats.

There was a 63% return rate (177 questionnaires received).

Question 2:

What potential impacts did consultation stakeholders identify?

- Concern that customers will lose human contact, which could lead to isolation and risk to welfare
- Will direct payments be sufficient to meet people's needs?
- Effects of budget cuts on old and vulnerable
- Still a need for culturally appropriate meals
- Concerns that any new arrangements may not provide the nutrition needed
- Opportunities for more choice and control

What positive impacts were identified? For people with which protected characteristics?
Some customers felt they would have more choice and control over what to eat and when. This relates to age, disability and religion/beliefs.
What negative impacts were identified? For people with which protected characteristics?
Stakeholders told us the following: <ul style="list-style-type: none"> • Concern that customers will lose human contact, which could lead to isolation and risk to welfare • Will direct payments be sufficient to meet people's needs? • Effects of budget cuts on old and vulnerable • Still a need for culturally appropriate meals • Concerns that any new arrangements may not provide the nutrition needed This relates to age, disability and religion/beliefs.

Question 3:

Did stakeholders indicate how positive impacts could be further promoted? How?
No
Did stakeholders indicate how negative impacts could be reduced or removed? How?
<ul style="list-style-type: none"> • By keeping the service as it is • By making sure that a hot meal delivery is still available • By ensuring the quality and nutritional benefits of any new arrangements • By providing advice and information about alternative options

Date completed15/10/13.....

Step 3: The recommendation (the recommended decision on how to change the service)

Question 1:

What changes are being recommended?
To cease the service as per section 1.
Who will be affected by these changes?
Service users, staff and providers.

Question 2:

What is the anticipated impact of these changes on people who share the following protected characteristics? Tick the anticipated impact below:
--

	No impact	Positive impact	Negative impact	Impact not known
Age		✓	✓	
Disability		✓	✓	
Gender reassignment				✓
Pregnancy and maternity				✓
Race		✓	✓	
Religion or belief				✓
Sex (gender)		✓	✓	
Sexual orientation				✓

Question 3:

For those likely to receive a positive impact, describe the likely positive impact for each group sharing a protected characteristic. How many people are likely to be affected?

Age, disability, race, religion and gender have been highlighted as areas likely to be impacted on through this project/proposal. The majority of people in receipt of meals are older people or disabled people and more women receive meals than men and these groups will therefore be disproportionately affected compared to other groups. Meals are delivered to people in all communities and their race, religion or belief may impact on their meal choice and current meal provider. People in some communities may be more affected than others therefore.

The positive impact is likely to be the same for each group affected, in that the change proposed would mean that people get reassessed and those eligible for services will receive support to choose a suitable alternative to mobile meals which they will then purchase with their personal budget (either directly through a Direct Payment or indirectly through a managed budget). This should result in people choosing options that meet their needs and suit their practical arrangements. With the current mobile meals provision many thousands of meals are wasted each year because meals can only be delivered at certain times so people are often out and miss them. If people can choose from a variety of places they should be able to arrange more flexible options that meet their needs both in terms of any cultural or dietary requirements but also in terms of preparation and delivery.

In addition people currently receiving a home care call may have their meal support needs met by home care support and again – this can be more closely tailored to chosen meal times, offering potential for evening calls as well as lunchtime.

It is possible those currently receiving frozen regenerated European, Halal, Punjabi and Kosher meals may experience a particularly positive impact as these meals have come under some criticism in terms of quality and portion size and service users can choose options which better suit them.

Question 4:

For those likely to receive a negative impact, describe the likely negative impact for each group sharing a protected characteristic. How many people are likely to be affected?

Age, disability, race, religion and gender have been highlighted as areas likely to be impacted on through this project/proposal. The majority of people in receipt of meals are

older people or disabled people and more women receive meals than men and these groups will therefore be disproportionately affected compared to other groups. Meals are delivered to people in all communities and their race, religion or belief may impact on their meal choice and current meal provider. People in some communities may be more affected than others therefore. The service user profile is as listed in Section 1 Question 3.

For all groups affected the impact will be similar – that is they will cease to receive the mobile meals service they currently get but they will each have an individual needs assessment that will identify an appropriate personalised alternative. Therefore although receiving a different service, it will still meet their needs and those affected should not be impacted on adversely. However, it is recognised that many people do not like change and may experience a negative impact from experiencing change itself as much as from the change of meal/provider. It is possible some people may have regular drivers delivering meals and may experience a negative impact as a result of the change.

As EWCP and WISCP already provide meals to customers through private arrangements it is possible that these users will continue to get their meals from the same source going forward (if they choose) but just under a different arrangement. It will not be an option for those receiving European, Halal, Punjabi and Kosher meals regenerated by City Catering and delivered by City Transport to continue to get this service as it will not be available to purchase on a private/individual basis going forward. It is therefore possible to suggest that those receiving European, Halal, Punjabi and Kosher meals may notice a bigger change therefore.

Impacts will vary depending on individual options chosen but one of the likely alternative options is or those who receive home care to have a meal prepared or reheated by a home care worker. In this case, for those who have meals delivered freshly currently – i.e. those who get Gujarati or African/Caribbean meals, a reheated replacement may provide a perceived lower quality option. There are 92 people currently receiving Gujarati meals and 12 receiving African/Caribbean meals.

However, it must be noted all service users can take the opportunity to take a Direct Payment and therefore could continue to purchase the meal type they wish.

Providers can set their own pricing arrangements and although we would anticipate they price themselves competitively it is possible that because the meals have been subsidised to date, when service users get to choose their own options they may not want to pay the “going rate” that is being set by the current providers and will therefore not continue to receive meals from EWCP or WISCP.

Soft market testing has been done with other providers in the market (as well as the current providers). There are indications that some customers will pay more under the new arrangements, particularly where they choose a like for like replacement – i.e. a hot meal delivery. This is because the Council currently subsidises the meals, when actually the food costs should sit with service users. It has been indicated through soft market testing that prices of African/Caribbean meals and Kosher meals may be dearer than other options when people purchase directly. There are 12 people in receipt of an African/Caribbean meal and none currently in receipt of Kosher meals.

Stakeholders raised the following specific points:

- Concern that customers will lose human contact, which could lead to isolation and risk to welfare
- Will direct payments be sufficient to meet people’s needs?
- Effects of budget cuts on old and vulnerable

- Still a need for culturally appropriate meals
- Concerns that any new arrangements may not provide the nutrition needed

How can these negative impacts be reduced or removed?

The following points consider the impacts stakeholders raised and how they can be addressed:

- Service users have a holistic assessment of their needs and meal provision is only one part of that. Service users who need social support will have this taken into account as part of their support planning and appropriate support put in place. This could be an alternative daily hot meal delivery if they require minimal contact or something such as befriending or community activities if more support is required.
- Soft market testing suggests that meals can be purchased for between £1.48 and £5.95 for frozen meals and £3.60 and £7.71 for a hot meal delivery. Service users currently pay £3.05 and if this contribution is added to the £2.28 Direct Payment amount towards meal delivery service users will have £5.33 per meal to spend. It should be noted that in practice, customers have their total needs met within the envelope of their Resource Allocation System (RAS) amount, rather than getting specific payments for specific things.
- The Council has a duty to ensure people with an assessed need have that need met and therefore anyone who is old and vulnerable as per the stakeholder comment would still have their need met.
- As above, the Council has a duty to ensure people’s needs – including cultural and dietary are met. Soft market testing suggests there are appropriate options available.
- Diet and nutrition form part of the assessment process. However, service users with capacity are responsible for their own meal choices and staff would only advise. Those without capacity will be supported to do this. In other circumstances, where for example a home care worker is reheating or preparing a meal, the nutritional value of the food will not have been checked in the same way as with a commissioned meal. In the contract specification for domiciliary care it does state the essential support skills for staff should include “promotion of healthy lifestyles including eating choices, meal preparation and activity”. If capacity was not there, workers would be able to choose a hot meal delivery from a contract framework (if this option is chosen) where nutritionally balanced meals are available or via a direct payment from a reputable source such as Wiltshire Farm foods.

Service users will be supported on a 1-1 basis to choose appropriate options that meet their needs and as part of the project management service users will be communicated with to explain the changes and reassure them.

A project team is in place and will oversee the process and will take into account the needs of all parties.

Question 5:

Are there any actions required as a result of this EIA?

If yes complete the EIA Action Plan on the next page. List up to 3 priority actions.

Date completed23/10/13.....

This EIA has been completed by:

Lead officer (signature)	Mercy Lett-Charnock
Date	23/10/13

The EIA has been signed off by the Equality Officer:

Equality officer (signature)	Irene Kszyk
Date	25/10/13

This EIA has been signed off by the Division Director:

Divisional Director (signature)	
Date	

EIA Action Plan

Please list all the equality objectives, actions and targets that result from the Equality Impact Assessment. These should be included in the relevant service plan for performance management purposes.

Equality Objective	Action required	Target	Officer responsible	By when?
Example: To know equality profile of all service users.	Example: collect monitoring data on disabled users (currently not being provided)	Example: To have data for first performance review	Example: Joe Smith	Example: Start collection of data in April 10
To understand the impact on external providers	Work with existing external providers as part of the implementation to see if support is required			

What to do next?

If this EIA has identified any issues that need to be addressed (such as plugging a data gap, or carrying out a specific action that reduces or removes any negative impacts identified), complete the attached EIA Action Plan to set out what action is required, who will carry it out, and when it will be carried out/completed.

Once your EIA has been completed, (signed by the equalities officer **and countersigned by your Director**) the equality officer will work with you to monitor this action plan.

Equality officers: Sonya Osborne 29 7738 Sukhi Biring 29 6954

EIAs will be made widely available and published on the Councils website and intranet.

Impact Analysis – Option 4

Mobile Meal recipients have been placed into 6 groups in order to make assumptions about the future services they may receive. This then enables consideration of possible changes to the charges that customers may have to pay.

	Assumption About Replacement Services	Customer Numbers	Number of Meals	Will Not Pay More	Will Pay More
1	Customers already in receipt of a mealtime home care visit	73	441	63	10
2	Customers in receipt of a DP for any other services	20	106	20	0
3	Customers who live alone and receive no other services	58	319	54	4
4	Customers who live alone and receive other services	39	230	38	1
5	Customers who do not live alone and receive no other services	23	136	22	1
6	Customers who do not live alone and receive other services	23	116	23	0
		236	1348	220	16
				93%	7%

How Many Customers Will Pay More Than Currently?

It is estimated that out of the 236 current mobile meals recipients 220 (93%) will pay no more than they do currently; 16 people (7%) are expected to pay more. This is based on applying assumptions about the future services that people will receive, along with information from financial assessments for the 70% who have had them.

How Much More Will People Pay?

Using information about the expected services that people will receive, and the outcomes of financial assessments already undertaken, it has been possible to estimate the future contribution amounts as follows:

People who will pay no more	220	93%
Pay less than £2.50 per week extra	1	0%
Pay between £2.50 and £5 per week extra	6	3%
Pay between £5 and £7.50 per week extra	0	0%
Pay between £7.50 and £10 per week extra	2	1%
Pay between £10 and £12.50 per week	2	1%
Pay between £12.50 and £15 per week	5	2%
	236	

Financial Impact for the Council

Under this scenario the total cost of replacement services would be in the region of £156k. This takes into account the additional income from chargeable replacement services. The forecast net cost of the Mobile

Meals service as at the end of August 2013 was £369k. There would therefore be annual savings in the region of £213k.

Impact Analysis – Option 5

Under this option, the cost implications for customers are expected to be the same as for Option 4. If a person receives a managed Direct Payment rather than a contracted service, then the charge to the customer would be identical. The cost to the Council would be slightly higher under Option 5 as a result of the additional cost of the third party DP support service.

How Many Customers Will Pay More Than Currently?

It is estimated that out of the 236 current mobile meals recipients 220 (93%) will pay no more than they do currently; 16 people (7%) are expected to pay more. This is based on applying assumptions about the future services that people will receive, along with information from financial assessments for the 70% who have had them.

How Much More Will People Pay?

Using information about the expected services that people will receive, and the outcomes of financial assessments already undertaken, it has been possible to estimate the future contribution amounts as follows:

People who will pay no more	220	93%
Pay less than £2.50 per week extra	1	0%
Pay between £2.50 and £5 per week extra	6	3%
Pay between £5 and £7.50 per week extra	0	0%
Pay between £7.50 and £10 per week extra	2	1%
Pay between £10 and £12.50 per week	2	1%
Pay between £12.50 and £15 per week	5	2%
	236	

Financial Impact for the Council

Under this scenario the total cost of replacement services would be in the region of £163k. This takes into account the additional income from chargeable replacement services. The forecast net cost of the Mobile Meals service as at the end of August 2013 was £369k. There would therefore be annual savings in the region of £206k.

Equality Impact

It is not possible to identify the individual people who will pay more in any scenario, since this will depend on the replacement service that each person will receive in the future (which, in turn, is dependent on their individual needs) and their financial circumstances.

However, as an indicator we can look at the 47 people whose financial assessment indicates that they could pay more. Care must be taken given the small number of people; numbers are shown alongside the percentages for perspective.

Gender

Proportion of each gender that have had a financial assessment and can afford to pay more:

Female	23%	(23 out of 101)
Male	38%	(24 out of 64)

Ethnicity

Proportion of each ethnicity that have had a financial assessment and can afford to pay more:

Asian or Asian British – Indian	24%	(18 out of 76)
Asian or Asian British - other Asian origin	67%	(2 out of 3)
Black Caribbean & White	100%	(1 out of 1)
Black or Black British – Caribbean	10%	(1 out of 10)
White British	35%	(24 out of 68)
White Irish	0%	(0 out of 1)
White –other	0%	(0 out of 5)
Other	100%	(1 out of 1)

Primary Client Type

Proportion of each Primary Client Type that have had a financial assessment and can afford to pay more:

Mental Health	27%	(13 out of 48)
Learning Disabilities	33%	(1 out of 3)
Physical Disabilities	28%	(31 out of 111)
Substance Misuse	50%	(1 out of 2)
Other Vulnerable People	100%	(1 out of 1)

Age

Proportion of each age group that have had a financial assessment and can afford to pay more:

18 to 64	41%	(12 out of 29)
65 to 74	20%	(5 out of 25)
75 to 84	25%	(12 out of 48)
85 to 94	28%	(16 out of 57)
95+	33%	(2 out of 6)

SCENARIOS – examples of how the options could affect customers

There are a wide range of potential permutations within the options. These depend on the particular customer, their needs and their funding thresholds. The scenarios below are indicators of how some of these people may be affected depending on what choices they may make.

The scenarios are based on indicative figures. In practice, customers have their total needs met within the envelope of their Resource Allocation System (RAS) amount, rather than getting specific payments for specific things.

Customer A - Already receives a direct payment and still needs a hot meal delivered	
What she currently gets	What could happen with new arrangements
Customer A currently receives a direct payment and arranges her own care. She also receives mobile meals 7 days a week. She wants to carry on having a hot meal delivered daily.	As Customer A already has a direct payment, she starts to receive an additional £15.96 per week. This is to cover the delivery part of her hot meals. She can then choose where to buy her meals from and how much she wants to spend. As she is used to paying £3.05 a day for mobile meals, this means that she now has a total of £37.31 a week to spend on having a hot meal delivered. That is £5.33 per meal. If she chooses meals that cost up to this amount, she will not be worse off. She may choose to pay more if she wishes. The average cost for a standard British/European meal, from the information we have, is £4.88.

Customer B - Has a managed direct payment and still needs a hot meal delivered	
What he currently gets	What could happen with new arrangements
Customer B has a direct payment, but it is managed for him so that he doesn't have to worry about making arrangements himself. He receives mobile meals 7 days a week. He wants to carry on having a hot meal delivery.	Customer B's direct payment is increased by £15.96 a week and this is managed for him along with the rest of his direct payment. He would receive initial support/advice to set up a new meal delivery and an independent organisation would manage the payments on his behalf. As he is used to paying £3.05 a day for mobile meals, this means that he now has a total of £37.31 a week to spend on having a hot meal delivered. That is £5.33 per meal. If he chooses meals that cost up to this amount, he will not be worse off. He may choose to pay more if he wishes. The average cost for a standard British/European meal, from the information we have, is £4.88. The difference between this customer and customer A is that a direct payment support service would help him manage the financial parts of the process.

Customer C – Can heat meals up but can't order for herself – she wants to order from a national frozen meal provider

What she currently gets	What could happen with new arrangements
Customer C receives mobile meals 7 days a week. However, she would prefer to have meals delivered that can be heated at a time that suits her. She can heat them, but she can't order them for herself. She does not receive home care and her financial circumstances mean that she would not have to pay for it.	Customer C starts to get half an hour home care each fortnight to help her with ordering her food. She chooses a dedicated meal delivery company, as when they are delivered, they would be put in the freezer for her. (If she orders from a supermarket this may not happen.) The financial impact on Customer C depends on where she chooses to buy her meals from. She previously spent £3.05 a day on her mobile meal. The extent to which she is better or worse off depends on his choice of provider. A frozen meal and dessert can typically be purchased for £3.50, but there is a wide variety to choose from. Based on £3.50 per meal, it would cost her £3.15 a week more.

Customer D - Already has a home care visit at lunch time and doesn't have to pay for care

What he currently gets	What could happen with new arrangements
Customer D has a home care visit at lunch time for half an hour. He also has a mobile meal 7 days a week. He doesn't have to pay towards his home care.	Customer D could have his home care visit extended by 15 minutes a day so that the carer can heat a frozen meal up for him. The costs of the food would be the same as for Customer C (above). As Customer D does not have to pay for his home care, the extent to which he is better or worse off depends on his choice of provider. Typically he could be an average of £3.15 a week worse off.

Customer E - Already has a home care visit at lunch time and has to pay for care

What she currently gets	What could happen with new arrangements
Customer E has a home care visit at lunch time for half an hour. She also has a mobile meal 7 days a week. She has to pay for her home care.	Customer E could have her home care visit extended by 15 minutes a day so that the carer can heat a frozen meal up for her. The costs of the food would be the same as for Customer C (above). As she has to pay for her home care, then she would have to pay an additional £21.77 per week for the extra home care. She could also have to pay an average of £3.15 a week extra towards food due to the cost of the food, but this depends on what choice of provider she makes. This means that she could be £24.92 a week worse off and would be unlikely to take this option.

Customer F – Does not have home care or a direct payment, and needs a Caribbean meal

What he currently gets	What could happen with new arrangements
Customer F currently receives a Caribbean mobile meal 7 days a week. He needs to continue receiving a hot meal daily and wants a direct payment.	Customer F starts to receive a direct payment for the delivery element of his meal. This is £15.96 a week. He finds a provider of Caribbean meals and the cost of each meal is an average of £6.20. Taking off the £15.96 for delivery and the £21.35 (£3.05 daily) for his food that he is used to paying, he would be an average of £6.09 a week worse off. However, it should be noted that the majority of Caribbean meals are between £5.95 and £7.71, which would mean that he may either need to decide to pay more or choose a different meal option.

Customer G- Needs a diabetic, low salt, Gujarati meal

What he currently gets	What could happen with new arrangements
Customer G currently gets a mobile meal 7 days a week. He does not receive home care. He has special dietary needs due to his health. He likes Gujarati meals.	Customer G could take a direct payment of £15.96 for delivery and arrange for meals to be delivered from a specialist provider of Gujarati meals. The cost of these meals, including delivery, is £5.25 (£36.75 a week.) Including the direct payment and the daily £3.05 he is used to paying, he has £37.31 available a week. This means that his meals will cost him 56p a week less.

Customer H - Still wants a hot meal delivered, arranged by the Council

What she currently gets	What could happen with new arrangements
Customer H currently gets a mobile meal 7 days a week. She does not have home care at the moment and a direct payment is not suitable for her.	The Council could contract with a provider to continue to deliver meals to Customer H. She would continue to pay the £3.05 per meal and there would be no additional costs to her. The only difference for Customer H is that someone else will be delivering her meals.

