APPENDIX 1

Scrutiny Board (Health and Wellbeing and Adult Social Care)

Living Well with Dementia in Leeds – Our Local Strategy (2012 – 2015)

Consultation Response on Draft Strategy

Introduction

1. In June 2012 we (the Scrutiny Board (Health and Wellbeing and Adult Social Care)) identified 'dementia' as one of our priority work areas for 2012/13. Therefore we welcomed the opportunity to consider Leeds' draft Dementia Strategy – *Living Well with Dementia in Leeds (2012-2015)* at our meeting on 25 July 2012.

2. This provided us with an opportunity to discuss the on-going work being undertaken around dementia and comment on the draft strategy, ahead of it being formally agreed and adopted later in the year (2012/13).

Background

3. We considered Leeds' draft Dementia Strategy – *Living Well with Dementia in Leeds (2012-2015)* – at our meeting on 25 July 2012. Attending that meeting to address the Board and answer our questions, were:

   - Dennis Holmes (Deputy Director) – Leeds City Council, Adult Social Services
   - Mick Ward (Head of Commissioning) – Leeds City Council, Adult Social Services
   - Tim Sanders (Integrated Commissioning and Transformation Manager, Dementia) – NHS Leeds and Leeds City Council

4. We are grateful to the above officers for attending our meeting and contributing to our discussion.

5. As a Board, we noted that the draft strategy was open for public comment until 30 September 2012 and, that following public consultation, the Strategy document and accompanying Action Plan would be published in autumn 2012.

6. We received a copy of the accompanying consultation questionnaire and, while not attempting to address each questioned posed, this has been used to inform the detail of the response provided below.

Comments on the draft Strategy

<u>Overview</u>

7. As briefly described in the draft document, dementia and living with its effects (both on individuals and their families) have been the subject of increased national attention and profile over recent years.

8. While we acknowledge that Leeds has a track record for being an early implementer of a number of initiatives around dementia, we welcome Leeds' draft strategy and accompanying action plan (to be drafted) as the local response to this national issue.

9. The draft document is well structured and relatively easy to read – despite some of the fairly technical issues it presents. It provides:

    - An overview of the issues and summary key facts about people with dementia in Leeds;
    - Clearly sets out the projected rise in the number of people suffering dementia; and,
    - Identifies areas for development to be addressed through the accompanying action plan (to be drafted).

10. The 'Dementia Journey' provides a useful summary of the stages of dementia and the accompanying areas of support and service provision necessary across the dementia continuum. Nonetheless, it terms of some of the detailed 'next steps' highlighted throughout the draft Strategy, we believe it might be useful to include some indication of timescales associated with action points and some indication of prioritisation. Clearly, it will be important to ensure these tally with the full and more detailed action plan due to be produced.

11. We also believe that, in common with similar strategy documents, the addition of a glossary of terms would be useful for service users, their families and other readers.

Assessment of need

12. We recognised that one of the main actions identified in the draft strategy is around improving understanding of the Leeds population and how current services are used. This will be achieved by completing a 'dementia needs assessment' for the population of Leeds. However, due to the nature of data sources used to collate the information on the number of dementia suffers, we understand that the number of dementia suffers from Black and Minority Ethnic (BME) communities is likely to higher than currently indicated. We believe it is essential that this is addressed through the needs assessment activity.

Early diagnosis

13. The importance of early diagnosis of the condition is recognised but we note it might take up to 12-months for some sufferers to seek professional help. We recognise the impact this may have on early diagnosis, therefore work around raising awareness is essential.

14. We also believe that at the point of diagnosis it is important to have early discussions about the future and ensure relevant plans are put in place as early as possible – particularly where financial issues are concerned, i.e. power of attorney.

Training and development

15. Alongside early diagnosis, we believe it is important to ensure that people with complex needs, co-morbidities or symptoms similar to early onset dementia are not misdiagnosed.

16. We also recognise the importance of training especially for medical staff dealing with people with dementia who also have other, often unrelated, health issues that required treatment.

17. It is also important for all care staff to receive appropriate training and ongoing support in order to help meet the needs of individuals suffering from dementia and their families. We recognise that appropriate training and development of all staff will remain key in the delivery of appropriate services.

18. During our discussion, we highlighted potential exploitation and abuse of dementia sufferers as a particular concern; alongside the need for all workers in health and adult care settings to be aware of this – including knowing the reporting mechanisms for suspected cases and understanding the role of the Adult Safeguarding Board.

Service issues and considerations

19. Given the potential impact of dementia on both individuals and their families, we believe that the needs of carers should be recognised and addressed within the overall strategy and accompanying action plan.

20. In particular, we believe there should be a particular emphasis on support for families and relatives in terms of explaining how changes in behaviour may manifest themselves, including depression, loneliness, aggression and psychotic behaviour in a previously "normal" individual. Alongside such information giving, it would also be helpful to provide examples of strategies or mechanisms around how best to cope with such distressing symptoms should they appear. The development and promotion of self-help/ support groups may offer useful opportunities to provide peer support.

21. We would also wish to highlight the potential benefits of using and encouraging the use of technology, for example telecare, mobile phones and other assistive technologies to improve the overall wellbeing of dementia suffers, their families and carers.

22. We believe it is important to ensure that any residential care provided is of high quality and the needs of couples, where one partner may be suffering from dementia, need to be carefully consider. During our discussions, we highlighted the potential role of extra care housing schemes in this regard.

23. We also highlighted the need to ensure adequate bereavement support for families, and the potential role hospices could have in providing help and advice to statutory health and social care bodies in this area.

24. We also believe there is a specific need to ensure the provision of age-appropriate care and services, especially for younger people experiencing early on-set dementia.

Leadership and partnership

25. Leeds' emerging Health and Wellbeing Board has a pivotal role in providing leadership and direction for a range of priority service areas. As such, we believe it is important that all members of the Health and Wellbeing Board support the final strategy and its accompanying action plan.

26. Operationally, it is important that the three Clinical Commissioning Group (CCG) representatives on the Health and Wellbeing Board disseminate the agreed strategy and action plan to their constituent GP practices and ensure dementia is identified within relevant target training programmes.

Financial and resource considerations

27. We note that, whilst dementia care had been identified as a nationally priority, it is unlikely that there will be any new funding available to support the local response, i.e. the strategy and supporting action plan. As such, it is clear that delivery against the strategy will need to be funded through existing resources. We believe it is important for this to be recognised within the strategy, alongside the overall financial environment and associated context for the health and social care economy.

28. The draft Strategy outlines that the largest increase in the number of people suffering from dementia is likely to occur in the 90+ years age bracket – which is likely to quadruple (from around 1,000 people to 4,000 people) over the next 25. It is perhaps more likely that as people in this age range move towards the 'End of Life care' stage of dementia, they will need to access more specialist care.

29. By the very nature of 'specialist care', this is likely to have a significant financial impact across health and social care services in Leeds. As such, we believe it might be useful to provide within the document an overall estimate of the current level of (health and social care) resources attributable to the provision of carer and support for people suffering from dementia.

30. We believe it would be helpful to use this information to demonstrate the impact of the projected increase in numbers, to help highlight the financial pressures such increases will undoubtedly have. We believe this will also help to reinforce the need to redesign how care and support is provided in the future and how, by working more closely and pooling resources, health and social care organisations might be better placed to identify the necessary efficiencies.

31. Given the undoubted ongoing financial pressures likely to affect aspects of all services across health and social care, we believe it is important to include the estimated financial costs and benefits against appropriate aspects of the action plan. Financial expenditure and efficiencies will then be able to monitored alongside the actions themselves.

Evidence of Good Practice

32. Finally, given the national profile of dementia and the services needed to support and care for sufferers and their families, we believe it is important to take note of and learn from identified areas of good practice. That is not to say that what works well in one local authority area will automatically be successful in Leeds – but equally, approaches should not automatically be ruled out of hand.

33. We note that the Department of Health publication *Living well with dementia: A National Dementia Strategy, Good Practice Compendium – an assets approach* was published in January 2011. We recommend that in finalising the draft strategy and accompanying action plan, consideration is given to merits of the different approaches adopted elsewhere in the country identified in this, and other, publications.

Councillor John Illingworth
Chair, Scrutiny Board (Health and Wellbeing and Adult Social Care)

October 2012