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Leeds CITY COUNCIL

HEALTH AND WELLBEING BOARD

Meeting to be held in The Carriageworks on
Wednesday, 22nd May, 2013 at 10.00 am
(pre-meeting for all Board Members at 9.30 a.m.)

MEMBERSHIP

Councillors

J Blake S Golton G Latty
L Mulherin
A Ogilvie

Directors

Sandie Keene	Director of Adult Social Services
Nigel Richardson	Director of Children's Services
Dr Ian Cameron	Director of Public Health

Representative of Third Sector

Susie Brown, Zest – Health for Life on behalf of Third Sector Leeds

Representative of NHS (England)

Andy Buck, Director, NHS England

Representatives of Clinical Commissioning Groups

Dr Jason Broch	Leeds North CCG
Dr Andrew Harris	Leeds South and East CCG
Dr Gordon Sinclair	Leeds West CCG

Representative of Local Healthwatch Organisation

Linn Phipps	Healthwatch Leeds

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A G E N D A

Item No	Ward/Equal Opportunities	Item Not Open		Page No
1			**APPEALS AGAINST REFUSAL OF INSPECTION OF DOCUMENTS** To consider any appeals in accordance with Procedure Rule 25 of the Access to Information Rules (in the event of an Appeal the press and public will be excluded) (*In accordance with Procedure Rule 25, written notice of an appeal must be received by the Head of Governance Services at least 24 hours before the meeting)	
2			**EXEMPT INFORMATION - POSSIBLE EXCLUSION OF THE PRESS AND PUBLIC** 1 To highlight reports or appendices which officers have identified as containing exempt information, and where officers consider that the public interest in maintaining the exemption outweighs the public interest in disclosing the information, for the reasons outlined in the report. 2 To consider whether or not to accept the officers recommendation in respect of the above information. 3 If so, to formally pass the following resolution:- **RESOLVED** – That the press and public be excluded from the meeting during consideration of the following parts of the agenda designated as containing exempt information on the grounds that it is likely, in view of the nature of the business to be transacted or the nature of the proceedings, that if members of the press and public were present there would be disclosure to them of exempt information, as follows:-	

3			**LATE ITEMS** To identify items which have been admitted to the agenda by the Chair for consideration (The special circumstances shall be specified in the minutes)	
4			**DECLARATIONS OF DISCLOSABLE PECUNIARY INTERESTS** To disclose or draw attention to any disclosable pecuniary interests for the purposes of Section 31 of the Localism Act 2011 and paragraphs 13-16 of the Members' Code of Conduct.	
5			**APOLOGIES FOR ABSENCE** To receive any apologies for absence	
6			**MINUTES - 27 MARCH 2013** To note the minutes of the shadow Health and Wellbeing Board held on 27 March 2013	1 - 8
7			**GOVERNANCE ARRANGEMENTS**	9 - 14
8			**APPOINTMENT OF ADDITIONAL MEMBERS** To consider whether to appoint any additional Members to the Board for the Municipal Year 2013/14	15 - 18
9			**JOINT HEALTH AND WELLBEING STRATEGY AND PERFORMANCE** Approval and publication of the Leeds Joint Health and Wellbeing Strategy. Current performance status of the indicators.	19 - 46

10			**DEMENTIA STRATEGY AND APPROVAL OF LEEDS AS A DEMENTIA FRIENDLY CITY** Update on the Dementia Strategy for Leeds and approval by the Board of Leeds as a Dementia Friendly City	47 - 114
11			**THE FRANCIS REPORT** Outline of the Francis Report and assurance to the Board regarding the steps in place to ensure quality of services in light of the Francis Report and the Government's response to this.	115 - 134
12			**LEEDS INNOVATION HEALTH HUB** Outline of LIHH and how its work will move forward.	135 - 144
13			**ANY OTHER BUSINESS**	
14			**DATE AND TIME OF NEXT MEETING** Wednesday, 24 July 2013 at 2.00 p.m.	

Minutes of the meeting of the shadow Health and Wellbeing Board held on 27 March 2013

Members Present:

Cllr Lisa Mulherin	Leeds City Council (Chair)
Cllr Judith Blake	Leeds City Council
Dr Jason Broch	NHS Leeds North Clinical Commissioning Group
Ms Susie Brown	Third Sector (Healthy Lives Leeds)
Dr Ian Cameron	NHS Leeds/ Leeds City Council
Cllr Stewart Golton	Leeds City Council
Dr Andy Harris	NHS Leeds South and East Clinical Commissioning Group
Cllr Graham Latty	Leeds City Council
Dr Gordon Sinclair	NHS Leeds West Clinical Commissioning Group
Cllr Lucinda Yeadon	Leeds City Council

In attendance:

Mr Chris Butler	Leeds and York Partnership Foundation Trust
Ms Judith Hurcombe	Local Government Association
Ms Sandie Keene	Leeds City Council Adult Social Care
Mr Rob Kenyon	Leeds City Council Partnerships
Ms Hannah Lacey	Leeds City Council Partnerships (secretary)
Ms Victoria Pickles	Leeds Community Healthcare NHS Trust
Mr Steve Walker	Leeds City Council Children's Services
Mt Rob Webster	Leeds Community Healthcare NHS Trust

Apologies:

Ms Maggie Boyle	Leeds Teaching Hospitals NHS Trust
Ms Pat Newdall	Leeds Local Involvement Network (Leeds LINk)
Mr Nigel Richardson	Leeds City Council Children's Services

Action

1.0 Welcome and introductions/apologies for absence

1.1 Councillor Mulherin welcomed all to the last meeting of the shadow Health and Wellbeing Board before it takes up its statutory duties in May, and welcomed Judith Hurcombe who attended the meeting to observe.

1.2 The above apologies were noted and although in her absence, the Chair formally thanked Pat Newdall for her dedication and contribution to the Shadow Board on behalf of Leeds LINk.

2.0 Minutes of last meeting on 23 January 2013

2.1 All agreed as a true record.

3.0 Matters arising

3.1 Rob Kenyon referred to minute 4.15 from the previous meeting and informed members that there will be a legal training session prior to the Board taking up its statutory responsibilities in May. This will be for Board members who are not elected members and planning for this is underway.

3.2 Referring to minutes 7.8 and 7.9 it was noted that Councillor Illingworth has also joined the Healthwatch working group through his role as Chair of the Health and Well Being and Adult Social Care Scrutiny Board.

4.0 Integrated Commissioning

4.1 Andy Harris introduced this item on behalf of all 3 clinical commissioning groups (CCGs) which was seen as a trial-run for the Board undertaking one of its statutory duties: "provide an opinion to each CCG on whether their draft commissioning plan takes proper account of the joint health and wellbeing strategy (JHWS)". Only the one page summary "plan on a page" was provided to the Board members and not the full commissioning plans.

4.2 These plans had been developed in line with CCGs becoming formally established on 1 April 2013 and as part of the National Commissioning Board's requirements for a 2013/14 plan. It was felt by the CCGs that these plans reflected the Leeds draft JHWS as they had input into the development of the strategy and this input reflected the joint strategic needs assessment (JSNA) and the needs of their local populations.

4.3 It was noted that as this was a first run, and with the many changes taking place in the health system, developing the plans had been a complex task to ensure that everything from NHS mandate to local people and member practices had been taken into account.

4.4 In addition to a commissioning plan, each CCG is required to have three local priorities which reflect the area and population which they cover.

4.5 It was questioned how much cross-referencing had taken place during the development of the commissioning plans, and confirmed that much had occurred, primarily through the Leeds Health and Social Care Transformation Programme Board (LHSCTPB). There are a number of themes which are common across all three plans and others which reflect the specific health needs of the population covered by one CCG.

4.6 In reference to the complexity of the plans the Board hoped that these were also presented in such a way that they are accessible and understood by members of the public and service users. Both the public and member GP practices were consulted during the formation of the plans and now that these were agreed it was work in progress to make them accessible reading

to all. It was confirmed that all plans would be public documents.

4.7 It was confirmed that all decisions regarding the flow of money and commissioning had now been taken and the situation was as clear as it could be. This did however raise the issue of working with multiple commissioners and the difficulties associated with the CCGs commissioning services which were previously the responsibility of primary care trusts and of tracking and funding people as they wove through the system between primary, secondary and tertiary care.

4.8 It was a concern that inequality could actually be created across Leeds if one CCG were to produce progress in a specific area. In response the CCGs emphasised that it was proper that each CCG had different areas of focus, given the different issues in their local areas however it was intended that good results would lead to shared learning across the city. Furthermore although there would be a targeted local approach, the intention was for the CCGs to tackle the pathways together particularly as the same providers were used by all three.

4.9 A member asked how the Local Authority could work with the CCGs to achieve shared aims. For example dementia which was mentioned in the CCG plans is also a concern of the Local Authority. It was confirmed that the commissioning plans were made up of strategies and actions which were already underway such as the Dementia Board, rather than new ideas. With reference to dementia strategy in particular, it was noted that the Dementia Friendly City strategy was on the agenda for the meeting of the Board on 22 May so that all could endorse this strategy.

4.10 There was concern amongst Board members over the lack of active reference to children across the three plans. Children were only explicitly mentioned in the plan of Leeds South & East CCG. This was as a result of this CCG taking the lead role in this area. Whilst it was accepted that these one page documents cannot cover everything and that there is extensive reference to children in the plans sitting below them, it was the consensus of the Board that there should be more reference to children throughout. This is both due to the links between adult's and children's issues and that inspection bodies such as OFSTED and the Care Quality Commission would expect to see these overt references or risk them assuming that children were not a priority in Leeds.

4.11 There was some discussion as to the degree that the Board felt the JHWS should be reflected in the commissioning plans of the CCGs with the general view being that this should be at least 50% if not higher. Some Board members felt that at this point in time, the JHWS was not evident enough in the CCGs' commissioning plans. The CCG's point of view however was that

plans did reflect the JHWS but were written with the requirements of the National Commissioning Board in mind and they saw the "real" plan on a page as being the JHWS. It was agreed that the main issues lay with presentation and accessibility which was noted by the CCGs for further work and to feedback to the Board at a later meeting. **CCGs**

4.12 It was confirmed that the commissioning plans were not static or completed. They would evolve and develop over time as needs changed.

4.13 It was still unclear at what point the Board would report to the National Commissioning Board on the CCG Commissioning Plans. Rob Kenyon agreed to investigate and produce a draft for circulation. **RK**

5.0 Provider insights on the new health and wellbeing arrangements

5.1 Rob Webster introduced the work of Leeds Community Healthcare NHS Trust (LCH) and how the organisation was affected by the changes in the healthcare system and the contribution it could make to the JHWS.

5.2 The aim was to align the work of LCH to initiatives such as "Best City" and "Child Friendly City". Rob Webster reported that LCH has a clear set of values and vision and aims to provide the best possible care through working with people and not deciding for them.

5.3 LCH provide a vast range of community services, both long term and short term and throughout all stages of life.

5.4 It was stated that it was a myth that providers were the stable ones in this changing environment. They were also moving from working with one commissioner to working with seven, were in consultation over restructuring and were under significant financial pressure.

5.5 LCH was working towards becoming a Foundation Trust in the next year.

5.6 LCH feels that it is a major partner in the delivery of the first four outcomes of the Leeds draft JHWS and a contributor to the fifth.

5.7 LCH would like to see the following from the Health and Wellbeing Board:

- Strong leadership
- Engagement with providers
- Ensuring of integrated service delivery
- Use of the Trust's membership
- Effective monitoring of outcomes
- Use National Commissioning Board voice on the Board in the best way possible to influence the whole system
- Link between the Health and Wellbeing Board and the LHSC Transformation Programme Board.

5.8 Chris Butler introduced the work of Leeds & York Partnership Foundation Trust (LYPFT) and thanked the Board for the opportunity to present the organisation's insights.

5.9 LYPFT provides specialist mental health and learning disability services across Leeds and York and in some cases wider across Yorkshire and the Humber. Contact in hospital is these days kept to a minimum with care provided at home where possible and the Trust has strong links to the voluntary sector.

5.10 As a Foundation Trust, LYPFT has around 16,000 members.

5.11 As a result of the changes from the Health and Social Care Act, LYPFT have had to tender to provide some services. Much of what the organisation will provide is similar to what it provided under the old regime but there would be some changes. Chris Butler said it was a rapid learning curve.

5.12 As a Foundation Trust the Council of Governors would be responsible for holding the Board of Directors to account. The Trust had also been working to establish a good working relationship with the local CCGs.

5.13 LYPFT was seen as a contributor to the five outcomes of the Leeds draft JHWS.

5.14 LYPFT would like to see the following from the Health and Wellbeing Board:

- City wide plan for dementia services
- Commissioning services for learning disabilities consistent with the Winterbourne View report
- Commissioning services to meet the needs of those with autism and ADHD – current high levels of need unmet
- Improvement of social inclusion and cohesion
- Provision of services takes into account sustainability of local providers

5.15 The providers were asked about the benefits received by and the selection of their members. As a Foundation Trust and a proposed Foundation Trust both LYPFT and LCH were required to have members. LYPFT has circa 16,000 and LCH 4,000. Members generally receive NHS fringe benefits and the majority of the Council of Governors were members and service users. Engagement with members on issues such as the upcoming budget cuts was seen as an important part of being a Foundation Trust and LYPFT had taken a wider view than what is required and as a result received valuable insight from those who were not routinely engaged.

5.16 A Board member questioned how much taking money out of CAMHs services was actually costing in the long run? It was agreed that some tiers of these services were due for review and the aim was to get the best value possible from the "Leeds Pound". LYPFT had been using a tool called

Lean6Sigma to map every process in a service user's journey and look at how it could be made more efficient.

5.17 In addition, the providers were confident that they worked collaboratively together for the good of Leeds, sometimes to the detriment of what would be best for one of the individual organisations. Each provider was required to a produce a detailed efficiency plan lasting 5 years which had a focus on the integration of services in order to reduce duplication. The LHSCTPB has had a very positive effect on the collective working arrangements which exist between the providers. This had helped to offset negativity which could have come about as a result of the increased competitiveness under the new arrangements.

5.18 It was also felt that the providers had good relationships with the CCGs and that this was due to the depth of partnership working already in existence. This feeling is reciprocal with the CCGs.

5.19 Leeds Teaching Hospitals NHS Trust unfortunately had to send last minute apologies to the meeting. Their paper however focused on the concern of sustainability. This was echoed by the providers who were at the table. The consensus was that there was a need to move away from a hospital centred model of care, towards 7 day working and greater focus on prevention and community and management of long term conditions. This was something which needed to be approached in unison.

5.20 The Chair thanked the providers for their attendance and useful insights and hoped that they had found the meeting mutually beneficial.

6.0 Any other business

6.1 It was raised by a member that there may have been some significant changes in the arrangements for minor illness clinics and that these changes had appeared suddenly and without consultation. No-one in the room was aware of any contract changes or changes in these services. It was agreed however that the board should at the very least be informed in advance of such changes affecting services users. The Chair of the Board was already investigating the matter raised and will feedback to the Board at a later meeting. **LM**

6.2 It was brought to the attention of the CCGs that the way in which organisations were being asked to invoice them was complicated and time consuming whereby 3 separate invoices needed to be sent for varying percentages and it was asked if anything could be done to simplify the process. The CCGs responded that they are three separate organisations with three separate budgets so it may be difficult however the comment will be fed back and simplifying the process will be explored with an update to **CCGs**

the Board at a later meeting.

7.0 Date and time of next meeting

7.1 The Chair confirmed the date of the next meeting as Wednesday 22 May 2013 09:30-12:30 (public meeting 10:00-12:00) in the Millennium Room at Carriageworks. This will be the first public meeting of the Health and Wellbeing Board.

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Leeds Health & Wellbeing Board

Report author: Liz Davenport
Tel: 24 78408

Report of City Solicitor

Report to Health and Wellbeing Board

Date: 22 May 2013

Subject: Governance arrangements

Are there implications for equality and diversity and cohesion and integration?	☐ Yes	☒ No
Is the decision eligible for Call-In?	☐ Yes	☒ No
Does the report contain confidential or exempt information? If relevant, Access to Information Procedure Rule number: Appendix number:	☐ Yes	☒ No

Summary of main issues

1. This report outlines the governance arrangements for the Health and Wellbeing Board which were approved by full Council at the annual meeting on 20 May 2013.

2. At that meeting Full Council resolved to consult with the Health and Wellbeing Board before making a direction about voting arrangements. The terms of the proposed direction are set out in paragraph 3 of this report.

Recommendations

3. The Health and Wellbeing Board is asked to:

   - Note the governance arrangements approved by full Council for the Health and Wellbeing Board, outlined in paragraph 3 of this report; and

   - Consider the proposed voting direction, set out in paragraph 3 of this report.

1 Purpose of this report

1.1 This report presents the governance arrangements approved by full Council for the Health and Wellbeing Board for the municipal year 2013-14.

1.2 The report also asks the Health and Wellbeing Board to respond to consultation by full Council about a proposed direction in relation to voting arrangements.

2 Background information

2.1 The Health and Social Care Act 2012 requires Leeds City Council to establish a Health and Wellbeing Board as a **committee** of full Council. The Act sets out the functions to be discharged by the Board and a minimum statutory membership, (to include representatives nominated by the Council Leader, appointed by each clinical commissioning group (CCG) and the Local Healthwatch organisation, and the three statutory directors of Adult Social Services, Children's Services and Public Health).

2.2 In relation to **voting arrangements**, regulations provide for all members on the Board (including Council officers) to be voting members, unless the authority has directed otherwise. Before making such a direction, the authority must consult with the Board. Any voting co-optees (including officers), will need to comply with the authority's Code of Conduct.

2.3 At its annual meeting on 20 May, full Council approved governance arrangements for the Health and Wellbeing Board, made appointments to the Board, and noted the appointments made by the CCGs and Healthwatch Leeds to the Board.

3 Main issues

3.1 The **terms of reference for the Health and Wellbeing Board** were approved, as set out in appendix 1 to this report. These closely reflect the statutory functions of the Board. No additional functions have to date been referred to the Board by the authority, under function 9 of the terms of reference.

3.2 Full Council also approved amendments to the **terms of reference** of the Council's **Area Committees** to allow those committees to advise or make representations to the Health and Wellbeing Board, and to consider any proposals refered to them by the Health and Wellbeing Board.

3.3 In relation to **membership,** in addition to the statutory membership, full Council appointed a representative of the third sector**,** and a representative of NHS (England). The Health and Wellbeing Board may itself appoint additional members to the Board, as it thinks appropriate – see further the following item on this agenda.

3.4 Full Council resolved that the **quorum** for the Health and Wellbeing Board should be 4, to include one councillor and a CCG representative.

3.5 Full Council also approved **substitute arrangements** for councillors who are members of the Board, via nomination from the relevant group whip. Substitute arrangements for other members are to be reviewed once the Board has considered whether to appoint any further members – see further the following item on this agenda.

3.6 In relation to **scrutiny**, the Council's Scrutiny Board (Health and Wellbeing and Adult Social Care) has general review functions in relation to functions discharged by the Health and Wellbeing Board.

3.7 By law, decisions taken by the Health and Wellbeing Board under its core statutory functions **cannot** be subject to **call-in** (a procedure under which key decisions made by the executive cannot be implemented until they have been reviewed by a Scrutiny Board). Key decisions by the Health and Wellbeing Board under functions delegated to it by the Leader would however be subject to the usual provisions about executive decisions, including the call-in process. However, as stated above, the Board has not to date been delegated any such functions.

3.8 In relation to **voting arrangements**, the Council resolved to consult with the Health and Wellbeing Board about the following direction:

"The council directs that all members of the Health and Wellbeing Board shall be non-voting except for:

- all councillors appointed to the Board by full Council;
- the representative directly appointed by each CCG;
- the representative directly appointed by Healthwatch Leeds; and
- the third sector representative.

Any substitute member appointed under the Council Procedure Rules who is attending a meeting in place of one of the above members, may also vote at that meeting."

3.9 This arrangement provides for a parity of votes between the Council and its partners, to reflect the nature of the Health and Wellbeing Board as a partnership. The Chair will have a casting vote in the event of an equality of votes.

3.10 The direction itself may be reviewed or amended at any time. Identifying non-voting members in this way (that is, by exception) secures the parity of voting arrangements, whatever additional appointments may be made by the Board.

4 Health and Wellbeing Board Governance

4.1 Consultation and Engagement

4.1.1 Consultation with a number of citywide strategic partnership groups (the Integrated Commissioning Executive, the Leeds Health and Social Care Transformation Programme Board and the shadow Health and Wellbeing Board)

was carried out before full Council considered the governance arrangements for the Board.

4.1.2 The Council is required by law to consult with the Health and Wellbeing Board before making any direction about voting rights.

4.2 Equality and Diversity / Cohesion and Integration

4.2.1 As a local authority committee, the Health and Wellbeing Board will have to meet public sector equality duties.

4.3 Resources and value for money

4.3.1 There are no specific resource implications arising from this report.

4.4 Legal Implications, Access to Information and Call In

4.4.1 This report is not open to call-in. No information in this report has been classified as exempt.

4.5 Risk Management

4.5.1 There are no risk management implications to this report.

5 Conclusions

5.1 Overarching governance arrangements have now been approved for the Health and Wellbeing Board. However, it remains for voting arrangements to be confirmed by way of the direction, and for the Board to consider the appointment of any additional appropriate members (see next item).

6 Recommendations

6.1 The Health and Wellbeing Board is asked to:

- Note the governance arrangements approved by full Council for the Health and Wellbeing Board, outlined in paragraph 3 of this report; and
- Consider the proposed voting direction, set out in paragraph 3 of this report.

Terms of reference

Leeds Health and Wellbeing Board

The Leeds Health and Wellbeing Board is authorised to carry out the following functions[1]:

1. to encourage integrated working[2] in relation to arrangements for providing health, health-related or social care services;

2. to prepare and publish a joint strategic needs assessment (JSNA)[3];

3. to prepare and publish a joint health and wellbeing strategy (JHWS)[4];

4. to provide an opinion to the authority on whether the authority is discharging its duty to have regard to the JSNA, and the JHWS, in the exercise of its functions[5];

5. to review the extent to which each Clinical Commissioning Group (CCG) has contributed to the delivery of the JHWS[6];

6. to provide an opinion to each CCG on whether their draft commissioning plan takes proper account of the JHWS[7];

7. to provide an opinion to NHS England on whether a commissioning plan published by a CCG takes proper account of the JHWS[8];

8. to prepare a local pharmaceutical needs assessment[9]; and

9. to exercise any other functions of the authority which are referred to the Board by the authority[10].

[1] "Functions" for these purposes shall be construed in a broad and inclusive fashion and shall include doing anything which is calculated to facilitate or is conducive or incidental to the discharge of any of these functions.
[2] In accordance with Section 195 Health and Social Care Act 2012. This includes encouraging arrangements under Section 75 National Health Service Act 2006 (the NHSA 2006).
[3] Section 116 Local Government and Public Involvement in Health Act 2007 (the LGPIHA 2007)
[4] Under Section 116A LGPIHA 2007
[5] Under Section 116B LGPIHA 2007
[6] Under Section 14Z15(3) and Section 14Z16 NHSA 2006
[7] Section 14Z13(5) NHSA 2006
[8] Section 14Z14 NHSA 2006
[9] Section 128A NHSA 2006
[10] The Leader may delegate executive functions to the Board at any time during the year, in accordance with the Executive and Decision Making Procedure Rules.

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Leeds Health & Wellbeing Board

Report author: E Davenport/Rob Kenyon Tel: 24 78408/24 74209

Report of City Solicitor/Director of Adult Social Services

Report to Health and Wellbeing Board

Date: 22 May 2013

Subject: Appointment of additional members

Are there implications for equality and diversity and cohesion and integration?	☐ Yes	☒ No
Is the decision eligible for Call-In?	☐ Yes	☒ No
Does the report contain confidential or exempt information? If relevant, Access to Information Procedure Rule number: Appendix number:	☐ Yes	☒ No

Summary of main issues

1. The report asks the Health and Wellbeing Board to consider whether to appoint any additional members to the Board for the municipal year 2013/14.

2. The Health and Wellbeing Board may appoint such **additional persons to be members** of the Board, as it thinks appropriate.

3. If the **direction** about voting arrangements is made in the terms proposed in the previous item on this agenda, additional members appointed by the Board would be **non-voting**, thus leaving voting arrangements unaffected.

4. Subject to approval of amendments to the Council Procedure Rules, additional Board members could substitute for relevant voting members.

Recommendations

5. The Health and Wellbeing Board is asked to:

   - Consider whether to appoint any additional members to the Board;

   - Seek nominations from relevant organisations in respect of any additional members which the Board resolves should be appointed; and

   - Consider whether to make any representations to the City Solicitor about substitute arrangements for non-councillor members of the Board.

1 Purpose of this report

1.1 The report asks the Health and Wellbeing Board to consider whether to appoint any additional members to the Board for the municipal year 2013/14.

2 Background information

2.1 The Health and Social Care Act 2012 sets out a minimum statutory membership for the Health and Wellbeing Board (to include representatives nominated by the Council Leader, appointed by each clinical commissioning group (CCG) and the Local Healthwatch organisation, and the three statutory directors of Adult Social Services, Children's Services and Public Health).

2.2 At its annual meeting on 20 May, full Council noted the appointments made by the CCGs and Healthwatch Leeds to the Board and made appointments to the Board. In addition to the statutory membership (including 5 councillors nominated by the Leader), full Council appointed a representative of the third sector**,** and a representative of NHS (England).

2.3 In recognition of the partnership nature of the Board, further appointments were left for the Health and Wellbeing Board to determine.

2.4 Full Council approved amendments to the Council Procedure Rules, to provide for **substitute arrangements** for councillors who are members of the Board, via nomination from the relevant group whip.

2.5 The City Solicitor was also delegated authority to amend the Council Procedure Rules, to provide for a non-voting representative to substitute for a relevant voting representative, should the Health and Wellbeing Board appoint any additional members to the Board.

3 Main issues

3.1 The Health and Wellbeing Board may appoint such **additional persons** to be members of the Board, as it thinks appropriate.

3.2 If the direction about voting arrangements is made in the terms proposed in the previous item on this agenda, additional members appointed by the Board would be **non-voting**. The parity of votes between the council and its partners would not therefore be affected by the appointment of any additional members by the Board.

3.3 From consultation with the shadow Board, the Director of Adult Social Services anticipates that such appointments are likely to be a second CCG representative from each CCG, and an additional Healthwatch Leeds representative.

3.4 In considering whether to appoint any additional members, the Board should take into account the potential for additional Board members to substitute for relevant

voting members. This may be a particular consideration in terms of securing voting participation at all meetings from statutory voting members.

4 Health and Wellbeing Board Governance

4.1 Consultation and Engagement

4.1.1 The issue of membership was been considered by the shadow Health and Wellbeing Board, as part of the consultation process before the Board was appointed.

4.2 Equality and Diversity / Cohesion and Integration

4.2.1 As a local authority committee, the Health and Wellbeing Board will have to meet public sector equality duties.

4.3 Resources and value for money

4.3.1 There are no significant resource implications arising from this report.

4.4 Legal Implications, Access to Information and Call In

4.4.1 This report is not open to call-in. No information in this report has been classified as exempt.

4.5 Risk Management

4.5.1 There are no risk management implications to this report.

5 Conclusions

5.1 Additional members may provide wider input and perspectives into the Board. Subject to amendments to the Council Procedure Rules, their appointment may potentially also facilitate substitute arrangements for relevant non-councillor voting representatives.

5.2 However, these potential advantages need to be reconciled with the aspiration of the shadow Health and Wellbeing Board to maintain a “lean commissioning based focus” to Board membership in order to be effective.

6 Recommendations

6.1 The Health and Wellbeing Board is asked to:

- Consider whether to appoint any additional members to the Board;
- Seek nominations from relevant organisations in respect of any additional members which the Board resolves should be appointed; and
- Consider whether to make any representations to the City Solicitor about substitute arrangements for non-councillor members of the Board.

Leeds Health & Wellbeing Board

Report author: Rob Kenyon
Tel: 0113 2474209

Report of: **Joint Health and Wellbeing Strategy Steering Group**

Report to: **Leeds Health and Well Being Board**

Date: **22nd May 2013**

Subject: **The Joint Health and Wellbeing Strategy for Leeds 2013-2015**

Are there implications for equality and diversity and cohesion and integration?	☐ Yes	☐ No
Is the decision eligible for Call-In?	☐ Yes	☐ No
Does the report contain confidential or exempt information? If relevant, Access to Information Procedure Rule number: Appendix number:	☐ Yes	☐ No

Summary

The Local Authority and the three Leeds Clinical Commissioning Groups (CCGs) have a joint statutory duty to prepare and publish a Joint Health & Wellbeing Strategy (JHWS) through the Health and Wellbeing board (H&WBB). This report summarises the development of the strategy, which has overseen Shadow H&WBB, and the latest version will be presented at the meeting for discussion and approval. Although partnership health plans have been developed for many years, this is the first time that they will be developed on a statutory footing. The publication of the JHWS is an important and exciting step for the H&WBB as the JHWS will set the strategic direction of travel for Leeds and be the framework against which commissioners across the city will be expected to base their plans. The JHWS should help the board to encourage greater integration of services and commissioning across the city leading to improved outcomes for the children, young people, adults and communities of Leeds and improved efficiency.

Recommendations

The Health and Wellbeing Board is asked to:

- Note the work of the Shadow Health and Wellbeing Board to develop the draft JHWS
- Discuss and comment on the final draft of the strategy for publication
- Subject to comments, approve the strategy for publication in June 2013

1 Purpose of this report

1.1 The Local Authority and the three Leeds Clinical Commissioning Groups (CCGs) have a joint statutory duty to prepare and publish a Joint Health & Wellbeing Strategy (JHWS) through the Health and Wellbeing board (H&WBB). The Shadow H&WBB has overseen the development of the strategy. Now that the H&WBB is legally constituted, it has the responsibility to formally approve the strategy for publication. This report summarises its development to enable the board to consider the draft of the strategy (Appendix 1).

2 Background information

2.1 One of the main statutory responsibilities of the Health and Wellbeing Board is to produce a Joint Health and Wellbeing Strategy for Leeds. This will provide the strategic direction, priorities and framework for commissioning decisions of the Council, the Clinical Commissioning Groups and NHS England.

2.2 The requirement to produce a Joint Health and Wellbeing Strategy (JHWS) was set out in Liberating the NHS: Legislative Framework and Next Steps (Dec 2010) and confirmed in the Health and Social Care Act 2012. Further statutory guidance from the Department of Health was published in March 2013. This requires Health and wellbeing boards to produce a high level strategy that brings together healthcare, social care and public health and should also consider the wider determinants of health such as education and housing. It should demonstrate how the city will address the health and wellbeing needs of the population of Leeds and reduce inequalities in health and wellbeing.

3 Main issues

3.1 Purpose of the JH&WS

3.2 The Leeds JHWS will be the focus for improving health and wellbeing and will help achieve the vision for Leeds to be a healthy caring city for all ages. It will:

- Achieve better health and wellbeing outcomes for the people of Leeds
- Ensure partners on the Health and Wellbeing Board agree together the outcomes we want to achieve and how they will contribute to the long term vision for Leeds 2030
- Provide the framework for commissioning plans for children, young people and adults healthcare, social care and public health
- Promote integration and partnership working between the NHS, social care, public health and other local services
- Inform the business plans of service provider organisations
- Promote more effective and efficient actions across the partnership

- Help to measure progress in making Leeds a Healthy and caring city for all ages

3.3 **How the content of the strategy was established**

3.4 Over the course of the last year a cross partnership steering group met to undertake the preparatory work for the JHWS. This group considered all the potential issues that might be incorporated as part of the strategy. The deliberations culminated in a high level partnership workshop (Chairs, Directors, Accountable Officers across LCC and CCGs) which synthesised the options about what should be included and excluded into a discrete proposal for the Shadow H&WBB to consider.

3.5 Many drivers were considered as part of this process including:

- The national outcomes frameworks for NHS, Adult Social Care, Public Health, Children
- The Joint Strategic Needs Assessment and demographic changes
- Current financial situation
- Improved quality of services and innovation
- Vision for Leeds 2030 and Leeds City Priority Plan 2011-2015
- National guidance
- NHS Mandate

3.6 In order to assist the steering group and shadow board to consider the options systematically, a set of principles were established to guide the development of the strategy. It was agreed that the JHWS should:

- Be simple, unambiguous and measurable
- Be small enough focus attention of H&WB Board
- Use an Outcomes Based Accountability approach
- Have no more than 5 outcomes
- Have as few priorities as possible
- Have as few indicators as necessary- 1-2 per priority
- Have indicators which measure one thing only
- Have indicators that relate primarily to the outcome
- Be to 2015 but subject to review over shadow year
- Have a clear rationale for each item
- Enable collective responsibility by achieving consensus, clear ownership and enable us to hold each other to account
- Priorities should normally apply to all ages
- Priorities should normally require action from >1 partner
- Not normally included something Leeds is good at
- Take into account trends and predictions not just as is
- Include priorities from all partners
- Include things capable of change locally

- Not try to do everything, or it might achieve nothing
- Have a wider set of plans which sit beneath it
- Achieve a sustainable Health and Social care system
- Be the right thing to do

3.7 Some of the most significant issues that were considered as part of the process but not proposed for the final draft were: Dementia, Safety and Disability. In the case of Safety, it was considered that this was best taken forward by the adults and children's safeguarding boards and the community safety partnership.

3.8 Dementia and Disability were considered to be of such significance that it would not be possible to achieve the JHWS without concerted action to address these needs across many of the priorities, and that they needed to be part of how we deliver the strategy as a whole rather than by identifying actions at a specific indicator.

3.9 It should be noted that the dementia strategy for Leeds is being presented as a separate paper for the board at this meeting.

3.10 **Must do's**

3.11 The board will work hard to ensure that the JHWS makes a difference to the children, young people, adults and communities of Leeds. All of the priorities are important to make sure that the outcomes are achieved. However, consistent with an Outcomes Based Accountability approach and building on the focus of the City Priority Plan, it is proposed to focus on four *must do's*:

- Support people to choose healthy lifestyles
- Ensure everyone has the best start in life
- Improve people's mental health and wellbeing
- Increase the number of people supported to live safely in their own home

3.12 **Next steps**

3.13 In order to ensure that the strategy is delivered the JHWS steering group will oversee the following:

- A cross partnership communications strategy has been developed by the shadow H&WBB. It is intended to publish the strategy using established networks.
- Action plans linked to the priorities will be reviewed and revised
- The strategy will be disseminated to the CCGs, NHS England and Leeds City Council to inform their respective commissioning plans
- The H&WBB will receive future updates on the extent to which partners have taken due regard to the strategy.
- The Board will undertake deep dives into the outcomes and priorities to influence pace and achievement

- The board will receive reports outlining progress [baseline presented as a separate paper to the Board at this meeting].

4 Health and Wellbeing Board Governance

4.1 Consultation and engagement

4.1.1 A steering group was established to drive forward the development of the strategy for the shadow H&WBB. Representatives included, Third Sector, Public health, CCGs, Adult Social Care and Children's services. Public engagement has taken place throughout the development of the Vision for Leeds 2030 and the City Priority Plan 2011 – 2015. The work on the JHWS builds on the City Priority Plan for Health and Wellbeing, the Joint Strategic Needs Assessment (JSNA) and maintains the focus on the priorities agreed by partners. A number of early engagement events were held culminating in a workshop with CEO/Director/Chairs on 7th July 2012 to develop the first full draft. This was agreed subject to revisions by the Shadow H&WBB on 13 July 2012 and a final working draft was agreed by the shadow H&WBB on 10 October 2012. Further engagement work has taken place during 2012/13 by partners with a number of groups including CCG membership, elected members [over third cross party], the Third Sector, Community groups, NHS providers' boards/exec teams, the Integrated Commissioning Executive [including NHS Commissioning Board- now NHS England], Scrutiny [as part of a wider shadow H&WBB report], and Children's Trust Board.

4.2 **Equality and Diversity/Cohesion and Integration**.

4.2.1 H&WB boards must meet the Public Sector Equality duty under the Equality Act 2010 and this includes the preparation of the JHWS. Its development follows on from a number of other strategic planning documents including the Leeds City Vision, City Priority Plans and the Joint Strategic Needs Assessment. As these have all been subject to full equality impact assessment, an equality impact assessment screening document was used for the JHWS. The key findings were:

4.2.2 Consultation and engagement with some groups needs to be improved to fully understand their health and social care needs

4.2.3 Health related data for some groups/conditions needs to be improved including older people; Lesbian Gay Bisexual and Transgender people; people with dementia; people with autism; carers; and physical and sensory impairments.

4.2.4 Groups have not routinely received feedback to consultation exercises.

4.2.5 At the heart of the strategy is the principle that "People who are the poorest, will improve their health the fastest". This will clearly have very positive impacts with regard to equality characteristics.

4.2.6 The board should be assured that plans to address the above form part of the JSNA development process. It will be important that equality considerations are

embedded within individual JHWS action plans for each of the five outcomes across relevant and appropriate equality characteristics. Each action plan should specifically consider relevant issues of equality. It should be particularly mindful of any negative impacts and propose ways in which to mitigate these

4.2.7 In addition the Board should be assured that the JHWS will provide a framework to encourage greater integration of services and commissioning.

4.3 **Resources and value for money**

4.3.1 The strategy establishes the overarching framework for the city against which commissioners will be expected to base their commissioning plans. This will encourage greater integration of commissioning plans and decisions with a view to making the best use of the collective resources at the city's disposal- the '*Leeds pound'*.

4.4 **Legal implications, access to information and call in**

4.4.1 The publication of the strategy discharges the duty of Leeds City Council, Leeds South & East Clinical Commissioning Group, Leeds North Clinical Commissioning Group and Leeds West Clinical Commissioning Group to prepare and publish a Joint Health and Wellbeing Strategy via the health and wellbeing board.

4.5 **Risk Assessment**

4.5.1 Failing to publish a JHWS leaves the LA, CCGs and H&WBB in breach of their statutory duty.

4.5.2 Failure to publish a JHWS leaves the care of children, young people and adults at risk due to the lack of a coordinated strategy

4.5.3 Failure to identify the most appropriate outcomes, priorities and indicators jeopardises the efficiency of commissioning decisions.

5 Conclusions

5.1 The establishment of the H&WBB presents a new and exciting way for the Council, NHS, Third sector and Healthwatch to provide leadership together with other partners to improve health and care services and to reduce health inequalities by placing partnership arrangements on a statutory footing.

5.2 The preparation and publication of the Joint Health and Wellbeing Strategy for Leeds is an important decision for the Board to take, as it provides the blueprint for the work of the Health and Wellbeing board and the framework for future commissioning decisions.

5.3 It will be the first step that the Board takes on its journey to achieve the vision for Leeds to be a healthy caring city for all ages, where people who are the poorest will improve their health the fastest.

6 Recommendations

6.1 Board members are asked to:

- Note the work of the Shadow Health and Wellbeing Board to develop the draft JHWS
- Discuss and comment on the final draft of the strategy for publication
- Subject to comments, approve the strategy for publication in June 2013

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Appendix 1: Draft outline of contents – Leeds Joint Health and Wellbeing Strategy

1. Foreword

Leeds is a magnetic city and has a vision to be the *best city in the UK* by 2030. As part of this vision to create a thriving liveable city, Leeds aspires to be the *best city for health and wellbeing*. Like many other cities, Leeds is facing huge challenges including a widening inequalities gap, an increasing population of young and older people, as well as reductions in public sector funding.

Of course, for Leeds to be the *best city for health and wellbeing*, it means making sure that the people can access high quality health and social care services: but it also means that Leeds is a Child Friendly city, a city that creates opportunities for business, jobs and training; a city made up of sustainable communities and of course a great place to live. In short, our vision is that Leeds will be a healthy and caring city for all ages, where people who are the poorest, improve their health the fastest.

To achieve this vision, we have come together as the Leeds Health and Wellbeing Board to make sure that we make the best use of our collective resources. We are committed to using the 'Leeds pound' and 'Leeds assets' wisely on behalf of the people of Leeds. This means that we will work together when spending public money, to make sure we are maximising the impact of each pound we have. Together we will make sure that more services are joined up and that people find them easier to use.

To help us to decide how best to use our collective resources in future, we will do two things. First, we will make decisions based on good information. We all have information about people and places and by looking at this information together; we can make decisions based on a more complete picture of Leeds. We have committed to improve how we collect and use this information and after extensive consultation, we have published this as the Joint Strategic Needs Assessment. Second, we will make decisions about how we spend the 'Leeds pound' together. Using jointly agreed principles we will make a plan for how we spend our collective resources, called the Joint Health and Wellbeing Strategy. Following widespread engagement, this document sets out the Joint Health and Wellbeing Strategy for Leeds for 2012-2015. It will provide the framework for how we use resources throughout the city and enable us to be accountable to local people. It will help the council and the NHS in Leeds, working with local communities and partner organisations, to make improvements to the health and wellbeing of local people.

The Health and Wellbeing Board will oversee how we continue to improve the health and wellbeing of the people of Leeds and this document is vital to how we will work together to make it happen. We would expect everyone to use the Joint Health and Wellbeing Strategy when making decisions about spending money and planning services over the next few years, and in doing so we can truly make Leeds the *best city for health and wellbeing*.

Cllr Lisa Mulherin,
Chair of the Leeds Health and Wellbeing Board

2. What is the Leeds Joint Health and Wellbeing Strategy?

Leeds City Council, Leeds North Clinical Commissioning Group, Leeds South and East Clinical Commissioning Group and Leeds West Clinical Commissioning Group have a new shared legal duty to prepare and publish a Joint Health and Wellbeing Strategy (JHWS) through the Health and Wellbeing Board. This document discharges that responsibility.

The JHWS is the result of commissioners coming together to provide the strategic direction and sets out how we will make the best use of our collective resources. It will be the 'framework' for all commissioners to use, and will help us to decide how we might bring into line the right level of resources for different needs across the city.

The JHWS spans the NHS, social care and public health across all ages and considers wider issues such as housing, education and employment. It provides a short summary of how we will address the health and wellbeing needs of Leeds and will help us to measure our progress.

It will help us to live our ambition to be the best city in the UK: a healthy and caring city for all ages where people who are the poorest improve their lives the fastest.

Leeds JHWS overview

Vision for health and wellbeing
Leeds will be a healthy and caring city for all ages

Principle in all outcomes
People who are the poorest, will improve their health the fastest

Overarching Indicator
Reduction in the differences in life expectancy between communities

The five outcomes
1. People will live longer and have healthier lives
2. People will live full, active and independent lives
3. People will enjoy the best possible quality of life
4. People are involved in decisions made about them
5. People will live in healthy and sustainable communities

How was the Leeds JHWS developed?

The Leeds JHWS has been developed from:
- Leeds JSNA including public opinion and research
- National guidance from the Secretary of State, including the NHS Mandate
- National Outcome Frameworks

- National data profiles
- Financial modelling

The JHWS has been created by focussing on a number of principles, including that it should:

- Be simple, unambiguous and measurable
- Guide strategic decision making
- Have indicators which measure one thing and that relate primarily to the outcome
- Have a wider set of local plans which sit beneath it
- Apply to all ages and be a consensus
- Include things capable of change locally
- Promote equality and meet the Public Sector Equality Duty
- Be the right thing to do

Why do we need one?

The Health and Wellbeing Board will use the JHWS to influence partners across the city to reduce inequalities and to improve the health and wellbeing of the people of Leeds. It will:

- Achieve better health and wellbeing outcomes for the people of Leeds
- Ensure partners on the Health and Wellbeing Board agree together the outcomes we want to achieve and how they will contribute to the long term vision for Leeds 2030
- Provide the framework for commissioning plans for children, young people and adults healthcare, social care and public health
- Promote integration and partnership working between the NHS, social care, public health and other local services
- Inform the business plans of service provider organisations
- Promote more effective and efficient actions across the partnership
- Help to measure progress in making Leeds a healthy and caring city for all ages

3. Where are we starting from?

Leeds is the UK's third largest city with a population of around 750,000, expected to rise to around 840,000 by 2021. It is one of the greenest cities in the UK with 20 major parks and two thirds of the district is classified as rural.

The most recent census (2011) indicates that the Leeds population has grown 5% since 2001. Leeds is a truly diverse city with over 140 ethnic groups including Black, Asian and Minority Ethnic populations representing almost 19% of the total population. In the coming years, Leeds is expecting to see an increase in the numbers of children of primary school age as well as the numbers of those aged over 75 and over 85.

Despite the economic downturn, the city's economy is considered to be one of the most resilient in the UK. It has changed from being dominated by industry to now being a key centre for finance, business, retail, healthcare, creative industries and legal services as well as a continued strength in

manufacturing. The current employment rate is 69%. Leeds remains a major centre for development with £4.3 billion worth of schemes completed in the last decade.

Leeds is home to one of the largest teaching hospitals in Europe and to the new NHS England, HealthWatch England and five other national NHS bodies.

However, the health of people in Leeds is generally lower than the England average. It is strongly associated with the high levels of deprivation experienced by the 150,000 people in Leeds who are living in the most deprived neighbourhoods nationally. Although overall life expectancy has been increasing for all Leeds residents, the life expectancy for a man living in a deprived Leeds neighbourhood is 12 years lower than a man living in an affluent part of Leeds.

It is estimated that adult healthy eating, smoking and obesity levels are worse than the England average, with smoking-related and alcohol-related hospital admission rates above average. The high prevalence of smoking in people with low incomes, compared to the rest of Leeds, is the biggest preventable cause of ill health and early death in the city.

Some of the major issues identified in the Leeds JSNA include: deprivation, mental health, smoking, alcohol, obesity, health conditions such as cancer and cardio vascular disease and dementia, children and young people's health, financial inclusion, housing, social isolation and older people, equality groups and issues for localities.

The JHWS will enable Leeds to turn the issues where there is deprivation and inequality into plans for action to enable Leeds to be the *best city for health and wellbeing*.

7. How will the JHWS make a difference?

It will enable us all to make better decisions about how we:

- Commission and decommission services by informing the commissioning plans of CCGs, Leeds City Council and NHS England
- Re-design services
- Use existing assets and resources of partners, including workforce, communities, buildings and information.
- Encourage service providers to work together to deliver services and act in ways that meet agreed priorities
- Influence the wider determinants of health and wellbeing through other partnerships and organisations

8. What is happening already?

Publishing the JHWS is a really important step to set the future direction and focus for reducing inequalities and improving the health and wellbeing of the people of Leeds. There is already a great deal of work underway in the city which is helping to change lives. We will build on the successes of this work, learn from others both nationally and internationally and use the JHWS to drive forward improvements to the outcomes we have agreed.

There is extensive work already being carried out in a range of areas linked to JHWS. These examples are just a snapshot of work underway:

(1) The Leeds Let's Change programme provides information and signposting on a range of issues to help people make healthy lifestyle choices including losing weight and stopping smoking.
(2) The Infant Mortality demonstrator sites in Chapeltown and Beeston & Holbeck are already helping families in to reduce sudden infant death, smoking in pregnancy and improve access to maternity services.
(3) The NHS Health Check has already started to help people reduce and manage their risk of heart disease, stroke, kidney disease and diabetes, and the COPD early diagnosis programme is improving prognosis for a condition far more prevalent within deprived areas of Leeds.
(4) Twelve new integrated health and social care teams are now live across the city. The teams, made up of community nursing, social care and other staff, will work closely with GPs, hospitals, the voluntary sector and patients themselves to plan care jointly.
(5) Intermediate Care teams and the reablement service are working closely together to provide support to people to ensure that they have the best possible chance of recovering from ill health.
(6) The Pudsey Wellbeing Centre has a group of volunteers helping people to cope better with managing their conditions by organising health walks, arranging social events, providing transportation so that patients can get around the area, providing one-one-one or group training sessions and leading health support groups.
(7) The NHS, council and third sector are already working together across the city and improving access to mental health services for minority groups.
(8) The "*Got a cough? Get a check*" campaign has already led to 2000 people from Inner East and Inner South Leeds to receive a screening x-ray and has identified 25 people with lung cancer enabling them to start treatment early.
(9) The NHS and council are working together to provide a single point of urgent referral. This improves access to services for patients in need of an urgent response from a community service.
(10) Neighbourhood network schemes are locally led organisations that enable older people to live independently and pro-actively participate within their own communities by providing services that reduce social isolation; provide opportunities for volunteering; act as a "gateway" to advice, information, and services; and promote health and wellbeing.
(11) Warm Homes Service grants are helping people who suffer from illness or have disability aggravated by cold and damp conditions to keep warm by insulating their properties.
(12) Support is available across the city which is helping people to claim the benefits which they are entitled to, leading to better finances for many people especially in poorer households.
(13) The Working Well Action Plan is supporting individuals into work and improving the health and wellbeing of employees within businesses across the Leeds economy.

9. What will we do next?

We will use the JHWS to review all the existing plans and strategies across the city to make sure that we are focusing our efforts and resources on the right things. This will help us to strengthen our action plans and make sure that we have not left any gaps.

The Health and Wellbeing Board has identified four 'commitments' which we believe will make the most difference to the lives of people in Leeds. If we make progress on these four commitments, then it is also likely that we will make progress with many of our other priorities too.
Our commitments

- Support more people to choose healthy lifestyles
- Ensure everyone will have the best start in life

- Improve people's mental health and wellbeing
- Increase the number of people supported to live safely in their own home

10. How will we measure progress?

We will measure our progress by focusing on the impact that the strategy will have on people's lives: these are the outcomes that we want to achieve. We have chosen a number of indicators for each outcome, which will help us to measure our progress. During the first year of the strategy we will develop these indicators to ensure we can measure progress accurately and that we can compare our progress with other areas. We will use an approach called Outcomes Based Accountability, which is known to be effective in bringing about whole system change. The Leeds JHWS has chosen to focus on some really tough areas that will make a sustainable difference to people's lives. We acknowledge that bringing about these major changes, will not happen overnight, so we expect to see gradual improvements over time rather than radical quick wins. The Health and Wellbeing Board will use its strategic influence to ensure that progress is made by partners across the city through:

- Regular performance reports as part of our city priority plans
- Local level reports in partnership with CCGs
- Outcome based accountability events to focus closely on particular issues.
- An annual report from the Health and Wellbeing Board

Leeds Joint Health and Wellbeing Strategy 2013-2015		
Vision for health & wellbeing: Leeds will be a healthy and caring city for all ages		
Principle in all outcomes: People who are the poorest, will improve their health the fastest		
Indicator: Reduce the differences in life expectancy between communities		
Outcomes	**Priorities**	**Indicators**
1. People will live longer and have healthier lives	1. Support more people to choose healthy lifestyles	1. Percentage of adults over 18 that smoke
		2. Rate of alcohol related admissions to hospital
	2. Ensure everyone will have the best start in life	3. Infant mortality rate
		4. Excess weight in 10-11 year olds
	3. Ensure people have equitable access to screening and prevention services to reduce premature mortality	5. Rate of early death (under 75s) from cancer.
		6. Rate of early death (under 75s) from cardiovascular disease
2. People will live full, active and independent lives	4. Increase the number of people supported to live safely in their own home	7. Rate of hospital admissions for care that could have been provided in the community
		8. Permanent admissions to residential and nursing care homes, per 1,000 population
	5. Ensure more people recover from ill health	9. Proportion of people (65 and over) still at home 91 days after discharge into rehabilitation
	6. Ensure more people cope better with their conditions	10. Proportion of people feeling supported to manage their condition
3. People's quality of life will be improved by access to quality services	7. Improve people's mental health & wellbeing	11. The number of people who recover following use of psychological therapy
	8. Ensure people have equitable access to services	12. Improvement in access to GP primary care services
	9. Ensure people have a positive experience of their care	13. People's level of satisfaction with quality of services
		14. Carer reported quality of life
4. People will be involved in decisions made about them	10. Ensure that people have a voice and influence in decision making	15. The proportion of people who report feeling involved in decisions about their care
	11. Increase the number of people that have more choice and control over their health and social care services	16. Proportion of people using NHS and social care who receive self-directed support
5. People will live in healthy and sustainable communities	12. Maximise health improvement through action on housing	17. The number of properties achieving the decency standard
	13. Increase advice and support to minimise debt and maximise people's income	18. Number of households in fuel poverty
		19. Amount of benefits gained for eligible families that would otherwise be unclaimed
	14. Increase the number of people achieving their potential through education and lifelong learning	20. The percentage of children gaining 5 good GCSEs including maths & English
	15. Support more people back into work and healthy employment	21. Proportion of adults with learning disabilities in employment
		22. Proportion of adults in contact with secondary mental health services in employment

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DRAFT: Health and Wellbeing Board Work Programme (April 2013 – March 2014)

Meeting date	Programme	Type of Item	Purpose of the board discussion – the action it will generate
22nd May 2013	**Board**		
10:00	Procedural issues	Information	Update Board with final arrangements as agreed by full council (will be late paper)
	Joint Health and Wellbeing Strategy and performance scorecards	Statutory function	Prepare and publish a Joint Health and Wellbeing Strategy. Where we are at vs JHWS
	Dementia Friendly City	Approval	Approval of Leeds as a Dementia Friendly City
	Leeds Innovation Health Hub	Presentation	Request received from Leeds & Partners
24th July 2013	**Board**		
14:00	People will live longer and have healthier lives	JHWS Outcome 1	Review to the Board of status and actions regarding outcome 1 including possible sign off of D&A strategy.
	Health Inequalities (tbc)	CPP Outcome 4	To receive a report on the progress on Health Inequalities and comment on future direction of travel (Review Action Plans in City priority Plan)
	Joint Strategic Needs Assessment	Statutory function	Review of the Joint Strategic Needs Assessment
	Health KAM	Information	Update to the Board on Key Account Management (CLT paper)
	Healthwatch	Information	Partner Perspective
Sept 2013	**Board**		
	People will live full, active and independent lives	JHWS Outcome 2	
	Children and adult safeguarding	Discussion	What can the Board do? (link with outcome 2)
	Integrated working	Statutory function	Encourage integrated working in relation to arrangements for providing health, health-related or social care services

Meeting date	Programme	Type of Item	Purpose of the board discussion – the action it will generate
20th Nov 2013	**Board**		
10:00	People's quality of life will be improved by access to quality services	JHWS Outcome 3	
	The authority's regard to the JHWS and JSNA	Statutory function	Provide an opinion to the authority on whether the authority is discharging its duty to have regard to the JSNA, and the JHWS, in the exercise of its functions
	Pharmaceutical needs assessment	Statutory function	Prepare a local pharmaceutical needs assessment
Jan 2014			
	People will be involved in decisions made about them	JHWS Outcome 4	
	CCG Commissioning Plans	Statutory function	Provide an opinion to each CCG on whether their draft commissioning plan takes proper account of the JHWS
Mar 2014			
	CCG contributions to the JHWS	Statutory function	Review the extent to which each CCG has contributed to the delivery of the JHWS
	CCG Commissioning Plan to NHS Commissioning Board	Statutory function	Provide an opinion to the NHS Commissioning Board on whether a Commissioning Plan published by a CCG takes proper account of the JHWS
	People will live in healthy and sustainable communities	JHWS Outcome 5	

Leeds Health & Wellbeing Board

Report author: A Cartwright/N Stephens
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Report of: **The Leeds Joint Information Group**

Report to: **Leeds Health and Wellbeing Board**

Date: **22nd May 2013**

Subject: **Joint Health and Wellbeing Strategy Indicators – Baseline Position**

Are there implications for equality and diversity and cohesion and integration?	√ Yes	☐ No
Is the decision eligible for Call-In?	☐ Yes	√ No
Does the report contain confidential or exempt information?	☐ Yes	√ No
If relevant, Access to Information Procedure Rule number:		
Appendix number:		

Summary of main issues

1. Ensuring an understanding of the twenty two core indicators as the basis for reporting future progress across the objectives and priorities identified with the Health and Wellbeing strategy.
2. Ensuring ownership of the core indicators by each of the fifteen priority areas.
3. Supplementing the core indicators with other measures within each priority area to ensure that the full breadth of improvement is achieved.

Recommendations

The Health and Wellbeing Board is asked to:

- Review and become familiar with the baseline position across the twenty two joint Health and Wellbeing Strategy indicators in order to better assimilate future performance reports.

1. Purpose of this report

1.1 This report is designed to provide Health and Wellbeing Board members with some initial familiarity of the indicator set that represents the fifteen priority areas of the Joint Health and Wellbeing Strategy.

1.2 This initial report represents a 'base-lining' exercise. It is not the intention of this report to make any particular recommendations or draw any specific points to the attention of the Health and Wellbeing Board.

1.3 However, in conjunction with the priority area leads, future reports will provide the Health and Wellbeing Board with a view on selected areas where it is deemed that matters of progress or issues should be brought to the Health and Wellbeing Board's attention.

2. Background information

2.1 Twenty two indicators have been consulted upon and then selected to cover the five outcomes and fifteen priorities as defined by the Joint Health and Wellbeing strategy.

2.2 Where possible, the indicators were selected to have the following features:

- Nationally defined and nationally available, for example, within a national 'outcomes' frameworks
- Stable over time
- Already familiar and meaningful to those committees, groups and work streams charged with improving the identified priority area, for example, the Children's Trust Board, Tobacco Management Board and Alcohol Management Board.
- Available against a benchmark
- Available below city-wide level

2.3 It should be noted that some definitions may be subject to change by the associated national body, however, the indicators themselves are now finalised.

2.4 These twenty two indicators form a core and key method of assessing progress against the joint health and wellbeing objectives and priorities.

2.5 However, it is expected that each priority work stream will use other indictors and other measures to illustrate the 'story' of improvement. It is likely that these will include service user perception and cost improvements.

2.6 As the indicators are sourced from a number of collection points within the NHS and Local Authority, the following features should be noted:

- Different indicators may cover different time periods
- Different indicators may be collected at different intervals
- Different indicators may use different peer comparator groups
- The latest formally reported information will be included

- Any local ‘intelligence’, in addition to the formal figures, may be used to provide a narrative in future reports.
- Not all indicators have targets set

3. Main issues

3.1 It is important that the twenty two core indicators are understood by the Health and Wellbeing Board, as well as those Officers leading the individual priority area work streams. The indicators can therefore be used effectively as the basis for reporting future progress.

3.2 It is recognised that the twenty two indicators do not represent the full story for each priority area, but rather a recognised set of core measures. Therefore, each priority area will likely use supplementary measures to describe that full picture.

3.3 The Joint Health and Wellbeing Strategy Steering Group is currently working to produce a transparent view of each priority area work stream, leadership and governance arrangements and a set of supplementary indicators for local use.

3.4 The Health and Wellbeing Board will likely want to take reports from individual priority areas that provide the full picture of the work underway to improve health and wellbeing within the city.

4. Health and Wellbeing Board Governance

4.1 Consultation and Engagement

4.1.1 The Joint Health and Wellbeing Strategy indicators have been consulted upon as part of the process to select the strategy objectives and priorities.

4.2 Equality and Diversity / Cohesion and Integration

4.2.1 Due regard has been given in the setting of the Joint Health and Wellbeing Strategy.

4.2.2 Consultation was undertaken at the start of the Joint Health and Wellbeing Strategy

4.2.3 An Equality Impact Assessment was undertaken for the Joint Strategic Needs Assessment which provided the intelligence to develop the Joint Health and Wellbeing Strategy.

4.3 Resources and value for money

4.3.1 The baseline gathering exercise has been undertaken using a collaborative approach across health and the local authority, using existing resources and coordinated by the Leeds Joint Information Group [JIG].

4.4 Legal Implications, Access to Information and Call In

4.4.1 There is a legal requirement as the Joint Health and Wellbeing Strategy is a statutory requirement.

4.4.2 All the information for the Joint Health and Wellbeing Strategy, including the indicators, will be publically available on the Council website and Leeds 'Observatory' website.

4.4.3 This is subject to 'call-in'.

4.5 Risk Management

4.5.1 The Health and Wellbeing Board are accountable for delivering the five strategic outcomes. The performance risks are managed within the individual priority areas.

5. Conclusions

5.1 This report represents a baseline against twenty two selected indicators that will provide the minimum level of assurance that progress is being made against the five objectives and fifteen indicators of the Joint Health and Wellbeing Strategy.

5.2 It is expected that Health and Wellbeing Board members will become familiar with this indicator set, as will the lead managers and senior executives leading those priority area improvements.

5.3 However, each priority area will use a broader set of measures to ensure that the full breadth of improvement is achieved.

6. Recommendations

6.1 The Health and Wellbeing Board is asked to:

- Review and become familiar with the baseline position across the twenty two joint health and wellbeing strategy indicators in order to better assimilate future performance reports.

Appendix 1: Joint Health and Wellbeing Strategy – Indicators report – BASELINE POSITION

Vision for health & wellbeing: Leeds will be a healthy and caring city for all ages

Outcomes	Priorities	Indicators	Local baseline measure	Direction of local measure	Peer baseline measure	Notes
1. People will live longer and have healthier lives	1. Support more people to choose healthy lifestyles	1. Percentage of adults over 18 that smoke. [Source: Public Health OF]	North CCG – 18.50% South & East CCG – 27.21% West CCG – 22.34% Leeds – 22.56%	Static ⇔	England – 20%	LOW is GOOD The baseline is Quarter 3 2012/13 data Reported by Public Health (LCC)
		2. Rate of alcohol related admissions to hospital [Public Health OF]	North CCG – 1,494.21 South & East CCG – 1,788.58 West CCG – 1,891.87 Leeds – 1,762.84	Not improving ⇩	England – 1,895	LOW is GOOD The baseline is 2010/11. The unit is directly age standardised rate per 100,000 population Reported by Public Health (LCC)
	2. Ensure everyone will have the best start in life	3. Infant mortality rate [Source: Public Health OF]	North CCG – 4.25 South & East CCG – 5.26 West CCG – 4.04 Leeds – 4.51	Improving ⇧ ⇧ ⇧ ⇧	England – 4.32	LOW is GOOD The baseline is 2009-11. The rate is per 1,000 live births. Calculations are based on the geographical coverage of the CCGs and registration with GPs in the CCG. Reported by Public Health (LCC)
		4. Excess weight in 10-11 year olds [Source: Public Health OF]	North CCG – 33.12% South & East CCG – 36.23% West CCG – 34.12% Leeds – 34.64%	⇧ ⇩ ⇧ ⇩	England – 33.4%	LOW is GOOD The baseline is 2009-11. Calculations are based on the geographical coverage of the CCGs and registration with GPs in the CCG. Reported by Public Health (LCC)
	3. Ensure people have equitable access to screening and prevention services to reduce premature mortality	5. Rate of early death (under 75s) from cancer. [Source: Public Health OF]	North CCG – 96.98 South & East CCG – 131.92 West CCG – 106.28 Leeds – 112.48	Improving ⇧	England -106.7	LOW is GOOD The baseline is 2008-10. Crude rate per 100,000 using primary care mortality database deaths and Exeter mid-year populations. Reported by Public Health (LCC)
		6. Rate of early death (under 75s) from cardiovascular disease [Public Health OF]	North CCG – 63.74 South & East CCG – 81.56 West CCG – 66.52 Leeds – 70.84	Improving ⇧	England – 62.0	LOW is GOOD The baseline is 2008-10. Crude rate per 100,000 using primary care mortality database deaths and Exeter mid-year populations. Reported by Public Health (LCC)

2. People will live full, active and independent lives	4. Increase the number of people supported to live safely in their own home	7. Rate of hospital admissions for care that could have been provided in the community [Source: CCGOI]	North CCG – 1141 South & East CCG – 1571 West CCG – 1238	⇩ ⇩ ⇩ Not improving	England – 1037	LOW is GOOD The peer is England average. The national baseline is 2011/12. The unit is directly standardised rates per 100,000 population. Arrows show direction of travel compared to 2010/11 figures. Future figures are likely to show improvement. Note. Current national figures are for the 19+ age range. This may change to all ages. Reported by CCGs
		8. Permanent admissions to residential and nursing care homes, per 1,000 population [Source: ASC OF]	795	⇩ Not improving	719.8	LOW is GOOD The peer is a comparator average for 2011/12. The Leeds reported period is Quarter 3, 2012/13. The unit is rates per 100,000 population. Reported by Adult Social Care
	5. Ensure more people recover from ill health	9. Proportion of people (65 and over) still at home 91 days after discharge into rehabilitation [Source: ASC OF]	90%	⇧ Improving	82.6%	HIGH is GOOD The peer is a comparator average for 2011/12. The Leeds reported period is Quarter 3, 2012/13 .The source is ESCR. The unit is percentage of cohort. Reported by Adult Social Care
	6. Ensure more people cope better with their conditions	10. Proportion of people feeling supported to manage their condition [Source: CCGOI]	North CCG 53.2% South & East CCG 52.9% West CCG - 54.6%	-	England 52.28%	HIGH is GOOD The peer is England average. The National baseline is July 11 to March 12. The unit is percentage of respondees weighted for non-response. The source is COF. Note. National baseline calculation currently differs from COF technical guidance. Note. Expect two GP patient surveys per year. Note. No direction of travel arrows can be shown for this indicator in this report due to changes to the questionnaire design, survey frequency and weighting scheme used. This prevents direct comparisons with previous years' data. Reported by CCGs

3. People's quality of life will be improved by access to quality services	7. Improve people's mental health & wellbeing	11. Improved access to psychological services: % of those completing treatment moving to recovery [Source: CCGOI]	North CCG 44.32% South &East CCG 36.39% West CCG 46.64%	⇩ ⇩ ⇩ Not improving	England – 45.87%	HIGH is GOOD The peer is England average. The period is Quarter 2, 2012/13. The unit is percentage of patients. Note. Arrows show direction of travel compared to Q1, 2012/13 (the earliest quarter for which CCG level data available) Note: This indicator is included in the CCG outcomes framework but the NHS England Area Team may wish to monitor CCG IAPT performance on % of population entering treatment. Reported by CCGs
	8. Ensure people have equitable access to services	12. Improvement in access to GP primary care services [Source: NHS OF]	North CCG – 80.39% South and East CCG – 74.98%* West CCG – 78.15% *Excludes York St Practice	-	79.15%	HIGH is GOOD The peer is England average. The local baseline used is Jul 11 to March 12. The unit is percentage of respondees. Note. No direction of travel arrows can be shown for this indicator in this report due to changes to the questionnaire design, survey frequency and weighting scheme used. This prevents direct comparisons with previous years' data. Reported by CCGs
	9. Ensure people have a positive experience of their care	13. People's level of satisfaction with quality of services [Source: ASC OF]	70%	⇧ Improving	63%	HIGH is GOOD The peer is a comparator average for 2011/12. The Leeds reported period is Quarter 3, 2012/13. The source is National PSS Survey. Reported by Adult Social Care
		14. Carer reported quality of life [Source: ASC OF]	8.7	NA	NA	HIGH is GOOD Base line data only. First time produced and no comparator data available. Progress will be shown in future reports. The source is National Carers Survey for period 2011/12. Measured as a weighted aggregate of the responses to the following aspects: Occupation (Q7); Control (Q8); Personal Care (Q9); Safety (Q10); Social Participation (Q11) Encouragement and Support (Q12) Reported by Adult Social Care

4. People will be involved in decisions made about them	10. Ensure that people have a voice and influence in decision making	15. The proportion of people who report that adult social care staff have listened to your views. [Source: Local]	93%	⇧ Improving	NA (local survey)	HIGH is GOOD The Leeds reported period is Quarter 3, 2012/13. The source is a local survey taking place every 6 months. The unit is percentage of respondents. Reported by Adult Social Care
	11. Increase the number of people that have more choice and control over their health and social care services	16. Proportion of people using social care who receive self-directed support [Source: ASC OF]	62%	⇧ Improving	39.8%	HIGH is GOOD The peer is a comparator average for 2011/12. This is a National Indicator sourced from ESCR. The Leeds reported period is Quarter 3, 2012/13. The forecast is over 70% by end of year Reported by Adult Social Care
5. People will live in healthy and sustainable communities	12. Maximise health improvement through action on housing, transport and the environment	17. The number of properties achieving the decency standard	96.92%	⇔ Static		The target figure is generally regarded as full decency as properties drop in and out of decency at various times.
	13. Increase advice and support to minimise debt and maximise people's income	18. Number of households in fuel poverty Note. Currently subject of a government consultation with a view to redefining [Source: Public Health OF]	17.2%	⇔ Static	England 16.4%	2010 data This is a national indicator sourced from DECC
		19. Amount of benefits gained for eligible families that would otherwise be unclaimed		-	-	In development

	14. Increase the number of people achieving their potential through education and lifelong learning	20. The percentage of children gaining 5 good GCSEs including Maths & English [DFE Performance Tables]	Leeds 55%	⇧ Improving	England - 59.4% Statistical neighbours – 58.8%	HIGH is GOOD The %age of pupils in Leeds achieving five or more GCSEs (or equivalent) at grades A*-C, including GCSEs in English and Maths, has improved 1.3 percentage points in 2012, to 55.0%. Leeds remains below the national figure, though national results improved by only half a percentage point to 59.4%, meaning Leeds has slightly narrowed the gap to the national average. Leeds is ranked 123 out of 151 local authorities on this indicator, putting Leeds in the bottom quartile in 2012. The improvement achieved in statistical neighbour authorities (2.4 percentage points) was higher than the improvement in Leeds; attainment in Leeds is now 3.8 percentage points lower than in statistical neighbour authorities. Reported by Children's Services
	15. Support more people back into work and healthy employment	21. Proportion of adults with learning disabilities in employment [Source: ASC OF]	6.22%	⇩ Not improving	6.5%	HIGH is GOOD The peer is Metropolitan District average for 2011/12. The Leeds reported period is Quarter 3, 2012/13. The source is ESCR. The unit is percentage of service users with record of employment. Reported by Adult Social Care
		22. Proportion of adults in contact with secondary mental health services in employment [NHS OF]	Leeds 22.94%	⇩ Not improving	England 27.42% ⇩	HIGH is GOOD Period: Quarter 1, 2011/12 Data is published at Local Authority Level only. Arrows show direction of travel compared to the same quarter the previous year. Reported by CCGs

Glossary

CCG – Clinical Commissioning Group
CCGOI – CCG Outcomes Indicator, published by NHS England
ESCR – Electronic Social Care Record
IAPT – Improving Access to Psychological Therapies, NHS programme
Public Health OF – Public Health Outcomes Framework
ASC OF – Adult Social Care Outcomes Framework, published by Department of Health
NHS OF – NHS Outcomes Framework, published by Department of Health
DFE – Department for Education

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Leeds Health & Wellbeing Board

Report author: Tim Sanders
Tel: 0113-247-8923

Report of: **Director of Adult Social Services and Clinical Director, Leeds North Clinical Commissioning Group**

Report to: **Health and Wellbeing Board**

Date: **Wednesday 22nd May 2013**

Subject: **Living Well with Dementia in Leeds – our local strategy 2013-16**

Are there implications for equality and diversity and cohesion and integration?	☒ Yes	☐ No
Is the decision eligible for Call-In?	☒ Yes	☐ No
Does the report contain confidential or exempt information? If relevant, Access to Information Procedure Rule number: Appendix number:	☐ Yes	☒ No

Summary of main issues

Living Well with Dementia in Leeds: Our local dementia strategy 2013-16 has been prepared by the Leeds Integrated Dementia Board. It collates a wide range of information and evidence about needs and services, and sets out a shared purpose and priorities. it has been co-produced with a wide range of partner organisations.

The local strategy is complemented by an action plan. Recent progress includes significant additional investment in memory services from 2013-14, to reduce waiting times, increase the number of people diagnosed, and improve post-diagnosis support.

"Dementia-friendly communities" is an initiative to promote positive attitudes and access to services in everyday life, beyond health and social care. The report considers the potential role of the Health and Wellbeing Board to promote dementia-friendly Leeds.

Recommendations

The Health and Wellbeing Board is asked to:

- Consider the strategy and its priorities, and support it as a basis for co-ordinated action across all local agencies which support people with dementia and carers.
- Sponsor the formation of a Leeds Dementia Action Alliance to promote positive attitudes and accessible services throughout local communities, businesses and service providers.
- Comment on the development of the actions to deliver the strategy, including the opportunities offered by other health and well-being initiatives.

1. Purpose of this report

1.1 To give an overview of the strategy document, *Living Well with Dementia in Leeds: Our local dementia strategy 2013-16* (summary at Appendix 1, full document at Appendix 2).

1.2 To describe how the strategy will be promoted and published alongside its action plan (Appendix 3).

1.3 To explain the rationale for setting up a Leeds Dementia Action Alliance, and invite Health and Well-Being Board to sponsor this initiative.

1.4 To show how the strategy and action plan will contribute to the objectives of Leeds Joint Health and Wellbeing Strategy.

2. Background information

2.1 The Department of Health Mandate to the NHS Commissioning Board (NHS England) includes a clear statement of the government's goal, *that the diagnosis, treatment and care of people with dementia in England should be among the best in Europe.* It asks NHS England to work with Clinical Commissioning Groups to make measurable progress by March 2015, *driving significant improvements in diagnosis of dementia.* Furthermore:

> *because people with dementia, their carers and professionals rightly need to feel confident that a diagnosis of dementia will improve the lives of people with the disease, the Board should work with CCGs to support local proposals for making the best treatment available across the country.*[1]

2.2 The strategy document was produced by engaging with people with dementia and carers, local NHS trusts, social care providers, voluntary and community organisations, social enterprises and other statutory bodies. Appendix 4 shows a list of those who contributed, either at engagement events or in writing. The views contributed by people with dementia and carers were important, and are evident in the strategy document, but the numbers of people were small, and the strategy includes working with Leeds Involving People to improve participation and influence.

2.3 The strategy gives an overview of local services involved along the "dementia journey" and brings together a wide range of policy and evidence. Feedback on the draft document indicated that people found it useful to have the descriptive local information.

2.4 The national Dementia Action Alliance (DAA) was formed in 2011, supported by the Alzheimer's Society. The Yorkshire and Humber Regional DAA was launched in Leeds in November 2012. These bodies support larger-scale initiatives, and enable shared learning with other places with the commitment to become

[1] https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/127193/mandate.pdf.pdf paras. 2.10 – 2.12

dementia-friendly. Understanding what works well is important at this stage, when practical action is required to achieve an aspiration. The local DAA will use the same sign-up and action planning arrangements as the national and regional groups, but focus on local businesses, organisations and community groups.

3. Main issues

3.1 The following paragraphs are a summary of the strategy and action that is already in progress. The introduction proposes a shared vision and sets out demographic information about numbers of people with dementia and the expected growth in numbers. It emphasises a positive approach to growing older, in line with the Leeds *Ageing Well* principles[2]. It proposes a person-centred view of living with multiple health needs, because it is estimated that 90% of people with dementia have other physical and mental health conditions.

3.2 The strategy describes a co-ordinated approach to improve awareness, diagnosis, and post-diagnosis support. This illustrates the value of a multi-agency approach, to ensure that the many initiatives to identify and refer people with possible dementia, do not lead to increased waiting lists, or to people with a diagnosis but little help as a result. An additional £400K has been allocated to increase capacity of the Leeds memory service during 2013-14, and the new posts are now being advertised. In the past year there have been new investments to develop further dementia cafes and pilot new activities such as singing groups and creative arts.

3.3 Leeds made the commitment to become a dementia-friendly city in March 2012. The "Tea-Cosy" dementia café at Rothwell and Otley Town Council have launched local dementia-friendly campaigns. Practical steps have included awareness raising talks to supermarket staff across Leeds and a Rothwell neighbourhood policing team. The local networks include bus operators, retailers and a leading provider of dementia-friendly signage. Funding has been identified to co-ordinate and support a Leeds Dementia Action Alliance, so that local groups and businesses can have support to develop plans and share learning, and to increase the profile and activity of the campaign.

3.4 It is proposed that a Leeds Dementia Action Alliance would be the best way to attract and involve people and organisations, who can contribute to Leeds being "dementia-friendly"; to publicise good initiatives and campaign to change attitudes and promote awareness. It is an opportunity for Leeds Health and Wellbeing Board to demonstrate its role within the wider community as well as health and social care.

3.5 Although dementia only accounts for approx. 3 - 4% of people with long-term conditions in Leeds, it is associated with a much higher proportion of care costs. It is estimated that 80% of people in care homes, and 25% of people in hospital, have dementia, alongside other long-term conditions. The Care Quality

[2] http://www.healthycities.org.uk/uploads/files/a_framework_of_principles_for_ageing_well_final.pdf

Commission have identified that: *the increasing complexity of conditions and greater co-morbidities experienced by people are impacting on the ability of care providers to deliver person-centred care that meets individuals' needs.*[3] The Leeds Integrated Health and Social Care programme is therefore supporting a project to improve the capacity of community health and social care staff to work with people with dementia. There are already mental health liaison services available to support people in care home and hospital settings, and the strategy identifies that a similar approach – linking specialist mental health services to primary and community care - is key to meetings people's needs at home.

3.6 Families and carers say that they wish to have better information, covering the impact of dementia, how the condition may progress, and about local services. The strategy describes the emotional and physical demands which particularly affect carers of people with dementia, and lead to needs for a diverse range of services for support and breaks. Carers Leeds have started offering the Alzheimer's Society's "Carers' Information and Support Programme" (CrISP) and have been given additional funding to cope with the demand. In 2011-12, £300K was allocated to increase home-based carer breaks.

3.7 All health and social care providers are responsible for ensuring that people with dementia receive care and support from staff who are appropriately trained[4]. Leeds Teaching Hospitals Trust have developed a three-tiered approach, which offers basic awareness training to eg. ward clerks and porters; training in person-centred care for nursing and health care assistant staff; and a leadership level. There are more than 90 older people's care homes and 30 domiciliary care providers in Leeds, and it is a particular challenge to ensure that the sector offers a consistently high standard of dementia care.

3.8 Dementia often causes a person's well-being to deteriorate faster than the progress of the underlying organic condition. For example, the condition can lead to loss of confidence to go out, or the ability to carry out the sequence of steps to make a snack or cup of tea. Communication difficulties can cause frustration, isolation or boredom. This means that there are opportunities to promote living well with dementia even if the condition itself cannot be treated. Local projects to develop eg. reminiscence, creative arts and reading aloud are being supported with short-term funding and / or working together to obtain external funding. Increased investment has been sustained for the care homes mental health liaison to promote education and training for care home staff, and a preventive approach, alongside responding to more urgent needs. A local guideline is being developed to avoid inappropriate use of anti-psychotic medication and increase awareness of services that can reduce agitation and aggression.

3.9 People with dementia too often suffer indignity from the assumption that one cannot participate in decisions and make choices; and opportunities are missed

[3] *The State Of Health And Adult Social Care In England*
http://www.cqc.org.uk/sites/default/files/media/documents/cqc__soc_201112_final_tag.pdf
[4] http://publications.nice.org.uk/dementia-quality-standard-qs1/quality-statement-1-appropriately-trained-staff

for people to consider “advance decisions” about care and treatment at the early stages of dementia. Making advocacy services available at key points in the journey – eg. after diagnosis, or after a care home admission - could promote individual rights, and avoid some unnecessary admissions to hospital near to end-of-life. Traditional service provision, based on specific tasks at predetermined times, is often too inflexible to meet needs. A small number of people with dementia in Leeds are benefitting from the flexibility of an individual budget to purchase social care, supported by Leeds Centre for Integrated Living. Increasing access to more flexible support, and to advocacy services are identified as priorities.

3.10 Leeds Teaching Hospitals Trust is improving personalised care by use of a “Know Who I Am” document which staff complete with the person and family; and seeking to improve carer support and ward environments. The trust has achieved the national target for screening, assessing and onward referral of people with possible dementia; and from April 2013 there are further incentives for staff training and a monthly audit of whether carers felt supported during hospital admissions.

3.11 Specialist mental health services in Leeds have undergone significant changes in the past year. Leeds and York Partnership Foundation Trust is training its community teams that work with adults, in dementia and the mental health needs of older people; improving the care environment for inpatients at The Mount; and developing the new capacity in memory services and care homes liaison, as described above.

3.12 The older people’s care home sector is, increasingly, caring for people with dementia, often alongside other long-term conditions and frailty. Leeds care homes are now working to a new service specification and quality standard, which incentivises care quality with the payment of a higher weekly fee for Council-funded residents, when set standards are achieved. This approach aims to reward investment in eg. staff training. Improved confidence and capability for dementia care will reduce hospital admissions and other care costs.

3.13 Care at the end of life must not be overlooked as an important service for people with dementia. It can itself be a terminal condition and main cause of death; or people may die with dementia when the primary cause is another health condition. The early stages of dementia may be, with the right help and sensitive conversations, be a good opportunity to prepare for the later stages, eg. with advance decisions, making a lasting power of attorney. Specialist palliative care services are developing a clinical guideline to detect and manage symptoms such as pain and nausea, with people who may not be able to communicate well, or co-operate with treatment.

3.14 It is proposed to create a Leeds dementia page on www.leeds.gov.uk to publish the strategy and action plan, and to update the action plan as progress is achieved and new actions and investments are agreed.

3.15 The strategy and its action plan will therefore contribute to the Leeds Joint Health and Wellbeing Strategy, in particular to the following outcomes:

- People will live full, active and independent lives
- People's quality of life will be improved by access to quality services.
- People will be involved in decisions made about them.

3.16 The summary document (Appendix 1) includes dementia-specific indicators and examples of health and well-being strategy indicators where a dementia 'sub-set' could potentially be used to monitor progress.

4. Health and Wellbeing Board Governance

4.1 Consultation and Engagement

4.1.1 The strategy has been overseen by the Leeds Integrated Dementia Board, which includes a CCG representative, all local NHS providers, adult social care, third sector and private provider representatives. The first draft of the strategy was influenced by the "Better Lives For People With Dementia Event" in May 2012, and then put out for consultation for 3 months, from September to July 2012. A focus group involving all three CCGs, senior clinicians, Leeds Alzheimer's Society and commissioners was held in September. The draft document was published on the NHS Leeds website, along with a short questionnaire intended for people with dementia and families / carers; and a longer questionnaire intended mainly for staff. Appendix 4 lists the organisations involved and some of the points which influenced the strategy.

4.2 Equality and Diversity / Cohesion and Integration

4.2.1 Dementia is itself a condition which causes cognitive and other impairment, and affects a diverse range of local people. It is suggested by community groups and professionals that poor understanding of the condition, and stigma attached to it, may present particular barriers to diagnosis and support in some minority ethnic communities. It is estimated that there are 100-200 older people living with dementia in Leeds Caribbean, Irish, Jewish, and south Asian communities.

4.2.2 Age is the main risk factor linked to dementia, and thus dementia is most prevalent in the more affluent and rural areas within the Council boundary, where life expectancy is longest. However, at any given age, the risk of developing dementia is highest in the more deprived, inner-city areas of Leeds.

4.2.3 A screening form has been completed in relation to the report content and the proposed decision being taken (Appendix 5). The "Key findings" section details aspects of the strategy document with reference to equality and diversity, and proposed actions under the strategy to address them.

4.3 Resources and value for money

4.3.1 The strategy document sets out a shared purpose and priorities, with specific investments to be set out in the action plan. The strategy contrasts the relatively

small investment in diagnosis and early support, to the high cost of people with dementia going into hospitals and care homes.

4.4 Legal Implications, Access to Information and Call In

4.4.1 There are no direct legal implications of this report. There is no confidential information or implications regarding access to information. It is subject to call-in.

4.5 Risk Management

4.5.1 The costs of caring for people with dementia would rise by c. 2% each year if change is not achieved as part of better management of dementia as a long-term condition, and developing integrated health and social care. Therefore doing nothing would itself be a risky strategy.

4.5.2 Dementia is a complex condition which requires co-ordination of strategy and care over many organisations. This creates risks to delivery. Therefore this strategy is put forward to co-ordinate development between agencies; inform providers and external funders what priorities we wish to see investment in; and encourage organisations to work to a shared vision.

5 Conclusions

5.1 The partner organisations who are represented on Leeds Integrated Dementia Board have set out a joint approach to improving health, social care and daily life in Leeds for people with dementia and carers. Progress is being made in key areas and key investments have already been identified and actions are in progress.

6 Recommendations

6.1 The Health and Wellbeing Board is asked to:

- Consider the strategy and its priorities, and support it as a basis for co-ordinated action across all local agencies which support people with dementia and carers.
- Sponsor the formation of a Leeds Dementia Action Alliance to promote positive attitudes and accessible services throughout local communities, businesses and service providers.
- Comment on the development of the actions to deliver the strategy, including the opportunities offered by other health and well-being initiatives.

Appendices

Appendix 1 - Summary of strategy
Appendix 2 - Strategy document, *Living Well with Dementia in Leeds*.
Appendix 3 - Action Plan
Appendix 4 - Organisations contributing to the development of *Living Well With Dementia in Leeds.*
Appendix 5 - Equality impact screening tool

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Appendix 1: Living well with Dementia in Leeds – summary of strategy 2013-16.

Version 1 – May 2013

1. **More people with dementia will be diagnosed, at earlier stages of the condition, and this will lead to better support and quality of life.**

   - Increase memory service capacity, to reduce waiting time for assessment and diagnosis.
   - Review the "shared care" for diagnosis, prescribing and post-diagnosis support. This will free up memory services capacity to work with people and carers according to need and complexity; improve consistency of care; and improve the experience for people and families.
   - Local initiatives to identify and assess people who may have dementia, to complement national schemes; including a local public awareness campaign.
   - Develop and implement a Leeds standard of post-diagnosis care and treatment, for people with dementia and families / carers. This will include opportunities for information, education, social and therapeutic activities, and peer support. It will ensure that diagnosis is a genuine gateway to help, and encourage people with memory problems to seek a diagnosis.
   - Sustain and develop key roles for voluntary and community groups and social enterprises ("third sector"); support innovative approaches to eg. overcome barriers to diagnosis; support people with difficult decisions; and cope with the impact of dementia on relationships.

   Results and Measures:

   - Diagnosis rate: All 3 Leeds CCGs have set target for annual improvement of 2.5%. This means that, each year, no. of people on Leeds GP dementia registers will increase by at least 200.
   - Reduced waiting time for memory assessment.
   - New national indicator for NHS and adult social care, specifically for dementia, which will *measure the effectiveness of post-diagnosis care in sustaining independence and improving quality of life* (expected 2014).

2. **Leeds will become more 'dementia-friendly', linked to our aspiration for Leeds to be the "best city", and similar initiatives to be eg. 'age-friendly' and 'child-friendly'. This will mean that people with dementia can participate more in everyday life, and maintain confidence and independence for as long as possible.**

   - Leeds dementia strategy, action plan and its projects will be influenced by the involvement and experiences of people with dementia and carers.
   - The Leeds Dementia Action Alliance will involve local communities, business and providers of services beyond health and social care, to develop initiatives that together will make Leeds dementia-friendly.

   Results and Measures:

   - Local organisations and businesses signed up to Leeds Dementia Action Alliance and committed to actions.
   - Leeds will be among the first local authority areas to be accredited with "dementia-friendly" status.

3. **People living with dementia alongside other health conditions and disabilities, will have integrated support to maintain emotional, psychological and physical well-being.**

   - Integrated health and social care teams will have access to dementia specialist support, including short-term investment in dementia liaison roles, to work alongside staff to develop skills through joint working.
   - Social care providers and NHS services will work together better, so that people with dementia, frailty and complex needs are supported by a multi-disciplinary approach. This includes a new

specification for the care homes liaison service, with capacity to provide educational and preventive approaches.

- Increase the opportunities for people to sustain daily routines, and participate in physical, creative and therapeutic activities, to promote dignity and self-esteem, and reduce boredom and frustration.

Results and Measures:

- Production of guideline for management of agitation and aggression; further reduction of inappropriate prescribing of anti-psychotic medication.
- Measures to be developed, including individual studies, of interventions which prevent admissions to hospitals and care homes.
- Consider a dementia 'sub-set' for joint health and well-being indicators which measure hospital and care home admissions.
- National indicator expected in Public Health Outcomes Framework – *dementia and its impacts*.

4. People with dementia and carers benefit from opportunities to plan and design care packages, and have support with decisions about treatment, care and daily living. This will help people to plan for the later stages of dementia; protect individual rights; and make it easier for people with dementia to accept services, and sustain social and community life.

- Improve access to advocacy at key points in the "dementia journey".
- Develop a plan to increase uptake of self-directed support, and overcome the barriers of understanding and administration for families and staff.

Results and Measures:

- More people with dementia with self-directed support.
- More people with advance care plans, especially in care homes.

5. Develop a confident and capable workforce which provides person-centred care for people with dementia, including people with other health conditions and frailty.

- Ensure NHS providers report on workforce eg. through quality accounts.
- Develop effective incentives and support for health and social care providers to train staff to the required level; eg. agreeing and achieving annual training plans.
- Make good use of the expertise within specialist services to provide training, and share skills.
- Offer training for voluntary and community organisations, and organisations outside health and social care, to improve dementia awareness, and promote inclusion in services.

Results and Measures:

- compliance with workforce statement from NICE quality standard: *People with dementia who receive health and social care services, are supported by appropriately trained staff.*

6. People with dementia and carers have support to plan and prepare for the end stages of dementia; decisions about treatment and care are informed by a shared understanding of prognosis; and ensure services at end of life offer good care for people with dementia.

- Promote awareness amongst clinicians and care providers of the signs and symptoms that dementia is reaching its end stages;
- Produce and disseminate clinical guidance for recognising and managing symptoms for people with dementia at end-of-life.

Results and Measures:

- Consider dementia 'sub-set' of national indicator: *Bereaved carers views of quality of care in the last 3 months of life*.

Appendix 2

LIVING WELL WITH DEMENTIA IN LEEDS

Our local strategy 2013-16

1 Foreword

Recent years have seen the National Dementia Strategy (2009), The Prime Minister's Challenge On Dementia (2012) and many other publications setting out a positive vision to transform health and social care for people with dementia. If people with dementia have earlier diagnosis leading to better information, support and treatment, then more people will stay well for longer, and have less need for admissions to hospital and care homes.

Local services in Leeds have been among the pioneers of many important developments, including memory services; specialist services to support people with dementia in hospital, and to return home from hospital; peer support; dementia cafés and activities offered by voluntary and community groups. However, there is a great deal more to do, to improve awareness, diagnosis and support; to ensure dementia is considered alongside other health conditions and needs, not in isolation; and to develop the workforce to provide person-centred care.

Change must go beyond health and social care, into our everyday lives. We can achieve a 'dementia-friendly' Leeds - the city, and our towns and villages - by listening to people's experiences, and working together to make changes.

This strategy gives an overview of local services and states our local priorities for the next three years. It goes with our action plan which sets out what local organisations are doing, and will do, to improve quality of life and quality of care, with people with dementia, families and carers.

Notes and explanations

If you are reading this document on a computer, then words which appear in blue should work as "hyperlinks" – if you are connected to the internet, clicking on these words will take you to eg. the relevant publication or website. These links were correct at the time of writing, but if the publisher has changed the website, you might need to do an internet search for the material.

If you are reading the paper document, then these words will appear as blue text or grey, depending on the print-out. If you are interested in the relevant document or information but do not have internet access to search for it, then please contact Tim Sanders (details below).

Where this document uses technical terms and jargon, it is explained in the text. The following definitions may be useful:

Adult social care	Services which help with eg. personal care, meals, daily living and social life; or assess the need for these services. In Leeds, these may be funded, arranged or provided by Leeds City Council.
Community health services	Services such as community nursing ("district nursing") which see people at home or in local clinics. In Leeds, these services are usually provided by Leeds Community Healthcare NHS Trust (LCH).
GP	Your doctor, or "General Practioner".
Primary Care	Health services, such as your GP, who are the first point of contact with any medical concerns. Most GP practices employ other staff eg. practice nurses to provide some services.
Secondary Care / Specialist Care	Health services which we usually access by a referral from our GP, eg. hospital treatment. In Leeds, the main providers are Leeds Teaching Hospitals Trust (LTHT); and Leeds and York Partnership Foundation Trust (LYPFT) as the provider of mental health and learning disability services.

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Contents

The term 'recovery' has developed a specific meaning in mental health. It has been defined as: *'A deeply personal, unique process of changing one's attitudes, values, feelings, goals, skills and/or roles. It is a way of living a satisfying, hopeful and contributing life, even with limitations caused by the illness…'*

W.A. Anthony, 1993, quoted in the national strategy No Health Without Mental Health.

The artwork in this document is from The Living Story project, led by West Yorkshire Artlink, working with people with dementia who were inpatients at Asket Croft and The Mount in Leeds, and staff from those units. The project was funded by the Evan Cornish Foundation. Further information and a book from the project are available from West Yorkshire Artlink http://www.artlinkwestyorks.org/projects.php

Front cover by May
Back cover by Rhoda
'Cup of tea' by Marjorie
'It's one of those days' by Jan and Angela
Red, pink, yellow, green, blue abstract by Victor

Hand massage photo by Tara Greaves, from Leeds dementia event, May 2012.

1 Introduction

> Once you have met a person with dementia, you have met one person with dementia
>
> *Tom Kitwood*

1.1 Dementia can be defined as:
….a set of symptoms which include loss of memory, mood changes, and problems with communication and reasoning. These symptoms occur when the brain is damaged by certain diseases, including Alzheimer's disease and damage caused by a series of small strokes.

Dementia is 'progressive', which means the symptoms will gradually get worse. How fast dementia progresses will depend on the individual person and what type of dementia they have. Each person is unique and will experience dementia in their own way…

Alzheimer's Society Factsheet, What Is Dementia?[1]

The risk of developing dementia increases with age, and the condition is becoming ever more prevalent as we live for longer and the balance of the population shifts towards more older people. As individuals, dementia is a disabling condition which we fear, for ourselves and our loved ones. As dementia becomes an ever-higher priority, we have the opportunity to enable more people to live well with the condition.

1.2 One purpose of a strategy is to bring people and organisations together to work towards a shared vision. This strategy describes how we want Leeds and its local services to be for people living with dementia. This includes family members and other carers. Our vision for Leeds is that:

> People and families affected by dementia will find that people are understanding and helpful, and experience excellent treatment and care, throughout the 'dementia journey'. We will work together so people can benefit from:
>
> - A voice for people living with dementia that influences local plans and services.
> - Living in a place which feels 'dementia-friendly'.
> - A helpful experience of early detection, diagnosis, and support, including honest and timely conversations about what to expect.
> - A health and social care workforce with the right approach, skills and understanding.
> - Treatment and care that works to keep people as well as possible, to plan ahead for the later stages of the condition, and to reduce admissions to hospitals and care homes.
> - Support throughout the dementia journey – timely access to help and advice when needed.
> - Equal and fair access to health and care services, overcoming the barriers that people with dementia often face.
> - The best possible experience of dying with or from dementia, with support when necessary from specialist palliative care.

[1] There are conditions defined as "dementia" which may not always be progressive, eg. some alcohol-related dementias can improve with treatment and abstinence from alcohol. This strategy is concerned with the progressive dementias, often associated with older age.

1.3 This strategy should help service providers to work together and plan; and inform local service providers to make investment decisions and design new services. It should enable local voluntary and community groups to apply for external funding with good evidence of local priorities.

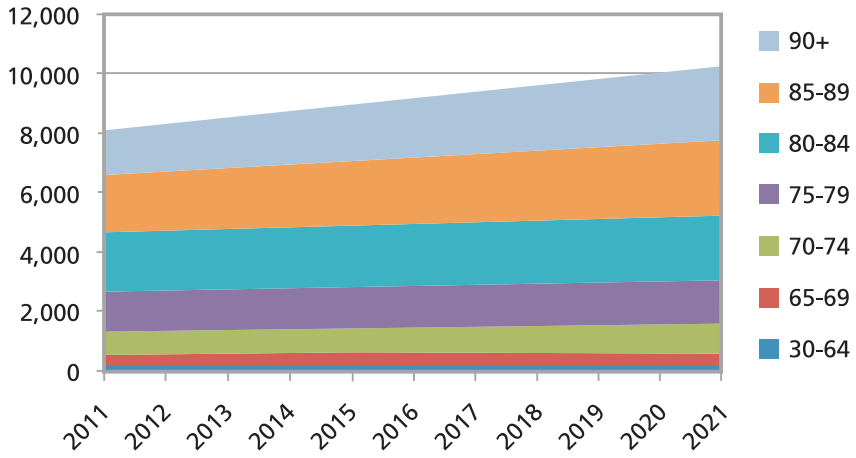
1.4 Older people in Leeds, as elsewhere, make huge contributions to social, community and economic life in the city, our towns and villages. Older people contribute in many ways, for example as leaders, grandparents, volunteers, unpaid carers. As we grow older, we might wish to continue with activities that we've always enjoyed, and we might wish to try out new activities, adapting to changes and taking advantage of opportunities. The Time Of Our Lives – Ageing Well in Leeds was launched in March 2012, and sums up our positive approach to later life in Leeds. This strategy aims to be part of that approach: honest and realistic about illness and loss, but continuing to value who we are and what we can do.

1.5 The Leeds Integrated Dementia Board is our local body which brings organisations together to set the strategy and co-ordinate action. Membership includes all local NHS organisations; Leeds City Council (Adult Social Care); the local Alzheimer's Society, Leeds Older People's Forum and other voluntary sector representatives and Leeds Care Association (private sector care providers). We wish to support and develop representation of people with dementia and carers.

1.6 This strategy comes at a time of pressure on public spending, when local authorities face severe cuts, and the National Health Service, although offered some protection from cuts, is still expected to find significant efficiencies to meet increased demand. We propose that supporting people early, will both lead to better quality of life and health, and reduce costs of more intensive care, such as admissions to hospitals and care homes. This fits with national and local policy for 'transformation' of health and social care.

1.7 There are an estimated 8,500 people with dementia in Leeds in 2013. This figure comes from research evidence which tells us how prevalent dementia is, applied to the local population figures . It is approximately 8% of the people aged 65 and over in Leeds. This is likely to increase, and estimated to become over 12,000 people with dementia in 2028 – a 35-40% increase in 15 years. These numbers conceal the great diversity of people with dementia and the effects it has on each individual. Some key facts and figures are shown in Box 1 and Figure 1:

Fig. 1: People with dementia in Leeds – by age band



[2]Population figures from Office of National Statistics *Interim 2011-based subnational population projections for England;* dementia prevalence by age from Alzheimers Society Dementia UK report (2007) .

BOX 1 – 8,500 PEOPLE WITH DEMENTIA IN LEEDS IN 2013

- Approximately 5,000 people of the 8,500 have Alzheimer's Disease; 2,000 have vascular dementia; the rest have mixed and rarer types such as frontal-temporal lobe dementia, and dementia with Lewy Bodies .
- approx. 52% of people with dementia in Leeds, have a diagnosis recorded on GP registers.
- Approximately 5,700 people of the 8,500 live at home, 2,800 in care homes.
- 200 people of the 8,500 are aged 64 and under.
- Nearly all of the increase in numbers of people with dementia will be people aged 85+, who are more likely to have other long-term health conditions, sensory impairments or to need some support with daily living.
- People with learning disabilities, especially Down's Syndrome, are at increased risk of developing dementia at a younger age.
- There are probably 100 – 200 people with dementia from each of the main black and minority ethnic groups in Leeds; older people of Caribbean, eastern European, Irish, Jewish, and south Asian origins.
- It is estimated nationally, that older people with dementia use 25% of all hospital bed capacity.
- 2,000 people every year experience new onset of the condition; perhaps 1,700 local people with dementia are in the last year of life.
- The more affluent and rural areas of Leeds have a higher proportion of the population with dementia, because there are more older people in these areas.
- However, the risk of dementia at any given age appears to be higher in urban areas with higher deprivation. This may be because vascular dementia is linked to high blood pressure, diabetes and heart disease. Older people of south Asian and Caribbean origins may therefore also be at higher age-related risk of dementia.
- Therefore, national prevalence figures may be an underestimate for some communities within Leeds.

1.8 How dementia affects the person depends on an individual's life-history, relationships and psychology, alongside the progress of dementia and other health conditions. One size does not fit all for people with dementia. Therefore, health and social care policies which promote 'personalisation' offer opportunities for better care and support.

1.9 A simplified model of the 'dementia journey' is shown on the following page. It is intended to help us think about what we have working well in Leeds, and what is missing. The rest of the document considers the stages of this journey, together with key themes such as families and carers; workforce; care homes and hospital care.

Priority

A "Dementia Needs Assessment" for the Leeds population will improve our knowledge and understanding of local need and current use of services. This information will be part of wider population needs assessment work regarding long-term conditions, and the needs of older people.

[3]Further information about dementia can be found from the Alzheimer's Society, eg: http://alzheimers.org.uk/Facts_about_dementia/What_is_dementia/

The 'Dementia Journey' in Leeds
A way to think about living well with dementia

Awareness, diagnosis and early support

- Prevention of dementia where possible.
- People in Leeds will be aware of the signs and symptoms and feel able to seek help.
- GPs respond consistently to assess memory problems.
- GPs and memory services work effectively to provide timely and supportive diagnosis.
- Sustain and improve annual increase in people diagnosed on GP registers, with diagnosis occurring at an early stage of dementia.
- Help, advice and explanation to overcome the barriers to diagnosis.
- Good information about dementia and the services available.
- Consistent and clear access to post-diagnosis support, treatment and review.

Well-being + person-centred care

People with dementia, families and carers will feel respected and valued, with:

- Leeds feeling like a "dementia-friendly" place.
- a positive response to individual abilities, likes and dislikes, and life history.
- support to ensure meaningful activity and social engagement.
- practical and emotional support to prepare and plan for the later stages of dementia, including advance care planning.
- self-directed support, to regain and remain in control of daily living.
- understanding and support with emotional and psychological needs.
- recognition of and treatment for health needs; access to routine checks; not assuming every symptom is because of dementia.
- support for individual rights and decision-making, including access to advocacy.

End of life care

- Carers, clinicians and other staff will have information and support to recognise the end-stages of dementia.
- We can have honest conversations and draw on earlier plans for a 'good death'.
- Recognition and treatment of pain, nausea and other symptoms.
- The right care and support will be available at one's preferred place of death, avoiding unnecessary admissions.

2 Awareness, diagnosis and early support

It's vitally important to get the diagnosis early because at least then you can try to sort out your future.

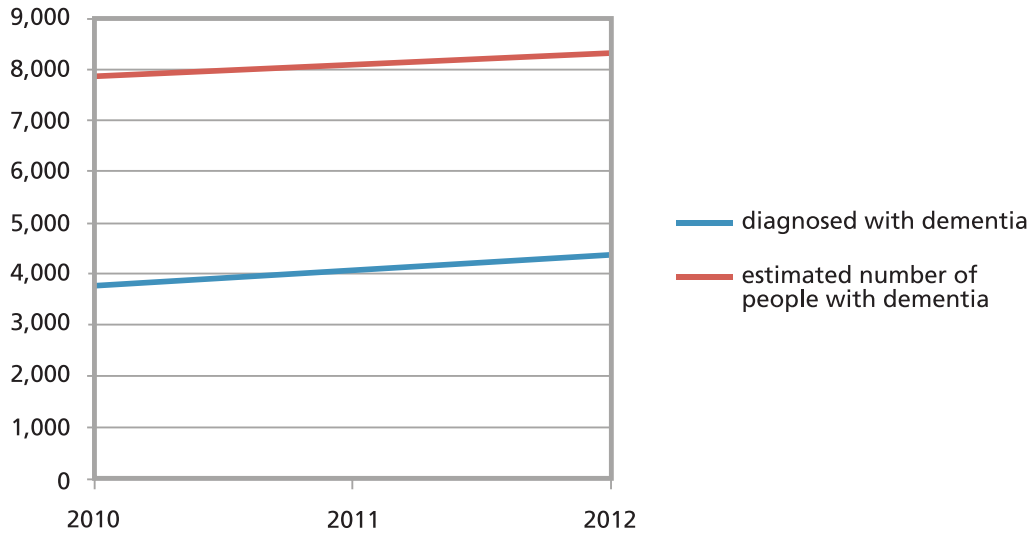
Agnes Houston, person with dementia and Chair of Scottish Dementia Working Group

Overview

2.1 It is likely that dementia is often undiagnosed, or diagnosed at a relatively late stage. The "diagnosis rate" is the number of people actually recorded on GP registers with a dementia diagnosis, divided by the estimated people with dementia in the population (the estimate is made as described in the previous section). At March 2012, the estimated diagnosis rate for Leeds was 52%, slightly above the national and regional rates, but still leaves 4,000 local people with dementia who do not have a diagnosis.

2.2 Nationally and locally, diagnosis rates are generally increasing, adding about 2 percentage points year-on-year. Any trend will be clearer when we have March 2013 figures. Full national data is available from the Alzheimer's Society "Mapping The Gap"[4].

Figure 2: Leeds - Comparison of estimated numbers of people with dementia, with actual numbers on Leeds GP practice dementia registers.



2.3 It can take a long time before help is sought for concerns about possible dementia. Colleagues who work in Doncaster memory services have found from interviewing patients, that it may take a year to share concerns within the family, and a further year to talk to a health professional.

[4] Please note that the 2011 Census shows Leeds has fewer older people than previously estimated, and at time of writing (March 2013) Mapping The Gap is yet to be updated, and therefore has a slightly lower figure for Leeds diagnosis rate.

2.4 There are conditions that can present in a similar way to dementia, but actually be treatable – for example under-active thyroid; sometimes depression in older people can cause forgetfulness and confusion. Therefore, the assessment process for diagnosing dementia, can discover other conditions which can be treated, and save some people from living with an incorrect belief about having dementia. Conversely, dementia may not always first present as memory and cognitive problems – depending on the type of dementia and part of the brain affected, it may present with behaviour changes, poor balance, or low mood. It is a complex condition, and initiatives to improve awareness and detection have to take this into account.

2.5 Therefore, public awareness is very important to encourage and support the first steps to seek help and diagnosis. There are barriers of fear; lack of understanding; myths around dementia, old age and mental health. Awareness campaigning should address these attitudes and barriers as well as providing information; and be well-designed with messages and methods appropriate to the diversity of Leeds.

She'd ask me to do something and then find I hadn't and she'd play pop with me but I'd be swearing blind she hadn't asked in the first place. It was causing a bit of tension between us, a bit of a rift that wasn't there before. I thought she was imagining it….

….The diagnosis of dementia is just saying that you've got a certain illness and then you learn to cope with it and make the most of your life. People don't know what dementia is and it's a bit scary at first….

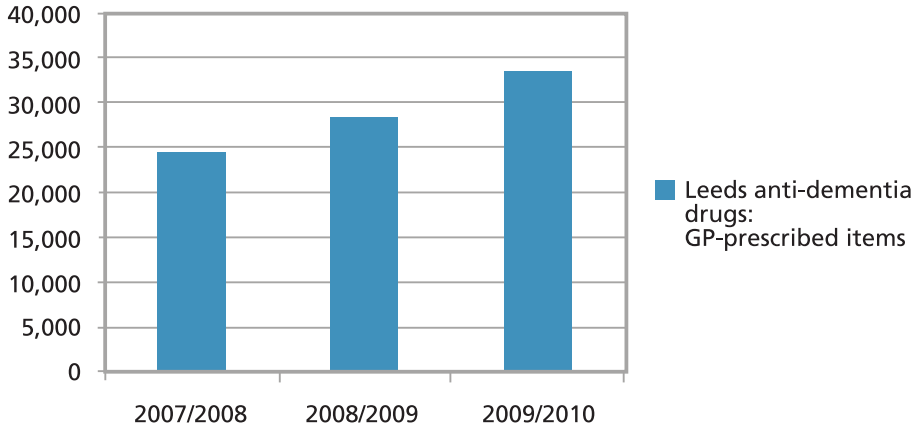
… Slowly, I found I was becoming more confident and positive, learning coping strategies and picking up things. It has grown from there and now my life has completely changed and I think I've got an amazing life.

Bob, person with dementia and member of Leeds peer support network

2.6 General Practitioners (GPs) are often the first point of contact for people concerned about possible dementia. The process may involve discussion of concerns with the person and family; a short cognitive test; and screening for other possible conditions. The GP may then refer on to a specialist memory service ("memory clinic" or "memory assessment") for further investigation and diagnosis, and follow-up treatment and support if dementia is diagnosed. In Leeds the memory service is provided by the Leeds and York Partnership Foundation Trust (LYPFT). Leeds residents living near the local authority boundary might be referred to neighbouring services eg. at Knaresborough for people with GPs in the Wetherby area. People with learning disabilities who develop possible symptoms of dementia may require a specialist service. This is provided by LYPFT from the Community Learning Disability Teams, working with colleagues in old-age psychiatry and memory services as required. (NB. LYPFT is developing a single 'pathway' for cognitive assessment which will take account of specific needs).

2.7 Following diagnosis, the memory service provides information, advice and support, either directly or via its links with Leeds Alzheimer's Society and other local services. The service offers "memory groups" to people diagnosed with dementia and families / carers, which include information, practical coping strategies and adjusting to having the condition. The service provides Cognitive Stimulation Therapy (CST), a series of sessions to stimulate and engage people, and offer the social benefits of a group; however, the number of CST groups is variable. There may be prescription of anti-dementia drugs. These can, for some people with Alzheimer's Disease, improve or slow the progress of symptoms. Benefits are less certain for other types of dementia, and at present there are no equivalent drug treatments for vascular dementia. The memory service is currently responsible for follow-up and review for people prescribed these drugs.

Fig. 3 shows the increasing prescription of anti-dementia drugs in Leeds.[5]



2.8 In 2011-12 the memory service saw 2,145 people, either for assessment / diagnosis (including people who turned out not to have dementia), or for follow-up. This is approximately 50% of the people in Leeds diagnosed with dementia, and 25% of the estimated number of people with dementia in the local population.

2.9 There are a range of services in Leeds, which help people with dementia and carers to "live well" with the condition. Sometimes this kind of support is referred to as "self-management" for a long-term health condition. Local services include:

- Dementia advisers, employed by the Leeds Alzheimer's Society.
- Carer support workers and carer support groups, provided by Carers Leeds and Leeds Alzheimer's Society.
- Peer Support Network, run by Leeds City Council.
- Dementia cafés, run by Leeds Alzheimer's Society, Carers Leeds and Leeds Neighbourhood Network Services and other community organisations.
- A range of activities, including intergenerational work and creative arts run by the Neighbourhood Networks and other groups.

2.10 Some services which support people after diagnosis, can also play a valuable role before diagnosis, helping to discuss concerns, explain the next steps and practical support to attend appointments. A listening ear and some advice could help a concerned family member of a person who appears to be developing memory problems, but does not seem to acknowledge them. This means that such services should take a flexible approach, and not depend rigidly on a diagnosis of dementia as a condition of offering help. For people who live alone, community groups might be the first to notice that possible signs and symptoms of dementia are developing.

2.11 There are several initiatives which introduce incentives to improve detection of dementia. This is because people with undiagnosed dementia may well have other long-term conditions, and are at particular risk of coming into services when there is a crisis, illness or injury. The 'national dementia CQUIN' for acute hospitals incentivises the screening and assessment of people aged 75+ who have emergency hospital admissions (CQUIN is short for Commissioning for Quality and Innovation). Further information

[5] From Leeds Mental Health Needs Assessment, 2011

is at section 9 of this document, The Right Care – people with dementia in hospital. A further local CQUIN in Leeds will (from April 2013) incentivise community health teams to identify people with dementia. The national NHS 'General Medical Services' contract with GPs for 2013-14 will include screening for dementia as a "Directed Enhanced Service".

2.12 Awareness raising about dementia and services is planned as part of the "NHS Healthcheck" initiative. The Healthcheck is aimed at adults aged 40 – 74, with dementia awareness promoted for the 65-74 age group.

2.13 The early stages of dementia can be an opportunity to prepare for the later stages. Family, friends and professionals can help by prompting timely and honest conversations. There will often be opportunities to notice and respond to the natural concerns that people have about the future. Examples include making a Lasting Power of Attorney, which can cover both financial arrangements, and preferences for future care and treatment.

What we need to improve

The benefits of dementia awareness, early diagnosis and support include:

- Detecting conditions that are not dementia, but which can present in a similar way, and can be treated.
- The opportunity to be prescribed anti-dementia medication for Alzheimer's Disease and some other types of dementia.
- The opportunity for non-drug treatments such as cognitive stimulation therapy.
- The opportunity to have useful information, support and to take part in activities.
- The opportunity to prepare and plan ahead.
- To sustain and recover social life and friendships.
- People are more likely to get to know important information and access other services.
- Family / carers can have a break, someone to talk to and get useful information.

2.14 Clinical Commissioning Groups (CCGs) must set a "target trajectory", the ambition for increasing dementia diagnosis over the next two years. This is part of the NHS Outcomes Framework, and CCG Outcomes Indicator Set (January 2013). The three CCGs in Leeds are aiming, as a minimum, to sustain an annual 2.5 percentage point increase in the diagnosis rate.

2.15 There appears to be variation in the understanding that GPs have of dementia and the 'pathway' for diagnosis, treatment and support. A National Audit Office survey published in 2010 showed only 47% of GPs agreeing with the statement that; *I received sufficient basic and post-qualifying training to help me diagnose and manage dementia.* The Leeds Clinical Commissioning Groups (CCGs) have organised GP training sessions on dementia in late 2012, as part of the "Target" programme. Further education and support will be considered to improve knowledge and develop consistent practice for their GP members, including the use of practice-by-practice data to see where it is most needed.

2.16 The Leeds memory service reports (October 2012) that waiting times from referral to first appointment are 6 – 18 weeks. The Department of Health has published a model service specification which is not compulsory, but suggests that 3 weeks from referral to first appointment should be the aspiration.

Clinical staff suggest that waiting times could be reduced if time could be used more for new patients, and less for routine reviewing with people prescribed anti-dementia medication.

2.17 There are a range of initiatives and innovations with potential to improve the effectiveness of the diagnosis "pathway" eg:

- public awareness of signs and symptoms; what to do if you are concerned; clear messages about the benefits of seeking a diagnosis and the help you will be offered.
- more diagnosis in primary care settings, and other accessible places eg. memory services running clinics in different places, GP diagnosis of severe dementia.
- GPs reviewing patients who may be at higher risk of dementia.
- GP practices checking that diagnosis of dementia is recorded correctly and that people with dementia and carers are invited for review.
- Leeds Teaching Hospitals Trust to work more closely with memory services on brain scanning.
- review "shared care" arrangements for anti-dementia drugs, and the overall partnership between primary care and memory services.

2.18 Leeds has good services which offer post-diagnosis support, but there is not as yet a clear, consistent and guaranteed standard of support for people with dementia and families.

2.19 This part of the 'dementia journey', from awareness through diagnosis to early support, requires a co-ordinated approach. People are more likely to understand the potential to live well with dementia, and understand the benefits of seeking diagnosis, if there is a clear, guaranteed offer of treatment and support.

Priorities

- Local awareness campaign including innovative methods and messages for reaching diverse communities.
- CCGs to work with GP practices to improve training, and to identify and assess people with possible dementia.
- Reduce waiting times for the Leeds memory service, including short-term investment to address the longest waits for assessment.
- Review the local "shared care"arrangements for anti-dementia drugs.
- To review the Leeds 'pathway' for diagnosis from the experience of people with dementia and families, and make changes in response.
- To develop a Leeds model for post-diagnosis treatment and support, and a business case to develop and sustain it.
- To invest further in post-diagnosis support, for people living with dementia and families / carers.

3 Involving people and dementia-friendly Leeds

Each organisation is committed to the following principles:

- Ensuring that the work they do is planned and informed by the views of people with dementia and their carers, and showing evidence for this…

The National Dementia Declaration

Overview

3.1 Leeds has excellent examples of involving older people, people with long-term health conditions and carers in planning services. However, this is not an area of strength regarding people with dementia. It is important to support and develop local involvement and is part of our commitment to the National Dementia Declaration.

3.2 Leeds signed up in March 2012 to become a 'dementia-friendly' city, one of six announced at the launch of the Prime Minister's Challenge On Dementia. This will require a sustained approach over 1-2 years and beyond, working with the Dementia Action Alliance to define and achieve the standards set. At that same event, the Alzheimer's Society published the report Dementia 2012, including a national survey of experiences of living with dementia. Box 2 shows some examples.

BOX 2 – PEOPLE'S EXPERIENCES OF DEMENTIA

- 17% of people with dementia responding to the survey said that they are not living well with dementia at all, 55% said they are living quite well with dementia and only 22% said that they are living very well with dementia.
- 68% of respondents had a gap of longer than a year between noticing their symptoms and getting a diagnosis. 8% of respondents experienced five years or more from first symptoms through to diagnosis. (This could be caused by reluctance to acknowledge problems and seek diagnosis, as well as waiting for services).
- When asked if they lost friends after their diagnosis of dementia, 12% of respondents said yes, most of them, 28% said yes, some of them, and 47% said no. 4% of respondents reported that they haven't told their friends.

The top five solutions that people with dementia report could be done…:

- Better understanding of dementia and less social stigma attached (25%).

  People with dementia would like the following to have more of an understanding of dementia: family (54%), friends (58%), neighbours (51%), health and social care professionals (58%), people working in banks, post offices and shops (62%), the police (54%).
- More public awareness of the condition (17%).
- More local activities and opportunities to socialise (13%).
- More tolerance and patience from others (7%).
- More community spirit (7%).

Dementia 2012 report - Alzheimer's Society

3.3 The Dementia Friends initiative has been launched nationally, with the aspiration that by 2015, "we want there to be a million people with the know-how to help people with dementia feel understood and included in their community." This would be more than the population with dementia, and means some 15,000 'dementia friends' in Leeds.

3.4 The greatest barrier faced by people with dementia is probably stigma and negative attitudes to dementia. This probably arises from fear of the condition, misunderstandings and lack of knowledge. It is strongly linked to the attitudes and stigma faced by older people and people with mental health needs. Anecdotal local examples included a person being banned from a supermarket having forgotten to pay for some shopping; and a bus driver refusing to let someone on the bus, thinking they were drunk.

3.5 The physical environment is important, because dementia can affect the ability to understand visual and aural information and stimuli. Better lighting, clearer signage, and steps to reduce noise are becoming standard practice in care homes and hospitals, and could make a real difference beyond health and social care. Older people may have eg. sight and hearing loss as well as dementia, which exacerbates the difficulties. The tendency for shopping centres and supermarkets to be "branded" throughout the whole of their interior design, can, inadvertently, make important information blend into the background. We have a Leeds-based company, Find Signage, who supply the care sector with such signage, and belong to the Dementia Action Alliance. There is an opportunity to pilot dementia-friendly environment in eg. a local supermarket.

3.6 Leeds Library Services have already taken initiatives such as drop-ins at Pudsey and Armley Libraries, for people with concerns about dementia to seek advice. Libraries have resources for people to learn, take part in activities and have quiet space not far from busy centres in Leeds and local towns and suburbs.

3.7 The aspiration for dementia-friendly Leeds includes includes the city centre, inner city areas, and suburbs of Leeds itself; and the towns and villages within the local authority boundary. Any geographical community can sign up to work towards dementia friendly status, starting with involving local people to decide the priorities. A local initiative has started at Rothwell, to ask local shops and businesses to sign up, and to make good use of the local people who volunteer at the "Tea Pot" dementia café.

What we need to improve

- The benefits of developing and listening to the local voice of people with dementia, will be a well-informed approach to service development, in line with the principles of the National Dementia Declaration.
- The benefits of a dementia-friendly and aware Leeds, are that people will feel less stigmatised, more able to seek and find help, and be able to continue with day-to-day activities.

3.8 A local event was held during dementia awareness week on May 23rd 2012, with a strong emphasis on dementia-friendly Leeds. Leeds City Council's Chief Executive, Tom Riordan spoke about 'opening doors' with local business and transport services, and the Joseph Rowntree Foundation led a workshop discussion which shared learning from the "Dementia Without Walls" project in York. The initiatives proposed from this discussion were:

- Target a local supermarket to become dementia-friendly, including staff awareness, and practicalities such as seating. Since the event, Leeds Alzheimer's Society has made links and given awareness talks to local supermarket managers and staff.

- Intergenerational work; for example Bramley Elderly Action have worked with a local school to involve older people with dementia, in groupwork with children – sharing reminiscence, learning, playing games - at a local primary school.
- Consider a card or "passport", which can be shown as a way to obtain understanding and support.

3.9 People living with dementia have been involved in Leeds, in awareness-raising activity, and in saying what "dementia-friendly" Leeds might mean. However, there is not yet supported and systematic involvement of people and carers, to design and influence local services, or at Leeds Integrated Dementia Board.

3.10 Leeds City Council and Leeds Teaching Hospitals Trust have joined the Dementia Action Alliance at national level and in Yorkshire + Humberside. The Council's Executive Board have supported the formation of a Leeds Dementia Action Alliance, so that local businesses and organisations can sign up and commit to practical actions, however small.

Priorities

- Our local dementia awareness campaign (see previous section) to include messages that challenge stigma and encourage positive attitudes to dementia.
- The involvement of people with dementia and carers, properly supported.
- Start up the Leeds Dementia Action Alliance, and identify funding to run it effectively.
- Raise staff awareness and pilot dementia-friendly environments with local supermarkets, and transport companies.
- Develop more intergenerational work, eg. with local schools.
- Towns, villages and neighbourhoods to make a commitment to become dementia-friendly.

4 Integrated care and support for the dementia journey

Like many other long-term conditions, dementia presents challenges that require vigilance and co-ordinated working between health and social care.

Dementia Commissioning Pack, Department of Health, 2011

Overview

4.1 Dementia is a "long-term condition", defined as *health problems that require ongoing management over a period of years or decades* (World Health Organisation) or a *condition that cannot be cured but can be managed through medication and/or therapy* (Department of Health). It can cause our capabilities to change and decline over time, sometimes irreversibly because of the progress of the condition; but often reversibly, because a little support can make a great difference physically, psychologically and emotionally.

4.2 Dementia is much more likely to be found alongside other health conditions, rather than in isolation:

- In Leeds, 68% of people with dementia are aged 80 or over; and nationally, 55% of people aged 80+ have at least 3 long-term conditions.
- Data from Kent and Medway suggest that, of 1,350 people diagnosed with dementia, only 6% have dementia on its own; 60% have dementia with three or more other conditions.
- Data from Scotland suggest that 83% of people with dementia have at least one other long-term condition.

4.3 People with long-term conditions may require support from a range of health and social care services, including GPs and other GP practice staff (primary care); community nursing teams and roles such as community matrons (in Leeds provided by Leeds Community Healthcare NHS Trust); and specialist health services such as outpatient clinics. Long-term conditions may increase the risk of poor emotional, psychological and mental health. Health and social care organisations in Leeds are working together and investing in integrated management of long-term conditions. This approach is based on:

- Find Me – as well as diagnosis of conditions, an approach called 'risk stratification' helps to indicate who is most in need of support to prevent a deterioration in health and an increase in care needs;
- Enable Me – promoting "self-management", involving the person with the condition, family, community groups, and supported by staff;
- Support Me – integrated teams which work with people at the highest risk to well-being, to support health and social care needs.
- Decide with me, at all stages.

4.4 Leeds will be among the places piloting the "Year of Care" funding model in 2013-14, a new approach to funding services for people with long-term conditions. Dementia will be one of the conditions included in this approach.

4.5 It is important that people with dementia can benefit from these new approaches. However, people with dementia, families and carers tell us that advice and help is often difficult to find, not only at the initial stages of concern, but as dementia progresses. It can take a long time to find information and help, and life can be very difficult in the meantime.

4.6 The level of post-diagnosis support can be variable. A person with dementia who is prescribed anti-dementia drugs might stay with the memory service for some years, for medication review. However, this type of medication is not appropriate to treat vascular dementia; so the level of follow-up may differ. GP practices have an incentive to keep a register of patients diagnosed with dementia, and to carry out annual reviews with those patients, under the Quality and Outcomes Framework (QOF). But there is variation in how consistently this is done, and the format of the review. People diagnosed with dementia aged under 65, benefit from a specialist Younger Dementia Team as part of Leeds and York Partnership Foundation Trust.

> Of our older patients admitted with a hip fracture, many have dementia. Often this has never been diagnosed; and sometimes we find that the person had been diagnosed with dementia a few years ago, but hadn't had any support since then.
>
> *Consultant in medicine for the elderly, Leeds*

4.7 The Department of Health has proposed a service model in the Dementia Commissioning Pack (2011). It assumes clinical responsibility will rest with GPs, except during the formal diagnostic process and during acute admissions to hospital. It describes how GPs can be supported in this role via a service specification for dementia: better care at home, and in care homes.

4.8 The role of 'dementia advisor' has been piloted in 22 places around the country as part of introducing the National Dementia Strategy. Most areas which piloted the role have managed to sustain it, though the national evaluation is not yet published. Dementia advisor is not a qualified clinical role, but provides a named contact throughout the journey with dementia; someone who understands the system and how to refer and "signpost" on for further treatment, care and support. The Leeds branch of the Alzheimer's Society has created two part-time dementia advisor posts.

4.9 The following section, Families and Carers, refers to the model of Admiral Nursing, which is specifically a carer support role, providing advice and support throughout the dementia journey.

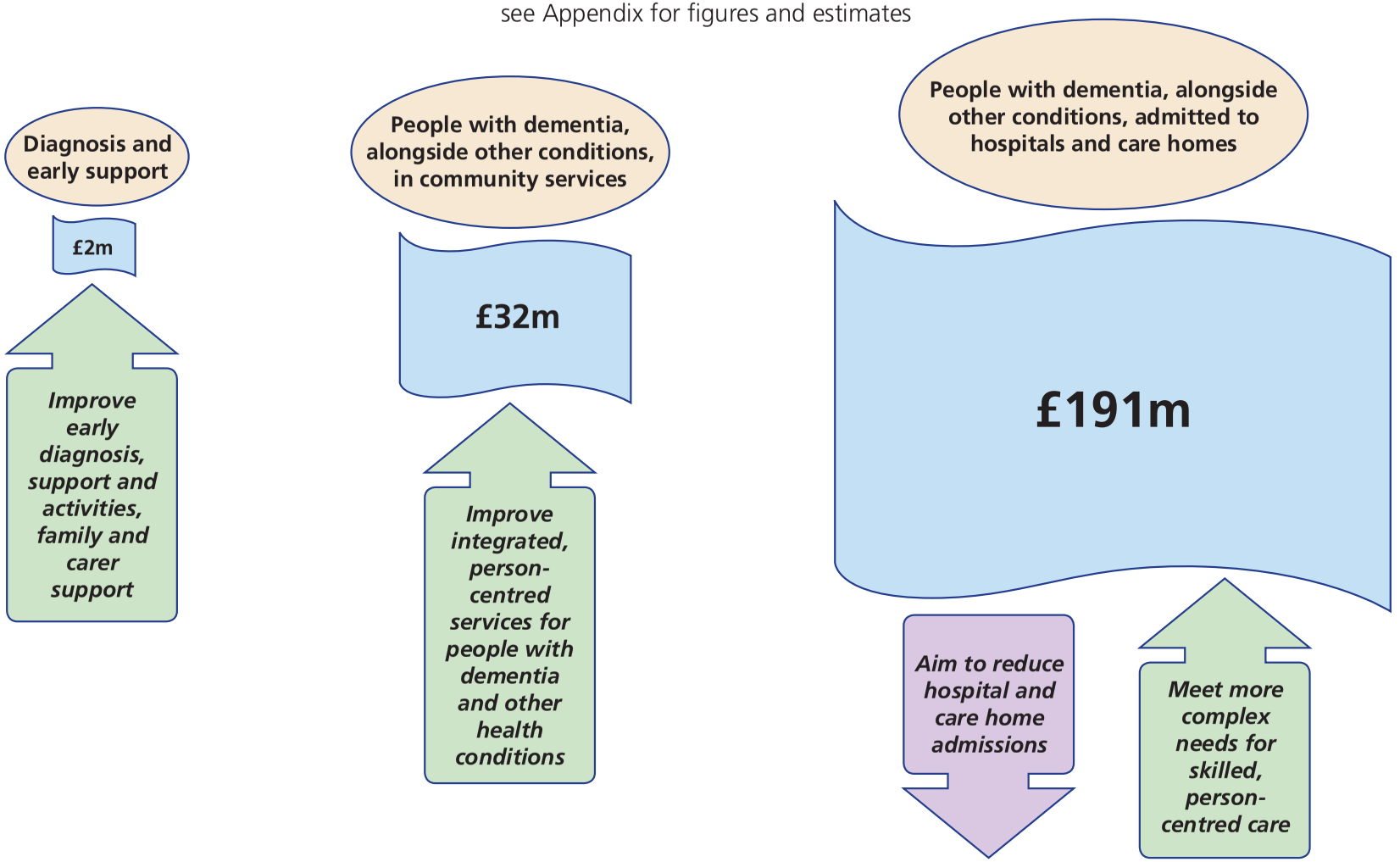
4.10 People who access services such as dementia cafés, carer support workers and dementia advisors, and other community support which includes people with dementia, can remain with these kinds of support for long periods. Therefore, the "early support" which starts after diagnosis, can provide support and a point of contact for the initial stages of the dementia journey.

4.11 Dementia is linked to high costs of health and social care. Nationally, there is evidence that people with dementia account for perhaps 25% of all hospital admission costs and 80% of older people's care home costs. This would total approximately £185m per year without including costs of care at home, specialist dementia inpatient beds, or accommodation; or the costs of unpaid caring and self-funded care which falls on families. Fig 4 summarises these estimates and compares to spending on other services. These costs are likely to increase, as the numbers of older people with dementia increase - in Leeds by approx. 2% per year. This indicates that to "do nothing" would be a very costly option.

Fig. 4:

Dementia in Leeds – estimated annual spend on selected services

see Appendix for figures and estimates



4.12 We will not reduce future costs of care by trying to tackle dementia on its own. It is important to have an integrated approach with other work going on in Leeds, to support people to live well with long-term conditions, and to reduce hospital and care home admissions. People at highest risk are likely to have other health conditions (co-morbidity) and frailty, defined as "an unstable state in which minor events – such as a urinary tract infection – can have major consequences such as delirium, falls or loss of mobility" [6] .

4.13 From April 2013 there will be an indicator shared between the NHS and adult social care outcomes frameworks. The Department of Health has funded research to inform the indicator, so the definition is not expected until 2014 at the earliest ; but it will be a measure of the effectiveness of post-diagnosis care in sustaining independence and improving quality of life for people with dementia.

What we need to improve

Benefits of integrated support for the dementia journey:

- People and families / carers will not be left alone with a diagnosis of dementia, and will have a route into support as the condition develops.
- We will promote well-being and independence as much as possible, and improve quality and experience of post-diagnosis care.
- It will support compliance with NICE quality standard for dementia.
- Work collaboratively to support people with different 'co-morbid' long-term conditions, maintain well-being and reduce future costs of care.

4.14 People with dementia and families / carers, need information, advice and guidance available at any point in the dementia journey. GPs have an important role and are often the first point of contact, but often require guidance and support from specialist NHS colleagues. This supports people to manage risks and crisis points as changes in the condition occur, and thereby reduce anxieties about coping in future.

4.15 People who have both dementia and other co-morbid conditions, which together cause higher levels of need and risk, do not consistently have good care from existing services. Services which provide eg. rehabilitation and preventive services do not all have staff with dementia awareness and skills, or ready access to support from dementia specialists; but neither are physical needs met by specialist mental health services. We already have a model of "liaison psychiatry" in hospital, which means clinicians can work together to treat physical and mental health needs. Community-based services have potential to benefit from a similar model.

Priorities

- Design of early support and "self management" services to ensure that they have capacity to meet needs for people in the mild to moderate stages of dementia, and routes to access specialist help when needed.
- A consistent standard of reviewing of people diagnosed with dementia and carers.
- Staff in primary care and community health and social care to have access to specialist support, training and advice, to better meet needs related to dementia.

[6] Prof Steve Iliffe, A Quick Guide To Commissioning Dementia Care, Pulse Today (2012)

[T] See Hansard, 26th Feb 2013, column 430-431W – answer from Norman Lamb to Hazel Blears. http://www.publications.parliament.uk/pa/cm201213/cmhansrd/cm130226/text/130226w0003.htm

5 Families and carers

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.
.....
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.

NICE quality standard for dementia

Overview

5.1 Carer support is addressed in national policy by Recognised, valued and supported – next steps for the carers' strategy (2010), and there are proposals to strengthen carers' entitlements to support and breaks in the White Paper Caring For Our Future (2012). Improving support for carers is essential to the well-being of carers, and people with dementia alike. The caring role is a very valuable one; at our Leeds dementia event in May 2012, a workshop on the needs of carers stated that carers should have high expectations and standards of services and support.

5.2 Caring for a person with dementia can be difficult, exhausting and frustrating, and even a few useful hints and tips can make a huge difference to the experience of caring. The experiences that families and carers find especially difficult include:

- The impact of dementia on individual and family relationships, social life and friendships
- If the person with dementia is unable to acknowledge the condition and their needs.
- Concerns about personal safety if the person is left alone.
- Lack of sleep if day-night orientation is affected.
- Frequent repetition of questions and conversations.
- If the person with dementia becomes frustrated and / or aggressive.
- Taking on financial affairs and dealing with legal arrangements.

Go with the flow - don't scold, don't contradict. Don't try and make things normal, because things may not be normal ever again.

Barbara Pointon, wife of the late Malcolm Pointon

5.3 Carers may take on the role of speaking up for the cared-for person, as mental capacity is affected by the progress of dementia. There are anecdotal examples of family carers being left out of assessments and discussions (eg. if not present at a hospital admission, or if a duty social worker is checking a referral on the telephone). The risk of omitting loved ones and carers from discussions is even greater if there is no official 'status' to a long-term relationship , e.g. for lesbian and gay older people.

5.4 Carers Leeds and the Leeds Alzheimer's Society have each recently appointed a dementia carer support worker, to strengthen our local offer of support. There are currently (March 2013) three carer support groups in Leeds for carers of people with dementia. The dementia café model in Leeds offers support to carers, who can attend alone, or with the person with dementia.

5.5 Leeds Shared Lives is a carer break service which involves a shared lives worker either coming to be with the person with dementia at home, or using the worker's own home as the base, so the carer can have a break. The carer can leave the house for a few hours, or overnight. The service is not exclusively for people with dementia, but in practice the model seems especially suited for, and is well-used by, people with dementia. The worker is selected by 'matching' for compatibility and shared interests, so the relationship can develop to feel like a natural and friendly one, and the person with dementia does not have to go into an unfamiliar environment. Leeds Shared Lives and other home-based respite provision has recently been supported through carer breaks funding via the NHS, with dedicated support to set up a direct payment arrangement to purchase the services.

5.6 Other carer break services are accessed via social care assessment including carers' assessment. Day care is valued by carers, and can offer sufficient support for a carer to remain in paid work. Short breaks, either with Shared Lives or in a care home ('respite care'), can enable a carer to go on holiday. Both these services mean that the cared-for person is away from home and from the family carer; for people with dementia especially, this requires a skilled approach to build trust and familiarity. Residential and day services in Leeds are going through a time of change, with some Council-run services having been closed, and further services having consultation about their future, at the time of writing.

5.7 The Admiral Nursing model is provided by Dementia UK, and is a service model aimed at supporting the carer to support the person with dementia. There is a national telephone helpline, (0845-257-9406; direct@dementiauk.org) but there are no Admiral Nurses in Leeds. Elsewhere in Yorkshire and the Humber, there are services in Kirklees (recently expanded to five posts), Hull, and North Lincs. The nurses are based with local services, eg. the local NHS mental health service provider, with Dementia UK providing support. It would require significant investment to create and sustain new posts in Leeds. We will listen to the views of local carers' organisations on this service model, and monitor its results in other areas.

5.8 Hospitals are expected to improve the identification and support of carers when people with dementia are admitted; there will be a financial incentive to do so from April 2013 as part of the dementia CQUIN (see section 9), which will reward hospital trusts for completing a monthly audit of carers of people with dementia to test whether they feel supported.

What we need to improve

The benefits of improving carer support and carer breaks:

- Carers are at less risk of becoming isolated and depressed.
- Carers can continue with social life, and have a life of one's own away from the caring role.
- Maintaining economic well-being, via paid work and / or benefit entitlements.
- Carers will be less stressed and better able to respond to the needs of the cared-for person.
- Services in Leeds will comply with the NICE quality standard for dementia.
- We will prevent crises and reduce costs of care.

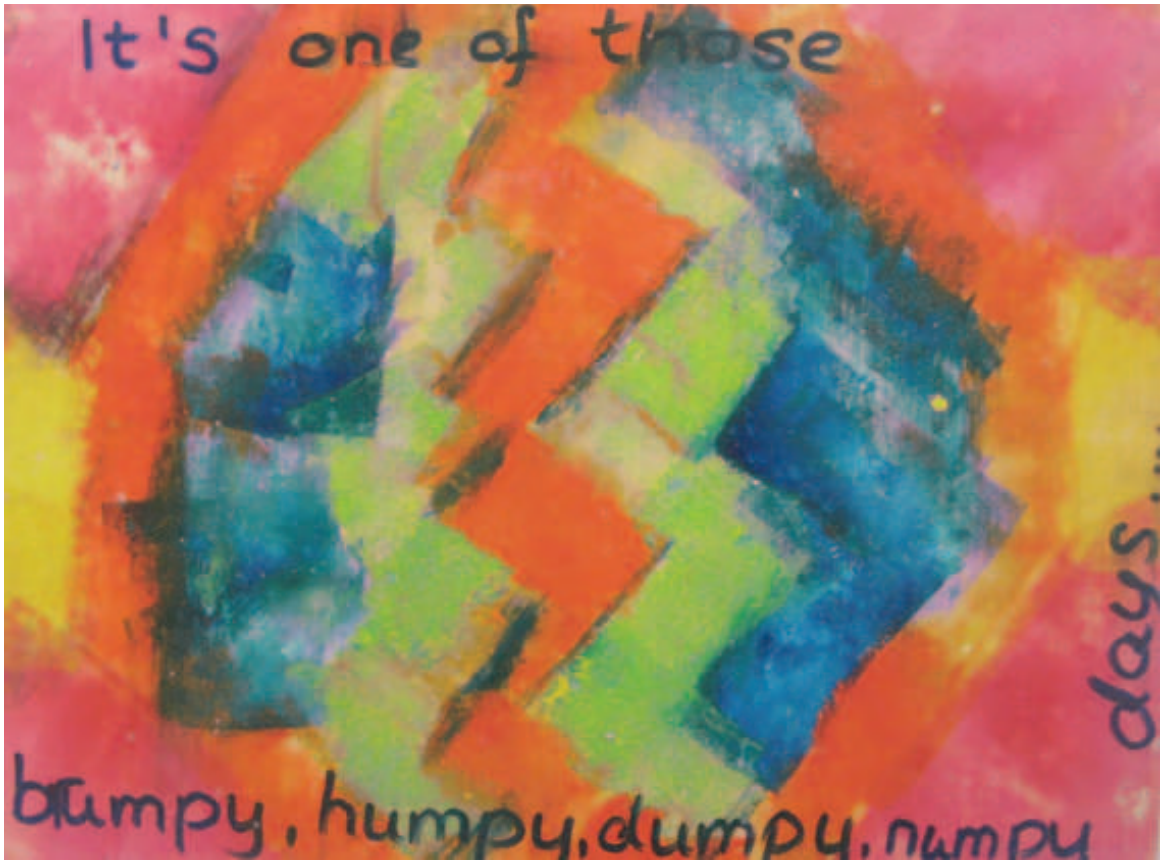
5.9 Leeds has services and groups for carer advice and support, for all carers and specifically for people with dementia. However, as with other self-management support, there is not yet a routine identification of carers and connection made to carer support. Carers comment that information provision could be improved, including information about the condition and how it progresses.

5.10 New investment has aimed to address with the waiting lists for Shared Lives and other home-based support, via the use of Direct Payments. There is a need to monitor that improvement has been achieved and is sustained.

5.11 There is reported lack of continuity in care home respite, when independent sector homes are used. This is because short respite breaks are purchased one at a time, and the availability of a bed cannot be guaranteed in the same care home. This can make it difficult for a carer to plan ahead.

Priorities

- development of self-management support and new investment (section 2), must include carer support, and improvements to information for carers.
- improve access to advice and support for carers, eg. to understand changes in a person's dementia, and develop coping strategies.
- improve the provision of carer breaks.
- the carers element of the hospital dementia CQUIN – carers feeling supported when the person cared-for is in hospital.



6 The workforce

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

NICE quality standard

Overview

6.1 The quality and sympathy of staff is crucial to the experiences that people with dementia have of treatment and care. The right values, attitudes, skills and knowledge are necessary to provide dignity and good outcomes from treatment and care. We need staff who understand dementia well, yet can see the person first and foremost, before the dementia.

6.2 Very simple and small changes can make a huge difference. For example, a person with dementia and sight loss might not understand that there is anything to eat on a pale-coloured plate with pale-coloured food; or be confident that an opaque plastic beaker contains anything they'd like to drink. People with even a mild dementia can become confused when unwell and admitted to an unfamiliar hospital setting. The skills and knowledge to understand people and how to respond can come from training courses, and from working alongside colleagues.

Our staff attended 'Food for Life' training and got the idea of using coloured plates for people with dementia, so the food on the plate is more visible than using a plain white or patterned plate. We tried this at the care home with two residents with dementia, and monitored weights for one month. They ate more and gained weight. For one of the gentlemen his nutritional intake improve so much over three months that his iron / vitamin medication was stopped.

Care home manager in Leeds, May 2012

6.3 The National Clinical Director for Dementia, Professor Alastair Burns, has suggested that health and care services need staff who are "100% dementia aware, 50% dementia trained, and 10% dementia specialist". This is a rule of thumb and will vary according to the nature of the service, but is a useful guide. A hospital ward or a care home must have all clinical and care staff, whether professionally qualified or not, competent to provide person-centred care. New ways of working, for example in integrated health and social care teams, will require new skills for working with people with dementia.

6.4 The NHS Operating Framework 2012-13 requires NHS providers to report on progress to the NICE dementia quality standard in their annual quality accounts. Commissioners are expected to ensure this is specified. Within the quality standard, the workforce statement is, arguably, the single one that all providers have in common, and within their direct control. Training of staff and leadership of ward teams is an element of the dementia CQUIN for NHS hospital trusts (see section 9) from April 2013. This means that there is a financial incentive attached to ensuring that there is clinical leadership and delivery of a training programme.

6.5 Staff and volunteers involved in well-being activities and services need dementia awareness and training. For example, ways of including people with dementia in mainstream activities; reminiscence work that helps a person feel validated rather than out-of-touch; supporting people to feel settled and join in. Training courses for volunteers and staff in voluntary and community groups, is being offered in January and February 2013, covering dementia awareness; training paid co-ordinators to train volunteers; inclusion in activities; and reminiscence work.

6.6 Dementia Care Mapping is a method for training staff to be person-centred in all interactions with people with dementia, and for managers to assess how well staff are relating to people with dementia. Leeds City Council has funded training for managers in its own services, and some independent sector care homes, and is bringing trained 'mappers' together to support each others' work. The Mount inpatient unit (run by LYPFT) has invested in training its staff in dementia care mapping.

6.7 Carers must, at times, be understood as part of the workforce. A carer is doing an important job, without ever having wanted or applied for it, and without any training. Carers and people with dementia can also contribute to paid staff training, to improve awareness and understanding.

What we need to improve

The benefits of improving workforce development are:

- People with dementia can be assured that staff have the right skills and knowledge.
- Carers are treated as expert partners.
- Services in Leeds will comply with the NICE quality standard.

6.8 A systematic approach is needed to ensure that Leeds health and social care providers progress to compliance with the workforce statement in the NICE quality standard. This is a major challenge across our NHS Trusts and over 100 private sector providers of domiciliary care and care homes.

6.9 There is a wide range of training available, including e-learning options for dementia awareness, but a lack of definition of what is a satisfactory standard, or how effectiveness is measured.

6.10 Dementia is usually experienced alongside other health conditions and disabilities ("co-morbidity") as described in section 4 above. The impact of this on care services, and the training needs of the workforce, is emphasised in the report The State of Health Care and Adult Social Care in England in 2011-12 (Care Quality Commission, 2013):

Overall CQC is finding that the increasing complexity of conditions and greater co-morbidities experienced by people are impacting on the ability of care providers to deliver person-centred care that meets individuals' needs. It is also seeing increasing pressures on staff, both in terms of the skills required to care for people with more complex conditions and in terms of staff numbers.

6.11 The workforce in community health and social work, including the integrated health and social care teams in Leeds, are responsible for care planning and co-ordination with people, families, carers and providers. There are skills needed to work in new ways to promote well-being and avoid admissions to hospitals and care homes.

Priorities

- Ensure all local NHS providers report on compliance with NICE quality standard, with high priority for workforce statement.
- Set and monitor workforce standards for social care providers; already included in care homes quality framework.
- Ensure Leeds Teaching Hospitals Trust plans achieve the workforce element of the dementia CQUIN.
- Consider local CQUIN incentives for other local NHS Trusts' workforce development.
- Run training for voluntary and community groups, and evaluate.

7 Emotional, psychological and physical well-being

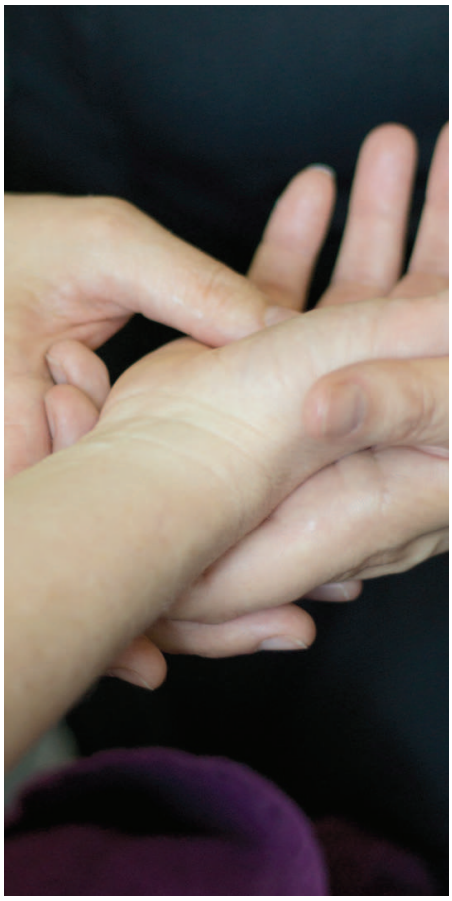
….the principles of person-centred care underpin good practice in the field of dementia care:

- 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.

NICE Clinical Guideline 42 – Supporting People with dementia and their carers in health and social care

Overview

7.1 Promoting well-being starts at the very beginning of the dementia journey. The risks to well-being are significant even for a person with mild dementia, and increase as the condition progresses. It can be especially harmful if every aspect of a person's difficulties is attributed to "dementia" as an irreversible and untreatable cause. People with dementia, as much or more than anyone else, suffer pain, boredom or loneliness; and struggle more to put it into words, or to do something about it. But the solution is nevertheless pain relief, meaningful activity, or company. The late Tom Kitwood at Bradford University led the way in promoting person-centred care, with psychological and social approaches to understanding and meeting needs.



7.2 Person-centred care includes:

- ✓ Meaningful activity
- ✓ Social engagement
- ✓ Access to health and well-being services

and this applies at all stages of the "dementia journey".

7.3 The "behavioural and psychological symptoms of dementia" (BPSD) is a term used to describe eg. agitation and aggression, but it is important not to over-medicalise this concept:
These symptoms can develop as part of the dementia, or they may be caused by a general health problem, for example, if the person is in pain or discomfort due to hunger, thirst or an infection. Symptoms can also be caused by problems related to the care the person is receiving, or their environment or social interactions. It is therefore very important to treat general health problems and pain and monitor changes in the person's living environment.

Alzheimer's Society website

7.4 The Right Prescription is an NHS "Call to action" (2011) to end the inappropriate prescribing of anti-psychotic medication for people with dementia. This is supported by a target to reduce prescribing of this type of medication by two-thirds for people with dementia. In Leeds, a series of audits have prompted GP practices and NHS Trusts to act to reduce prescribing according to clinical guideline, and measure whether this has been achieved. These medications can cause side effects such as increased risk of falls and stroke. The use of anti-psychotic medication in dementia remains part of the Clinical Commissioning Groups Outcome Indicator Set from April 2013.

7.5 There is evidence from projects that engage people in creative activities, that people can appear happier, talk more, and show less frustration and aggression. The inpatient wards at The Mount have run projects with The Wellbeing Centre, involving hand massage, and Artlink West Yorkshire, involving reading and creative art. If we are lucky enough to be healthy, we might see such things as 'add-ons' to services; but the less well one becomes, it may be that creative approaches and opportunities become essential for well-being.

I enjoyed having contact with my husband who usually struggles to speak to me

Carer, trained to give a simple hand massage, Leeds

She used to sit in the lounge all scrunched up and tense, leaning forward in her chair, ready to throw her juice at the next passerby. The staff said, 'Don't sit with her – she'll probably try to hit you'. So I sat down a safe distance away and said, 'I'm just going to try reading this poem. If you don't like it that's fine, but let's see what you think of it.' I read the poem through. She relaxed back in her chair, went very quiet, and at the end she said, straight away, 'read another'."

The Reader Organisation, Liverpool (from The Guardian, 5th October 2010)

By the time Barbara brought Malcolm home in 2000 he was barely speaking. Pointing to an oil landscape he painted on the wall she says: "There was a wonderful moment when he saw that painting, smiled his first smile for a long time and said 'Home'. There was a tremendous feeling of release and relief."

Interview with Barbara Pointon (from The Guardian, 12th December 2007)

7.6 Person-centred care concerns the whole of a person's daily experience. A short activities session, however enjoyable, may still leave many unoccupied hours in a day. Involvement in daily routines, and activities based on what a person can do are often beneficial. The approach of Dementia Care Mapping concerns the quality of daily interactions with others, and has been developed for care home settings and, more recently, domiciliary care / supported living.

7.7 People with dementia may have poor access to 'mainstream' health care, either because clinicians need specific support to work with the person, or because of misunderstandings and negative attitudes. Examples of important services would be testing and correction for sight and hearing loss; rehabilitation services; and psychological therapies for depression, for both people with dementia and carers.

What we need to improve

The benefits of improving well-being people with dementia include:

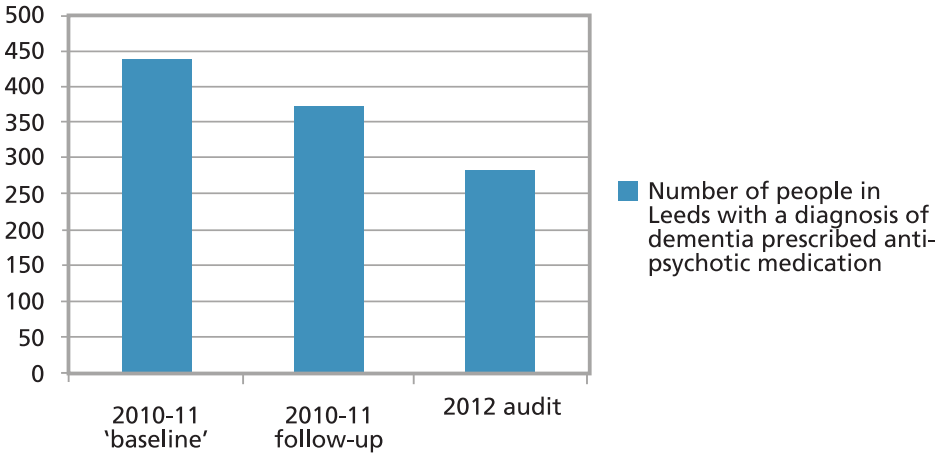
- better quality of life and sense of dignity;
- delaying the onset of care needs, reducing hospital admissions;
- reduced inappropriate use of anti-psychotic medication and side-effects;

More advice on how to reduce the decline – activities to exercise the mind, ways that the person is encouraged to do things for themselves, rather than just sat staring into space all day.

Son of an older person living with dementia, Leeds

7.8 A series of local audits has shown that anti-psychotic prescribing for people diagnosed with dementia has decreased over the past two years (Fig 5). This shows significant decreases have been achieved, and the 2012 audit requires each GP practice to plan actions to review patients. A follow-up audit has been carried out and results will be analysed in spring 2013.

Fig 5. Reduction in anti-psychotic prescribing in dementia.



NB:
- 2012 figure includes people aged 65+ on a low-dose anti-psychotic, who have not had a diagnosis of dementia recorded.
The Right Prescription estimated that 20% of people with dementia are prescribed anti-psychotics, which would equate to 800 people with a dementia diagnosis in Leeds.

7.9 To ensure good practice is embedded in Leeds, a task group has been established by the Leeds Dementia Board and Leeds Area Prescribing Committee, to produce a local guideline to include:
- local information about approaches such as improving person-centred care and "watchful waiting". Local audit showed evidence in only 43% of cases that such approaches had been tried before prescribing.
- improving clarity and handover at transitions of care, eg. between NHS Trusts and GPs, and geographical moves.

7.10 There is wide variation in care practice, which could be improved by support for families and carers, and training and development for the workforce. Staff may lack the time, skills and / or confidence, to improve standards of care. Enabling staff to spend time in positive occupation and stimulation, and responding to signs of loneliness and emotional need, could reduce the time spent reacting to agitation and aggression.

7.11 Opportunities for occupation and creative activity are limited. Recent small grants have promoted more opportunities run by community groups, including creative arts, singing and supported outings.

Priorities

- Task group to complete a Leeds guideline for management of "behavioural and psychological symptoms in dementia", including anti-psychotic prescribing.
- Workforce initiatives (section 6) must go beyond dementia awareness, to include competence to provide for emotional and psychological well-being.
- Promote and evaluate therapeutic and creative activities in community and care settings, including supporting applications for external funding.

8 Rights, risks, choice and control

We all face risk in our everyday lives and regularly make judgements, sometimes unconsciously, about risks and benefits for everyday actions. It is a challenge to tread the line between being overprotective (in an attempt to eliminate risk altogether) while respecting individual freedoms.

Alastair Burns, National Clinical Director for Dementia
Foreword to *Nothing Ventured, Nothing Gained – risk guidance for people with dementia* (2010)

Overview

8.1 People with dementia are at risk of losing self-determination and a sense of control over one's own life as dementia progressively affects the ability to understand information and make decisions independently. There is, however, a range of legislation and guidance that supports people's rights, and support available to manage risks. This section considers:

- mental capacity legislation.
- advocacy.
- support for personal safety.
- self-directed support in social care and health care.
- safeguarding procedures.

8.2 The principles of the Mental Capacity Act (2005) are:

- Every adult has the right to make his or her own decisions and must be assumed to have capacity to make them unless it is proved otherwise.
- A person must be given all practicable help before anyone treats them as not being able to make their own decisions.
- Just because an individual makes what might be seen as an unwise decision, they should not be treated as lacking capacity to make that decision.
- Anything done or any decision made on behalf of a person who lacks capacity must be done in their best interests.
- Anything done for or on behalf of a person who lacks capacity should be the least restrictive of their basic rights and freedoms.

Dementia often affects the ability to retain and analyse information, and understand the consequences of a decision; but the legal framework does not permit any kind of "blanket" approach to dementia and decision-making. It is wrong to assume that a diagnosis of dementia makes a person incompetent to make a decision. Furthermore, it is wrong to generalise when we might be competent to make some decisions, but less competent to make others.

8.3 People with dementia are among those most at risk of losing one's autonomy, and may require advocacy, defined by Action for Advocacy as *taking action to help people say what they want, secure their rights, represent their interests and obtain services they need*. There are different types of advocacy, all of which are important for people with dementia. "Statutory advocacy" describes specific services

which must be provided, including Independent Mental Health Advocate (IMHA) and Independent Mental Capacity Advocacy (IMCA). "General advocacy" describes a broader advocacy service, which is not directly specified by name in any legislation, but at the very least contributes to fulfilling equality duties regarding access to service provision.

8.4 From the beginning of the dementia journey, we are faced with a confusing and worrying situation, and difficult decisions to weigh up, which are very difficult to do alone. Therefore advocacy can be very helpful to support 'self-management' of dementia. Further on, the risks associated with dementia can lead to disagreements between the person and concerned family members, and indeed professionals; again advocacy can play a valuable role. In the later stages of dementia, people might have severe difficulties understanding information and expressing oneself, yet there are important decisions to be made about safety, treatment and care. This means that"uninstructed" advocacy may be important to make certain that decisions are taken with due consideration for their unique preferences and perspectives (Action for Advocacy).

8.5 The early stages of dementia can be an opportunity to make a Lasting Power Of Attorney, which can be drawn up to cover both financial affairs and / or health and welfare. It is a good idea for everyone to make a Lasting Power of Attorney (LPA), it can be done alongside making a will, and like a will, it can reduce complications and distress at difficult times for one's family. To make an LPA requires the capacity to make the necessary decisions, but it is activated when the capacity for relevant decisions is lost.

8.6 Staying safe and secure at home can be an early concern for people with dementia, and often a concern for families which the person with dementia might be less aware of. Anecdotally, it may often be the first thing that causes family members to think that a move to supported accommodation or residential care might be needed. However, there is a lot of help available to improve home safety. West Yorkshire Fire and Rescue Service offer fire safety checks for vulnerable people. West Yorkshire Trading Standards have recently obtained Lottery funding for work in Leeds and Bradford to prevent 'scams' and doorstep crime; they also work with local Neighbourhood Watch schemes eg. on "No Cold Calling" zones, for example in areas of Otley. The Leeds Telecare service provides devices which can eg. detect gas if a hob is left on and unlit, or whether a door has been opened in the middle of the night. Leeds Care and Repair can fit equipment and minor adaptations to reduce risk of falls, or improve home security.

8.7 Reablement, skills support and a specialist home care service are provided by the local authority's home care (domiciliary care) service. The majority of home care for older people, including older people with dementia, is from independent sector home care providers. The local authority purchases care only from providers which qualify via its "provider framework". When this is next tendered out, will be an opportunity to review and set standards for care of people with dementia.

8.8 Self-directed support is an entitlement for people who have needs and risks at which are eligible for social care services. This represents a real opportunity for people with dementia and carers, because 'traditional' care packages (home care, day care, residential 'respite' stays) do not always meet the needs related to dementia. For example, a person with dementia:

- may need help at unpredictable times, or someone on hand throughout the day, rather than the same tasks at regular times;
- may not trust others to help with personal care;
- may become agitated on a long journey to a day centre.

A Direct Payment or other form of personal budget can be used to design one's own package of care, and develop flexible arrangements with a personal assistant or care provider. Support is provided by the Leeds Centre for Integrated Living (CIL) through their ASIST service to eg. recruit personal assistants,

and set up managed bank accounts. People with dementia have used this scheme to develop self-directed support, though numbers are small at the moment.

8.9 Extra-care housing is a service model which combines one's own tenure of a flat, with 24/7 availability of care and support. It can offer an alternative to residential care; the opportunity for couples to stay together when one person has care needs; an enabling environment which can reduce care needs; and improved access to activities and stimulation. There is limited provision for people with dementia in two of the seven schemes in which Leeds City Council has been a partner. Future development is in the planning stages (at time of writing) and are an opportunity to ensure that people with dementia and spouses / partners are included in new developments, and the at new schemes can meet needs as dementia progresses.

8.10 People with dementia , along with other vulnerable adults, are covered by the arrangements under the Leeds Safeguarding Adults Partnership, for protection from abuse and neglect. All service providers must follow the agreed policy and procedures when there are safeguarding concerns. Dementia generally makes people more vulnerable and less able to speak out, therefore safeguarding can be a crucial service.

What we need to improve

The benefits of improving practice to support people's rights are:

- People with dementia do not experience violations of human rights and other legal rights.
- People with dementia feel valued.
- Treatment and care will work better, from being suited to individual needs.

8.11 The understanding of clinicians and care staff about people's rights, the mental capacity framework and advocacy provision.

8.12 Awareness and co-ordination of the support available to stay safe and secure.

8.13 More people with dementia to benefit from the opportunity for self-directed care, and the support to manage an individual budget; eg. to purchase home-based carer breaks, or a personal assistant to assist the person both at home and to go out.

8.14 There is local provision of extra-care housing for people with dementia, but a relatively small capacity.

8.15 Better understanding of safeguarding concerns and service complaints involving people with dementia.

Priorities

- Capacity for dementia advocacy services to increase provision, and promote awareness and uptake of advocacy, for people with dementia and carers.
- Information about practical help to be safe and secure, to be included in the post-diagnosis provision of information.
- Promote good examples of self-directed support and increase the numbers of people with dementia who benefit from it.
- Extra-care housing developments in Leeds to ensure suitability people with dementia, with the capacity to meet people's needs and prevent further moves to residential care.
- Understand what safeguarding and complaints information can tell us about dementia care standards and how to improve services.

9 The Right Care – people with dementia in hospital

Good care can make an incredible difference. On her first visit to hospital my mother received brilliant care. The kindness and skill of the hospital staff reassured and comforted her. However, when she was admitted for the second time no one even realised she had dementia. The doctor didn't have time to find her notes and was under the impression my mother had to go home to look after my father despite the fact that my father has been dead for five years.

Angela Rippon, foreword to Counting the Cost…, Alzheimer's Society (2009)

Overview

9.1 This section refers to people admitted to "general" or "acute" hospital, rather than to specialist inpatient units for people with dementia. This service in Leeds is provided by the Leeds Teaching Hospitals Trust (LTHT) at Leeds General Infirmary, St James Hospital, and by the smaller hospitals (which now have mainly eg. outpatient services, day surgery). Dementia is important because the condition, and sometimes lack of support with the condition, increases the risks of physical health problems developing and of hospital admissions. At any one time, it is estimated that 25% of hospital beds are occupied by people with dementia. This estimate has support from research evidence and is commonly quoted in national policy.

9.2 It is likely that this is caused by not only the numbers of people with dementia admitted to hospital; but also to the lengths of stay once admitted. In Leeds, there were developments in liaison psychiatry and intermediate care from 2006-10, which led to:

- improved detection of dementia (up 57% over the 4 years)
- reduced lengths of stay for people with dementia (down 30% over the 4 years).

Therefore Leeds hospitals may have fewer than the national average inpatients with dementia. Up-to-date data is required to verify this.

9.3 Acute hospitals have a financial incentive to improve the detection of dementia and provision of treatment and care. This is through the NHS Commissioning for Quality and Innovation scheme (CQUIN). The dementia CQUIN from April 2012 applies to people aged 75+, admitted 'unplanned' for more than 72 hours, and covers the process of "Find – Assess and Investigate – Refer" (FAIR) for detection of dementia and increase in diagnosis. The CQUIN from April 2013 will cover this FAIR process, plus staff training and leadership, and carer support.

9.4 Leeds Teaching Hospitals Trust has incorporated the FAIR process in its 'pathways' from Accident and Emergency admission through inpatient care to discharge. Each stage of the screening, assessment and referral process is built into existing documentation, and staff training has been rolled out across all departments. Generally, the referral route is to the GP, using the electronic discharge advice note (eDAN), recommending referral to memory clinic. The Trust is now meeting the 90% target for the CQUIN. Initial figures suggest this is producing 70 - 90 recommendations to GPs each month, to either refer to memory services or to assess further.

9.5 The Right Care is an NHS Call To Action to improve the experience and the results for people with dementia admitted to hospital.

- The environment in which care is given.
- The knowledge, skills and attitudes of the workforce
- The ability to identify and assess cognitive impairment
- The ability to support people with dementia to be discharged back home
- The use of a person-centred care plan which involves families and carers

9.6 The Care Quality Commission (CQC) states in its annual publication The State of Health and Adult Social Care in England in 2011-12, that in the coming year it will carry out a follow-up inspection programme looking at issues of dignity and nutrition in 50 NHS hospitals; and review information and data on dementia care during admissions to hospital.

What we need to improve

The benefits of improving hospital care for people with dementia will be:

- Better experience and well-being for people with dementia and carers".
- All hospital staff trained, more able to meet needs of people with dementia, and to feel satisfied with the care they're giving.

9.7 The Leeds Teaching Hospitals Trust long-term quality plan refers to the dementia CQUIN, but not to the broader aspects of care quality and people's experiences in hospital. The publication of The Right Care and ensuring compliance with NICE quality standard, are opportunities to promote a broader perspective on quality of dementia care. LTHT has designed and is implementing a training programme for all its staff, which has identified the different levels of traning required for the different staff roles within the hospitals.

Priorities

- Implement the *Call To Action – The Right Care* within Leeds Teaching Hospitals Trust (LTHT).
- Develop Dementia-friendly environments on wards used by older adults; this will require capital investment
- Formalise a care pathway to detect and manage dementia, delirium and depression.
- Ensure clinical leadership capacity to implement change, eg. through a lead nurse role.
- Implement 'Know Who I Am' document and ensure it is used and referred to, to plan and deliver high quality dementia care in hospital.
- To ensure compliance with NICE quality standard for dementia, in particular workforce statement (cf. section 6 of this document).

10 Specialist NHS services

A comprehensive dementia commissioning programme includes: .....specialist mental health care services for patients with dementia who present with behaviours that challenge, patients whose dementia is complicated by comorbid functional mental health problems, and those with complex diagnoses....
This service will have a strong community focus, but will have access to a limited number of inpatient beds.

Joint Commissioning Panel for Mental Health – Guidance for commissioners of dementia services

Overview

10.1 The Leeds and York Partnership Foundation Trust (LYPFT) provides a range of services, some of which are referred to elsewhere in this document:

- Memory service: This is a dementia-specific specialist service, and has been referred to in section 2 and elsewhere.
- Liaison psychiatry: Supports patients and clinicians in acute hospital settings, when there are both physical and mental health needs, and is referred to in section 9.
- Care homes liaison service: Supports people and staff teams to meet mental health needs, and is referred to in section 11.

This section covers the other specialist mental health services which people with dementia use. People living near the Leeds local authority boundary may be referred to neighbouring NHS services.

10.2 LYPFT has introduced important changes as part of its internal "transformation" programme, including:

- a Single Point of Access, so referrals come in on a single number, and are directed to the appropriate team or person.
- community teams which work with all adults, to replace separate services for "working age" and older adults.

10.3 There are three community-based specialist services for adults with mental health needs. Community Mental Health Teams are multidisciplinary teams which support people judged to be at highest risk / most complex needs, using the Care Programme Approach (CPA). Intensive Community Services (ICS) offer home-based interventions, including hospital discharge support; and a Crisis Assessment Service responds to urgent need.

10.4 LYPFT provides a specialist Younger People With Dementia Team, working with people whose onset of dementia is, generally, under the age of 65. There are specific needs such as parenting, employment, relative physical fitness, that benefit from a specialist multidisciplinary service, as recommended in the NICE clinical guideline (para. 1.1.2).

10.5 There is a dementia-specific inpatient service at The Mount, with the role to care for and treat people when the person is experiencing and presenting with severe and complex needs, and cannot be supported for safe assessment and treated in other settings. There are now (March 2013) 40 beds (20 in an all-male ward, 20 in an all- female ward), following the change of use of Asket Croft during

2012. This provision includes people who have been detained compulsorily under mental health legislation. The service is developing its environment, including a new garden area opened in 2012. The service has invested in 20 places for training in dementia care mapping (DCM) at Bradford University, and has two clinicians trained at practice development level DCM. This method aims to evaluate person-centred care, observing interactions with staff from the perspective of the person with dementia.

What we need to improve

Benefits of improving specialist mental health services include:

- Better integrated care for people with both physical and mental health needs.
- Better access to community support for people at home, or leaving hospital.

10.6 Better integrated working between specialist services and other community health and social care services (see section 4).

10.7 The new service configuration has meant that staff without experience of older people's mental health needs, are providing specialist mental health services for people with dementia. Therefore there are staff training needs within specialist community services.

10.8 Hospital-based clinicians have stated that the ICS team has not been able to offer the same levels of service for people leaving hospital, as the former Mental Health Intermediate Care Teams was able to. LYPFT review of the new services has acknowledged the need to ensure older people's access to services and increase the use of home-based treatment.

10.9 The service at The Mount is planning further environmental improvements, to develop use of the new garden area, promote better orientation and confidence around the ward areas, and improvements to bedrooms to promote good sleeping patterns.

Priorities

- Improving the skills of workforce to meet needs related to dementia, to ensure all-adult teams are compliant with NICE dementia quality standard.
- LYPFT recommendations following service transfomation – to improve the capacity of the all-adult teams to meet needs related to dementia, especially in people's own homes.
- Environmental improvements at The Mount, including bedrooms and ward reception areas. These will require capital investment.
- Better local understanding of specialist service provision via the dementia needs assessment.

11 Living well in care homes

It can be difficult for staff to know what is important for individual residents with dementia…. In the day-to-day bustle of 'getting on with the job', there is always a tendency for staff to resort to what they think a resident wants.

Put yourself in my place – Cantley and Wilson / Joseph Rowntree Foundation (2002)

Overview

11.1 It is estimated that 80% of older people living in care homes have dementia, with the proportion ranging from 50% in "mainstream" residential homes, to 100% in some specialist homes. This estimate comes from the Alzheimer's Society's *Low Expectations* report (2013), and revises the previous estimate of 65% (from their *Dementia UK* report, 2007). Although much of this strategy is concerned with promoting well-being and independence, and avoiding admissions, nevertheless the provision of good care in care homes is very important for people living with dementia and for families. Other sections of this strategy have specific relevance to care homes: workforce; rights, risks, choice and control; and emotional and psychological well-being.

11.2 Leeds City Council has introduced a new 'quality framework' to set minimum contractual standards for local homes, and offer a financial incentive for homes to invest in and demonstrate high standards, including working with people with dementia.

11.3 Leeds and York Partnership Foundation Trust (LYPFT) provides a care homes liaison service, which responds to requests from care homes and GPs to work with residents and develop care plans. A new service specification is being developed which aims to raise the standards of dementia care in the care home sector, and promote a skilled and confident approach which reduces the need for crisis intervention.

11.4 NHS support to care homes covers a wide range of conditions and initiatives in addition to and linked to dementia - such as end-of- life care and falls prevention. Leeds South and East Clinical Commissioning Group are introducing a "local enhanced service" for their GPs to provide an increased level of service for people in care homes.

11.5 Many local care home providers belong to the Leeds Care Association, which is represented on Leeds Dementia Board, as well as being a training provider linked to Skills for Care.

What we need to improve

The benefits of improving quality of care in, and support to, care homes, are:

- Improved well-being for people living in care homes;
- Families and carers will feel less anxious;
- Staff teams are more confident to meet needs and prevent crises occurring;
- Reduced admissions from care homes to hospitals.

11.6 There is wide variation in care home standards regarding quality of care and quality of life. Improving the quality of care homes means improving dementia care, across the sector and not just for specialist homes.

11.7 This is a real challenge for the care home sector, with the number of older people in care homes reducing as more people are supported to stay at home. As this trend continues, people living in care homes are more likely to be those with more complex needs. The *Low Expectations* report (see above) emphasises the constraints on public funding, the need to improve information for families, aspire to high standards, improve support from NHS services, reduce moves between care homes.

Priorities

- New service specification for care homes liaison (LYPFT).
- An integrated approach to care home support from health services.
- Developing the workforce (cf. section 6) to improve care standards.

12 End of life care

There are three ways in which people with dementia die:

- People who die from the complications arising from end-stage dementia
- People who may be in the early stages of dementia who die from another illness, e.g. cancer
- People who die with a mix of mental and physical problems. Dementia may not be the main cause of death but it interacts with other conditions.

Alzheimer's Society, position statement on palliative care, citing Cox and Cook, 2002

12.1 Dying with or from dementia is the experience of an estimated 1,500 people each year in Leeds. In common with palliative care for any terminal or long-term illness, the experience of 'a good death' is important for the person and for family and friends. The stigma attached both to death and to dementia, can make this difficult to discuss and therefore to achieve.

12.2 My life until the end – Dying well with dementia is an Alzheimer's Society report exploring the experiences of families, the importance of a "good death", and what this means with dementia.

It makes recommendations including:

- public awareness, promoting honest conversations and reducing stigma.
- care planning and decision-making, including planning well in advance.
- dignity, based on understanding and person-centred care.
- pain - the skills to both diagnose and relieve pain for people with dementia.
- decisions about withdrawing and withholding treatment, and the importance of specialist palliative care services.
- Emotional and spiritual concerns.
- Place of death.

12.3 People with dementia, especially at the late stages, might struggle to communicate feelings and symptoms, or to understand and co-operate with e.g. the usual methods for administration of medication.

12.4 The complexity of needs in the late stages of the condition, means that the majority of people die in a care home or in hospital. This may be the choice of the person and family, and is entirely appropriate when a care home has been the person's home for some time. However, unplanned admissions very near to end of life can be upsetting, and can often be prevented by community services.

12.5 This is best achieved where there is a shared understanding that the person is approaching end-of-life, and there has been the opportunity to agree with the patient (if possible) and family that the focus of care should be aimed around good symptom management and maintaining quality of life and dignity, not attempts at prolonging life at all costs. This information needs to be available , eg. via GP palliative care register, to all professionals involved so mechanisms can be put in place, including the availability of medications, to ensure patients can be cared for and die in the usual place of residence where possible.

12.6 Specialist palliative care services in Leeds have taken the lead to improve support for people with dementia near to end of life. In practice, this includes encouragement to consider Advance Care Planning at an early stage and the production of information for clinicians on the end of life signs ('prognostic indicators') for dementia; and how to recognise and treat end of life symptoms such as pain and nausea.

12.7 Bereavement for families and friends may be complex and difficult, and we need to understand local needs and how well services are supporting people. Support might come from families, friends or from providers who have been involved with the person during the dementia journey. The better we do at including people with dementia and families in social and community life during the dementia journey, the less isolated people will be in grief.

What we need to improve

The benefits of improving end-of-life care will be the opportunity for people with dementia and families to plan and prepare, more people experiencing a comfortable and dignified death, and avoiding preventable and undesirable moves near to end of life.

12.8 Very few people are supported to plan and prepare for the end of life when dementia is at a relatively early stage. It is not easy to raise the subject, especially when the emphasis is on living well with dementia and being positive about the condition.

12.9 There appear to be unnecessary admissions to hospital near to end of life. Hospitals can provide very good end-of-life care, but the Alzheimer's Society report (above) includes examples where people have died on noisy wards and staff did not, or were not able to, provide for a good death. A recent local audit of hospital admissions from care homes, from people who died in hospital in the end-stages of long-term conditions, showed poor evidence of advance care planning, which may have helped the person to remain at the care home.

Priorities

- Complete and introduce clinical guideline to detect and manage pain and other symptoms in later stage dementia.
- To ensure dementia is included in local plans to improve end of life care and planning.
- Advance care planning in the care home sector, and avoiding unnecessary admissions.
- Improve provision of advocacy to support care planning decisions.

Some people who have lost loved ones with dementia find that they grieve so much during the course of the illness that they have no strong feelings left when the person dies. Others experience a range of overwhelming reactions at different times. These may include:

- *numbness, as though their feelings are frozen*
- *inability to accept the situation*
- *shock and pain, even if the death has been expected for a long time*
- *relief, both for the person with dementia and themselves*
- *anger and resentment about what has happened*
- *guilt over an incident that happened in the past*
- *sadness*
- *feelings of isolation*
- *a feeling of lack of purpose.*

It can take a long time to come to terms with the person's death. Those who have been full-time carers for a long time will be left with a huge void when this role ends.

Alzheimer's Society Factsheet – Grief and bereavement

Appendix -

Spending on selected services for people with dementia – detail

People with dementia, alongside other health conditions, in hospitals and care homes

- People with dementia are an estimated 25% of hospital inpatients (Alzheimer's Society Counting The Cost report cites evidence for this figure). 25% of the local annual NHS spend on Leeds hospital admissions is **£120m**.
- People with dementia make up 80% of people in care homes. (Alzheimer's Society Low Expectations report cites evidence for this figure). 80% of Leeds City Council annual spend on care home admissions is **£65m**.
- Specialist inpatient beds for people with dementia – this service is allocated **£6m** of the overall contract funding for Leeds and York Partnership Foundation Trust.

Total estimate £191m

People with dementia in community services

- Leeds City Council spent £28.2m on older people's home care services in 2011-12. A study by the Public Social Services Research Unit (PSSRU) Community Support Services For People with Dementia (Challen et al 2010) found that 32% of people using their sample of services, had dementia www.pssru.ac.uk/pdf/MCpdfs/CSSr.pdf. There was no evidence comparing amounts or costs of care, so estimate assumes that dementia does not affect the average care package. 32% of £28.2m gives estimated **£9m**.
- Leeds Community Health received £127m funding for services to patients in 2011-12. NHS data for community nursing referrals suggests that two-thirds of referrals are for people aged 65+[1]. A conservative estimate has been made from this, that older people account for 50% of expenditure. It has been assumed that the profile of older people using the service is similar to home care, ie.32% have dementia. 32% of 50% of £127m gives an estimate of **£20m**.
- Leeds and York Partnership Foundation Trust contract for 2012-13 gave allocations of contract funding for older people's services, prior to the creation of all-adult teams. The total allocation for Older People's Community Mental Health Teams and Mental Health Intermediate Care was £5.2m. It has been assumed that people with dementia were 50-60% of caseloads. Estimate of **£3m**.

Total estimate £32m

Diagnosis and early support

- Spending on LYPFT memory services allocated from LYPFT contract funding 2012-13 was £1.3m.
- Total dementia advisor and carer support roles, dementia cafes, activities, and peer support: c. £600K.

Totals approx. £2m pa.

NB: *This is not a comprehensive 'map' of spending, but is intended to give a picture of the overall balance of expenditure.*

[1] http://webarchive.nationalarchives.gov.uk/20130107105354/http://www.dh.gov.uk/en/Publicationsandstatistics/Statistics/StatisticalWorkAreas/Statisticalhealthcare/DH_4092111

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Useful information

- Alzheimer's Society Factsheets http://alzheimers.org.uk/factsheets
- Symptoms and diagnosis – Alzheimer's Society info http://alzheimers.org.uk/site/scripts/documents.php?categoryID=200341
- Admiral Nursing Direct: www.dementiauk.org/what-we-do/admiral-nursing-direct/
- Leeds Directory www.leedsdirectory.org/ tel. 0113-391-8333
- This Is Me template- http://alzheimers.org.uk/site/scripts/download_info.php?fileID=849
- Making arrangements about mental capacity – e.g. lasting power of attorney https://www.gov.uk/power-of-attorney/overview
- Information about advance care planning www.goldstandardsframework.org.uk/AdvanceCarePlanning
- Information about cognitive stimulation therapy www.cstdementia.com/
- Leeds Centre for Integrated Living – support to use an individual budget for social care www.leedscil.org.uk/
- Advocacy for Mental Health and Dementia in Leeds - www.a4mhd.org.uk/our-services/
- Reducing the use of anti-psychotic drugs – Alzheimer's Society booklet - http://alzheimers.org.uk/site/scripts/download_info.php?fileID=1133
- Position statement on palliative care - Alzheimer's Society www.alzheimers.org.uk/site/scripts/documents_info.php?documentID=428
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- Quality Outcomes for People with Dementia (2010) www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_119827

- The Right Prescription: A call to ACTION on the use of anti-psychotic drugs for people with dementia (NHS Institute (2011). www.institute.nhs.uk/qipp/calls_to_ACTION/Dementia_and_antipsychotic_drugs.html
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- NICE dementia quality standard. www.nice.org.uk/guidance/qualitystandards/dementia/dementiaqualitystandard.jsp
- The Operating Framework for the NHS in England 2012-13. www.dh.gov.uk/prod_consum_dh/groups/dh_digitalassets/documents/digitalasset/dh_131428.pdf
- Dementia Commissioning Pack (DH 2011) www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/Browsable/DH_127381
- Using the Commissioning for Quality and Innovation (CQUIN) payment framework - Guidance on new national goals for 2012-13 (DH 2012) www.dh.gov.uk/prod_consum_dh/groups/dh_digitalassets/@dh/@en/documents/digitalasset/dh_133859.pdf
- Recognised, valued and supported – next steps for the carers' strategy – Dept. of Health (2010) www.dh.gov.uk/prod_consum_dh/groups/dh_digitalassets/@dh/@en/documents/digitalasset/dh_122393.pdf
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- Guidance for commissioners of dementia services (Royal College of Psychiatrists / Joint Commissioning Panel for Mental Health, 2012) www.rcpsych.ac.uk/pdf/JCP-MH%20dementia%20(March%202012).pdf
- Dementia Diagnosis Resource Pack (NHS COmmissioning Board / NHS South of England, 2012) http://www.dementiapartnerships.org.uk/wp-content/uploads/DPC-resource-pack-v1.pdf
- Long-term conditions and Year of Care model – presentation by Sir John Oldham (2013) - http://www.kingsfund.org.uk/sites/files/kf/sir-john-oldham-year-of-care-capitation-payments-jan13.pdf

A-Z of dementia

- The Alzheimer's Society's "A-Z" of "bite size information on a variety of dementia related topics": http://www.alzheimers.org.uk/site/scripts/az_home.php?categoryID=200361

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Appendix 3: Leeds Dementia Action Plan 2012-13

DRAFT – 1st May 2013

Key:

	completed
	in progress, on track
	agreed, yet to commence

Priority areas covered in this plan:	abbreviations
- Population needs assessment - Improve diagnosis of dementia - Improve post-diagnosis support for 'self management' - Involving people and dementia-friendly Leeds - Supporting families and carers - Integrated care and the dementia journey - Emotional, psychological and physical well-being - Rights, risks, choice and control - The Right Care in general hospitals. - Specialist NHS Services - End-of-life care	*CCG* – Clinical Commissioning Group *CQUIN* – Commissioning for Quality and Innovation – NHS incentive scheme, part of providers' contractual payments depends on achieving identified targets. *GP* – General Practitioner – your doctor. *KPI* – Key Performance Indicator. *LCC* – Leeds City Council *LCH* – Leeds Community Healthcare NHS Trust (NHS provider of community health services) *LTHT* – Leeds Teaching Hospitals Trust (NHS provider of acute / general hospital services) *LYPFT* – Leeds and York Partnership Foundation Trust (NHS provider of specialist mental health services) *memory service* – specialist service which takes referrals from GPs for people with possible dementia. Provides diagnosis, prescribing and support. *Primary care* – health services provided from your GP practice. *WRVS* – Women's Royal Voluntary Service

Priority area	Action	Outcome from action	Lead person / agency	When	Use of funding / resources	Funding agreed / needed	Status
Population needs assessment	Research and report data as identified in strategy document.	To address gaps in understanding of local needs and service use.	Bernadette Murphy – Public Health	to be decided	Part of needs assessment work for long-term conditions / older people.	-	
Improve diagnosis of dementia	Memory pathway review	Understanding of patient experience and blocks on the pathway from awareness, through diagnosis, to early support.	Judy Beckett – independent researcher	July 2013	Research team to gather and analyse patient experience and staff views.	£30K	
	Agree local CQUIN incentive for Leeds Community Healthcare (LCH)	Increased detection and referral of people with possible dementia, who are already known to community health services.	Leeds S+E CCG	April 2013	-	-	
	Improve LYPFT memory service with new investment and contract variation.	- Clearing of backlogs and reduced waiting times. - Coping with expected additional demand.	Leeds North CCG + LYPFT	April 2013	Investment agreed across all CCGs. To recruit additional clinical staff in memory services.	£400K pa.	
	Redesign 'shared care' between primary care and memory service.	- Improve experience for people with dementia and carers. - More consistent services.	Leeds North CCG – to lead Task Group.	December 2014	-	-	
	Local dementia awareness campaign	People in Leeds more likely to: understand help available; have positive attitudes to dementia; see GP with concerns.	Ayeesha Lewis, Public Health	November 2013	Costs of designing a campaign, events and publicity.	£30K	
	Pilot and evaluate pre-diagnosis support for south Asian older people.	Overcome barriers to seeking and obtaining diagnosis.	Touchstone Leeds	Sept 2013	support worker role.	£25K	

Priority area	Action	Outcome from action	Lead person / agency	When	Use of funding / resources	Funding agreed / needed	Status
	Training and support for GP practices.	- Better understanding and more consistent response from GPs.	CCGs	Sept 2013	Training and 'backfill'	£40K available	
Improve post-diagnosis support and 'self management'	Improve access to dementia cafes and activities	More services and activities accessible to local communities.	Leeds Alzheimer's Society	throughout 2013-14	Cafe development post (temp). Additional capacity to develop singing groups; activity start-up costs.	£28K £15K	
Involving people and dementia-friendly Leeds	Launch the Leeds Dementia Action Alliance.	Local businesses and organisations commit to actions which make Leeds more dementia-friendly.	Leeds City Council	July 2013	Capacity to co-ordinate the Leeds DAA, and work with local businesses and groups.	£25K	
	Dementia awareness training for relevant Leeds City Council customer-facing staff.	People with dementia and carers have sympathetic approach from all Council departments.	Leeds City Council	next 1-2 years	To train / brief staff	to be assessed	
	Dementia awareness week event	Local publicity and contribution to national awareness week; opportunities to involve people.	Leeds Involving People / Leeds Alzheimers Society	May 2013	venue, publicity, lunch.	£2K	
	Support Dementia-friendly neighbourhoods.	Initiatives in Rothwell, Otley and across the local authority area have support and can share ideas and learning.	Leeds City Council / Dementia Action Alliance.	continuing	small grants to support campaigning and publicity.	c.£5K	
Supporting families and carers	Improved access to "Carers Information and Support Programme" (a 4 session course).	Improved ability to cope for at least 40 carers, including clearing current waiting list.	Carers Leeds	through 2013-14	Sessional staff, resources, room hire, evaluation report.	£15K - £25K	

Priority area	Action	Outcome from action	Lead person / agency	When	Use of funding / resources	Funding agreed / needed	Status
Integrated care and the dementia journey	Three liaison staff roles to develop health and social care team skills, over 12-18 months.	Better outcomes from work with people with high levels of need, linked to dementia with other health conditions.	Leeds Integrated Health + Social Care Programme	to start c. Sept 2013	Time-limited staff roles.	£250K	
	Complete an analysis of hospital admissions and lengths of stay linked to dementia.	Improved understanding of where to intervene to improve outcomes and reduce costs.	to be decided	September 2013 ?	-	-	
Emotional, psychological and physical well-being	Complete and issue local guideline for agitation, aggression, use of anti-psychotics	Support to offer person-centred care; improved reviewing of anti-psychotics; reduced inappropriate prescribing.	Leeds North CCG	July 2013	Capacity to produce guideline; dissemination costs across Leeds health and social care economy	c. £25K	
	Implement and review new specification for care homes liaison.	A more confident and capable care home sector.	Leeds North CCG	throughout 2013-14	Continue the previous funding for development project, to sustain clinical staff roles; merge project team with existing care homes team.	£200K pa.	
The Right Care in general hospitals.	Achieving new dementia CQUIN scheme	- increased detection and diagnosis. - carers feel supported. - improved workforce and leadership	LTHT	April 2013 – March 2014	-	-	
	Delirium and dementia pathway design	improved recognition of symptoms and better outcomes for patients.	LTHT	Dec 2013 ?	LTHT and LYPFT liaison staff	-	
	Implement "Know Who I Am" document on wards.	People with dementia will have better care because staff will refer to personalised information.	LTHT	to be confirmed	-	-	

Priority area	Action	Outcome from action	Lead person / agency	When	Use of funding / resources	Funding agreed / needed	Status
	Volunteer support with nutrition	People with dementia drink and eat better, when prompting / support needed.	LTHT / WRVS	TBC	-	-	
Specialist NHS Services	Environmental improvements to The Mount	Improved quality of patient experience, more settled at night.	John Needham, LYPFT	March 2014	improvements to bedrooms and ward environment.	TBC	
	Review of dementia services post-transformation	- Dementia care skills improved. - Better access to home-based treatment.	LYPFT	through 2013-14	-	-	
End-of-life care	complete and disseminate local guideline for detection and management of symptoms at end of life.	better quality of care and dignity at end of life.	Specialist Palliative Care Services	Sept 2013	? dissemination costs	?	

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Appendix 4

Organisations contributing to the development of *Living Well With Dementia in Leeds.*

Leeds Integrated Dementia Board

Representatives from Leeds Alzheimers Society, Advocacy for Mental Health and Dementia, Carers Leeds, Leeds Older People's Forum, Volition (mental health network), 8 clinical leads and managers from the three Leeds NHS trusts (LCH, LTHT, LYPFT[1]); Chief Officer and Head of Commissioning, adult social care; Clinical Director, NHS Leeds North Clinical Commissioning Group; Specialist Palliative Care Services.

Leeds dementia event, May 2012

Event addressed by Christine Bailey, a person living with dementia.

Workshops at the event included:

- Dementia-friendly Leeds: led by Dementia Without Walls (York), with Joseph Rowntree Foundation, Leeds Alzheimer's Society, NHS Leeds Public Health.
- Staying safe and secure: led by Leeds City Council, with West Yorkshire Trading Standards, Neighbourhood Watch Otley, Care and Repair Leeds, West Yorkshire Fire and Rescue
- Early diagnosis and support: led by LYPFT Memory Services; Leeds City Council Peer Support Service; person living with dementia.
- Supporting carers: led by Leeds City Council carers' commissioner, Carers Leeds, Shared Lives Leeds.

Event attended by:

- 22 staff from adult social care
- 19 staff from independent sector care providers
- 27 neighbourhood network and third sector organisations
- 16 staff from NHS organisations.
- 5 people with dementia or carers.

Consultation on draft, July – Sept 2012

Written contributions:

- 8 short online questionnaire responses from family members / carers.
- 6 long online questionnaire responses from staff.
- Leeds Older People's Forum
- Advocacy for Mental Health and Dementia

[1] Leeds Community Healthcare NHS Trust; Leeds Teaching Hospitals Trust; Leeds and York Partnership Foundation Trust.

- Combined response from Armley Helping Hands, Bramley Elderly Action, Farsley Live at Home Scheme, Pudsey Live at Home Scheme, Stanningley and Swinnow Live at Home Scheme.
- West Yorkshire Fire and Rescue Service.
- Specialist Palliative Care Services.
- NHS Leeds Continuing Healthcare;
- Leeds Integrated Health and Social Care Programme lead.
- Social business event: current and potential service providers.

Meetings / events:

- LCC Adult Social Care Scrutiny Board
- Leeds Community Healthcare lunchtime seminar.
- Leeds third sector networks event, attended by: Advocacy for Mental Health and Dementia; Leeds Alzheimers Society; Anchor, Burmantofts Senior Action; Carers Leeds; Chapel Allerton Good Neighbours; Community Links; Health for All; Leeds Black Elders; Leeds Housing Concern; Leeds Irish Health and Homes; MAE Care; Neighbourhood Action in Farnley, New Farnley & Moor Top; OPAL (Older People's Action in the Locality); Relatives and Residents Association Leeds Branch; Shantona; Sikh Elders Service; Stanningley and Swinnow Live at Home Scheme; United Response; Leeds Library and Information Service.

Further meetings

- Dementia focus group – including clinical commissioners from all 3 Leeds CCGs; NHS Leeds; Leeds City Council adult social care; clinical leads from all 3 Leeds NHS provider trusts; Leeds Alzheimer's Society; Community Links; Integrated Health and Social Care Programme.
- Carers Leeds / carers commissioners.

Feedback which influenced the strategy:

- National statistics may underestimate dementia prevalence linked to health conditions such as diabetes and high blood pressure, in more deprived areas and some BME communities.
- People are experiencing very long waiting times for memory services in some areas of Leeds.
- Service provision should not depend upon diagnosis, because of the barriers to diagnosis and in particular the needs of families and carers for information and support pre-diagnosis.
- The need for information,eg. a "tube map" of the 'dementia journey' and services.
- The importance of sustaining and supporting carers; the difficulties carers have in remembering one's own needs, when having to speak up for the person with dementia.
- Receiving a diagnosis is very difficult, but sometimes life has already become very difficult before diagnosis, and it is the starting point for life to improve.

- Bereavement support for families / carers.
- Concern that policy priorities will lead to an increase the numbers of people diagnosed without then offering post-diagnosis support. Therefore local investment is needed.
- The 'third sector' has a key role at all stages of the "dementia journey", is already doing a lot, and is keen to develop services. Support is needed to involve people with dementia in 'mainstream' activities and services, eg. training for staff and volunteers.
- Consistent standards of support, and integration of health and social care are essential.
- The idea of "rights, risks, choice and control" to encompass the personalisation of care services, support for decision-making and potential impact of improving access to advocacy.
- Activities and occupation must not be seen as "extras" over and above basic care, they are essential to avoid boredom, frustration, "sat staring into space all day".
- Strategy document is helpful, but it needs an action plan / specifics / timescales.
- The strategy document is quite long, but people appreciated the information / description of local services.

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Appendix 5: Equality, Diversity, Cohesion and Integration Screening

As a public authority we need to ensure that all our strategies, policies, service and functions, both current and proposed have given proper consideration to equality, diversity, cohesion and integration.

A **screening** process can help judge relevance and provides a record of both the **process** and **decision.** Screening should be a short, sharp exercise that determines relevance for all new and revised strategies, policies, services and functions. Completed at the earliest opportunity it will help to determine:

- the relevance of proposals and decisions to equality, diversity, cohesion and integration.
- whether or not equality, diversity, cohesion and integration is being/has already been considered, and
- whether or not it is necessary to carry out an impact assessment.

Directorate: Adult social care	**Service area: Commissioning**
Lead person: Tim Sanders	**Contact number: (0113-) (24) 78923**

1. Title: Living Well With Dementia In Leeds					
Is this a:					
✓	**Strategy / Policy**		**Service / Function**		**Other**
If other, please specify					

2. Please provide a brief description of what you are screening
A strategy document that sets out a shared vision and priorities for improving services for people with dementia in Leeds. People with dementia and carers are supported by a wide range of services, provided by NHS trusts, private sector social care, local authority and third sector. Hence the need for a co-ordinated approach.

3. Relevance to equality, diversity, cohesion and integration

All the council's strategies/policies, services/functions affect service users, employees or the wider community – city wide or more local. These will also have a greater/lesser relevance to equality, diversity, cohesion and integration.

The following questions will help you to identify how relevant your proposals are.

When considering these questions think about age, carers, disability, gender reassignment, race, religion or belief, sex, sexual orientation and any other relevant characteristics (for example socio-economic status, social class, income, unemployment, residential location or family background and education or skills levels).

Questions	**Yes**	**No**
Is there an existing or likely differential impact for the different equality characteristics?	✓	
Have there been or likely to be any public concerns about the policy or proposal?		✓
Could the proposal affect how our services, commissioning or procurement activities are organised, provided, located and by whom?	✓	
Could the proposal affect our workforce or employment practices?	✓	
Does the proposal involve or will it have an impact on • Eliminating unlawful discrimination, victimisation and harassment • Advancing equality of opportunity • Fostering good relations	✓	

If you have answered **no** to the questions above please complete **sections 6 and 7**

If you have answered **yes** to any of the above and;

- Believe you have already considered the impact on equality, diversity, cohesion and integration within your proposal please go to **section 4.**
- Are not already considering the impact on equality, diversity, cohesion and integration within your proposal please go to **section 5.**

4. Considering the impact on equality, diversity, cohesion and integration

If you can demonstrate you have considered how your proposals impact on equality, diversity, cohesion and integration you have carried out an impact assessment. Please provide specific details for all three areas below (use the prompts for guidance).

- **How have you considered equality, diversity, cohesion and integration?**

(**think about** the scope of the proposal, who is likely to be affected, equality related information, gaps in information and plans to address, consultation and engagement activities (taken place or planned) with those likely to be affected).

The document refers to specific points relevant to 'protected characteristics' eg.

- dementia prevalence may be underestimated in more deprived areas and among some BME populations, and identifies this as a gap in our knowledge.
- dementia as a disability which affects equality of access to services;
- other health conditions that occur alongside dementia, and the effect on access to dementia services.
- barriers to detection, diagnosis and support, linked to stigma associated with older age and to mental health.
- specific additional barriers in BME communities
- the older age of people with dementia, and therefore the age of spouse / partner carers
- services failing to identify and involve carers in assessment and treatment – exacerbated if person with dementia is in lesbian / gay relationships.
- the risk of people being excluded from all decision-making by 'blanket' judgements about lack of mental capacity – the importance of advocacy to support decision-making, taking the person's wishes into account even if full capacity is lacking.

- **Key findings**

(think about any potential positive and negative impact on different equality characteristics, potential to promote strong and positive relationships between groups, potential to bring groups/communities into increased contact with each other, perception that the proposal could benefit one group at the expense of another)

- population needs research to improve understanding of prevalence across geographical and BME communities.
- dementia awareness-raising: messages and methods appropriate to diverse communities.
- support is needed pre-diagnosis to overcome barriers; diagnosis should not be a pre-condition of services. Pilot project is planned with third sector support for BME older people.
- services for diagnosis of dementia to move closer to primary care (GP practices) to reduce unnecessary appointments and improve access for people with multiple conditions.
- better information, support and breaks for carers; including coping with relationship changes and home-based breaks.
- priority to improve access to advocacy, including support to make and record advance decisions.
- defining consistent standards for post-diagnosis support.
- It is well-known that most carers (ie. unpaid carers, usually family members) are women. This is not directly referenced in the strategy document, but actions to support carers will benefit women.

These are addressed in the strategy document itself.
• **Actions** **(think about** how you will promote positive impact and remove/ reduce negative impact) The strategy document sets out the overall strategic approach and identifies positive actions to improve diagnosis and support for people with dementia and carers. It is complemented by a more detailed action plan to address the above findings.

5. If you are **not** already considering the impact on equality, diversity, cohesion and integration you **will need to carry out an impact assessment**.	
Date to scope and plan your impact assessment:	
Date to complete your impact assessment	
Lead person for your impact assessment (Include name and job title)	

6. Governance, ownership and approval Please state here who has approved the actions and outcomes of the screening		
Name	**Job title**	**Date**
Tim Sanders	Integrated Commissioning and Transformation Manager, Dementia	9th May 2013

7. Publishing This screening document will act as evidence that due regard to equality and diversity has been given. If you are not carrying out an independent impact assessment the screening document will need to be published. If this screening relates to a **Key Delegated Decision**, **Executive Board**, **full Council** or a **Significant Operational Decision** a copy should be emailed to Corporate Governance and will be published along with the relevant report. A copy of **all other** screening's should be sent to equalityteam@leeds.gov.uk. For record keeping purposes it will be kept on file (but not published).	
Date screening completed	8th May 2013
If relates to a Key Decision - **date sent to Corporate Governance**	13th May 2013
Any other decision – **date sent to Equality Team (equalityteam@leeds.gov.uk)**	n/a

Leeds Health & Wellbeing Board

Report author: Diane Hampshire
Tel: 0113 8435470

Report of: **Integrated Commissioning Executive**

Report to: **Leeds Health and Wellbeing Board**

Date: **22 May 2013**

Subject: **Key findings of the Mid Staffordshire inquiry report (Francis report), the Government's initial response, next steps and our local response**

Are there implications for equality and diversity and cohesion and integration?	☐ Yes	☐ No
Is the decision eligible for Call-In?	☐ Yes	☐ No
Does the report contain confidential or exempt information? If relevant, Access to Information Procedure Rule number: Appendix number:	☐ Yes	☐ No

Summary of main issues

1. The Sir Robert Francis Report highlighted a lack of care, compassion and leadership across the whole health economy, with a fundamental failure to deliver care quality within Mid Staffordshire NHS Foundation Trust.
2. This briefing paper summarises the key themes from the Sir Robert Francis Report and begins to consider how organisations in Leeds are responding to these findings and the role that various boards can play to ensure that lessons are learned and that quality and safety is upheld across the system.

Recommendations

The Health and Wellbeing Board is asked to:

- Receive the paper and note its contents
- To support the outlined next steps
- To receive an update on the proposed next steps in 3 months

1 Purpose of this report

1.1 This briefing paper summarises the key themes from the Sir Robert Francis Report following the public enquiry into the quality of care at Mid Staffordshire NHS Foundation Trust between 2005 and 2009. The paper also begins to consider how local organisations are responding to these findings, the next steps and the role of the health and wellbeing board in this context.

2 Background information

2.1 In 2010 an independent inquiry, chaired by Sir Robert Francis QC, examined the care provided by Mid Staffordshire NHS Foundation Trust between January 2005 and March 2009. The inquiry considered individual cases of patient care, so that further lessons not already identified by previous investigations could be learned. The independent inquiry reported on 24 February 2010.

2.2 A copy of this report is at http://www.midstaffsinquiry.com/documents.html. A range of other background information can be found on the previous inquiry's website at: www.midstaffsinquiry.com

2.3 In February 2013 Sir Robert Francis QC published his findings following the completion of the subsequent public inquiry into the care provided by Mid Staffordshire NHS Foundation Trust. A copy of the executive summary of the report, full copies of the inquiry and supporting papers can be found at http://www.midstaffspublicinquiry.com/

2.4 In summary, the report describes a lack of care, compassion and leadership across the whole health economy, with a fundamental failure to deliver care quality within the Trust.

2.5 The report highlights how all parts of the system contributed to this failure including the staff and Board of the Trust, commissioners and the strategic health authority, and the national bodies who regulate providers, such as the Care Quality Commission and Monitor.

3 Main issues

3.1 Key Themes from the Public Inquiry Report

3.1.1 The findings and lessons from the experience in Mid-Staffordshire have very significant implications for the whole of the NHS and can be summarised under five key themes highlighted by Robert Francis in his press statement, as follows:

- Fundamental standards of care with rigorous inspection and sanctions should be created. Standards to be defined by patients and the public and should include staffing matters. Non-compliance should not be tolerated.
- Openness, transparency and candour are essential, throughout the system. Every healthcare organisation and everyone working for them must be honest, open and truthful in all their dealings with patients and the public, and

organisational and personal interests must never be allowed to outweigh the duty to be honest, open and truthful.

- Improved support for compassionate caring and committed nursing are required. An increased focus on proper standards of nursing care and the caring and compassionate aspect of the nursing role is needed. There should be values-based assessment for entry to the profession and training must include hands-on education. Nurses should be given effective support and recognition, and be empowered to use the qualities of compassion, caring and commitment to maintain standards. Healthcare support workers need adequate training and regulation. No one should provide hands-on care if not properly trained and registered to do so.
- Strong and patient-centred leadership is needed. The report recommends that an NHS Leadership College should be established to promote common training for senior NHS staff. Leaders should be held to account for failures of care.
- Accurate, useful and relevant information should be available. More sophisticated information is needed to demonstrate compliance with fundamental standards. The Trust Board is accountable for compliance with fundamental standards and it should be a criminal offence to wilfully omit information.

3.1.2 The executive summary presents 290 recommendations for change within the NHS as a whole, based on the five themes, and all the supporting findings and analysis in the report. These recommendations span the whole of the culture, operations and regulation of the NHS.

3.2 Initial National Response

3.2.1 The government's formal response to the Francis public inquiry, 'Patients First and Foremost', was received published in March this year and sets out an initial overarching response on behalf of the whole health and social care system. Patients First and Foremost details clear key actions required to ensure that patients are the 'first and foremost consideration of the system and everyone who works within it'. This response acknowledges that between 2005 and 2009 in one hospital Mid Staffordshire NHS Foundation Trust, many patients received appalling care and the wider system established to identify and prevent poor care failed. It sets in context that many thousands of committed, caring and hardworking NHS Staff provide good or excellent care every day of the year. But the response is clear in that there are pockets of poor care elsewhere in the system and that the tragedy of Mid Staffordshire should never be allowed to happen again. It suggests that some of the features that contributed to the tragedy – patients and families ignored, staff disengaged or unable to speak up – point to wider problems.

3.2.2 The initial response sets out a five point plan which, it suggests, will revolutionise care within the NHS, putting an end to failure and issuing a call for excellence:

A. Preventing problems
B. Detecting problems quickly
C. Taking action promptly
D. Ensuring robust accountability
E. Ensuring staff are trained and motivated

3.2.3 The report suggests that delivering this response will end decades of complacency about poor care, ensuring that the system takes real responsibility for fixing problems urgently and effectively. Whilst it acknowledges that the Inquiry focused on acute hospitals, like Mid Staffordshire NHS Foundation Trust, it explicitly recognises that many of the messages from the Inquiry are equally relevant to other health and care settings. Issues such as the culture of care and the vital importance of listening to and being open with patients, their families and advocates apply across the health and care system. It makes the link that these sorts of problems were also identified in the terrible failures of care at the independent sector assessment and treatment unit, Winterbourne View.

3.2.4 A copy of the Executive Summary is available in Appendix 1.

3.3 **Initial Local NHS Response**

3.3.1 All local NHS organisations have held discussions and/ or taken papers on the Francis Report to their respective Boards/ Governing Bodies. NHS Providers have held listening exercises with staff to hear their views on the Francis Report and the Government's interim response. A citywide workshop hosted by NHS Leeds West Clinical Commissioning Group (CCG) on behalf of all 3 Leeds CCG's which will include representatives from each of the main providers to discuss the Mid Staffordshire Inquiry Report and the implications of the government's response will be held in June. CCG's have raised the findings of the reports in a number of different ways, talking to member practices and staff.

3.4 **Implications of the reports for the NHS and its stakeholders in Leeds**

3.4.1 One of the central messages to take from the Francis Report and Patients First and Foremost is the need to reinvigorate the very core of NHS values and culture, as enshrined in the NHS Constitution, and rebuild public confidence; confidence both in the quality of care that can be expected within NHS services, and confidence in the organisations held jointly accountable for the outcomes for patients.

3.4.2 In particular, the message that rings through the report is that the quality of patient care is paramount, and achieving a caring and compassionate service is everybody's responsibility.

3.4.3 The NHS has embarked on the response to Francis just at the point when the commissioning changes created by the passage of the Health and Social Care Act take effect.

3.4.4 While there is a need to examine the recommendations for organisation specific challenges and actions, there is also a "call to action" here for the NHS as a whole.

The initial response by the government goes further in that it details actions to ensure that patients are the first and foremost consideration of the health and care system and everyone who works within it. It outlines how a culture of compassion will be a key marker of success, hospital and care homes will be encouraged to strive to be the best; best values of dignity and respect will be central to care training; and if things go wrong patients and their families will be informed.

3.4.5 The establishment of commissioning organisations (including NHS England at national level, and local Clinical Commissioning Groups at a local level) has led to a range of new arrangements being created within the NHS which came into effect on a statutory basis from 1st April 2013.

3.4.6 It is important that in Leeds the local Health and Wellbeing Board, Healthwatch, and Scrutiny Boards understand the specific impact of these changes on roles and responsibilities with respect to care delivery and quality assurance.

3.5 **Safeguarding**

3.5.1 It is recognised that if the recommendations of both the Inquiry and the Government's response are implemented effectively, problems that might otherwise result in neglect or abuse of children or adults at risk of harm will be dealt with swiftly, preventing the need for the instigation of safeguarding procedures. Both the Leeds Safeguarding Adults Board and the Leeds Safeguarding Children's Board include all the NHS organisations as full members, and are keen to support the implementation of the recommendations.

3.5.2 Reports from each Leeds NHS organisation have been provided to the Leeds Safeguarding Adults Board. The Leeds Safeguarding Children's Board recognise that whilst the Francis Inquiry mostly related to adults, the implementation of the new "Working Together to Safeguard Children" guidance will require the Board to have a mind to the findings of the Francis Inquiry.

3.5.3 Given the changes within the structures and the challenge that Francis presents to tackle cultural change, it is important that a joint commitment is made by local NHS and Social Care leaders showing how a culture of care and compassion will be driven in Leeds and that there is public confidence in these developments.

3.5.4 It is therefore essential that:

- A clear, credible and coordinated approach is taken in Leeds to respond to the Francis report and the initial response from the government
- Assurance of quality and safety is secure in the new system
- New roles and responsibilities, especially within new commissioning structures, are clear
- Assurance is delivered in the context of improved democratic accountability in health.

3.6 **Proposed Next Steps**

3.6.1 It is proposed that a briefing is requested from the identified NHS and Social Care leads on quality assurance and safety in the health and care system. Quality and safety within the NHS are the responsibility of Executive Directors. Director Leads from within adult and children's Social Care have been or are being identified.

3.6.2 The requested briefing should be designed to enable discussion within the Health and Wellbeing Board and should include:

- A clear description of the roles and responsibilities for quality assurance within the new commissioning arrangements, including how local and regional level quality surveillance groups contribute to the arrangements
- A clear description of the roles and responsibilities for quality assurance within social care
- How local Boards will improve the transparency of care quality and quality assurance, through for example routine reporting in public board meetings and the process to produce and publish annual quality accounts.

3.7 **Clarifying Roles for Health Scrutiny and Health and Wellbeing Boards in Quality Assurance**

3.7.1 The role of the Health and Wellbeing Board does not duplicate existing commissioning roles and responsibilities in quality assurance but is necessarily concerned with the collective strategic intent and performance of local commissioning partners to deliver improved outcomes for health and wellbeing across the local population.

3.7.2 The Health and Wellbeing Board will therefore be concerned that the three key strands of NHS quality assurance (safety, effectiveness and user experience) are secure in the delivery of the Joint Health and Wellbeing Strategy, and if there are deficits to address, that these are being tackled through the appropriate governance routes, for example via the governance arrangements within individual commissioner or provider organisations, through accountabilities between these organisations contractually, or with the involvement of regulatory bodies.

3.7.3 There may be specific activities where the Health and Wellbeing Board will need to seek further information, feedback or assurance in the process of discharging its duties. The intention is that the NHS and Social Care briefing recommended above will promote this dialogue as well as provide an up to date picture about the quality assurance systems that operate in the NHS and Social Care landscape.

3.7.4 Local Healthwatch organisations will be similarly interested in the NHS and Social Care Quality and Safety Briefing, as they develop their relationships with local health and care organisations. The information and intelligence they gather with respect to consumer views and experiences will be a further strand of quality assurance and challenge within the system. Their representation at the Health and Wellbeing Board will ensure they are engaged in the work to shape the local response to the Francis report at the earliest opportunity.

4 Health and Wellbeing Board Governance

4.1 Consultation and Engagement

4.1.1 This paper was written in partnership between CCG and Council quality/safeguarding leads

4.2 Equality and Diversity / Cohesion and Integration

4.2.1 There are no specific issues in this paper

4.3 Resources and value for money

4.3.1 There are no specific issues in this paper

4.4 Legal Implications, Access to Information and Call In

4.4.1 There are no specific issues in this paper

4.5 Risk Management

4.5.1 Failure to understand and act on the implications and recommendations of the Francis report poses a threat to patient safety

5 Conclusions

5.1 The initial steps outlined above are intended to promote an early informed dialogue about the local response to the Francis report and the government's initial response, clarify roles and responsibilities for quality assurance, and to ensure a coordinated response within Leeds to improve the culture of care, compassion and transparency within our local NHS and Social Care Services.

6 Recommendations

6.1 The Health and Wellbeing Board is asked to:

- Receive the paper and note its contents
- To support the outlined next steps
- To receive an update on the proposed next steps in 3 months

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Appendix 1: Executive Summary

Introduction

1.

This document sets out an initial overarching response, on behalf of the health and care system as a whole, to the Mid Staffordshire NHS Foundation Trust Public Inquiry (the Inquiry). It details key actions to ensure that patients are 'the first and foremost consideration of the system and everyone who works in it' and to restore the NHS to its core humanitarian values. It sets out a collective commitment and a plan of action to eradicate harm and aspire to excellence.

2.

This is a watershed moment for the NHS and a call to action for every clinician, everyone working in health and care, and every organisation. Many thousands of committed, caring and hard working staff deliver good or excellent NHS care every day of the year. Yet in one hospital from 2005 to 2009 many patients received appalling care, and the wider system failed to identify the problem and then failed to share information and act on warning signs. This was unforgivable and must never happen again. Yet whilst the case at Mid Staffordshire NHS Foundation Trust was unique in its severity and duration, pockets of poor care do exist elsewhere and some of the features that contributed to the tragedy – patients and families ignored, staff disengaged or unable to speak up – point to wider problems.

3.

Robert Francis' first independent inquiry looked at what went wrong inside the Trust and reported in 2010. Since then, we have

taken action to strengthen the focus on the quality of care and the safeguards to protect patients from harm, including through the work of the National Quality Board, the Nursing and Care Quality Forum, the improved processes for Foundation Trust authorisation, and the introduction of dignity and nutrition inspections amongst many other measures.

4. But it is clear we now need to go further. This response starts from a simple premise and a simple goal – that the NHS is there to serve patients and must therefore put the needs, the voice and the choices of patients ahead of all other considerations. This response to the shocking findings of the Inquiry sets out a five point plan to revolutionise the care that people receive from our NHS, putting an end to failure and issuing a call for excellence:

A.

Preventing problems

B.

Detecting problems quickly

C.

Taking action promptly

D.

Ensuring robust accountability

E.

Ensuring staff are trained and

motivated

5. Delivering this response will end decades of complacency about poor care, by detecting and exposing unacceptable care quickly and ensuring that the system takes real responsibility for fixing problems urgently and effectively. It will drive coasting hospitals to improve and it will give greater freedom to care for the good and the excellent. It will

underpin the compassionate values of NHS staff with the right training and leadership needed to ensure consistently safe, effective and respectful care. It puts in place fair and robust systems to ensure that where organisations let patients, staff and the NHS down, there is proper accountability for those failings.

6. The recommendations of the Inquiry focussed on acute hospitals like Mid Staffordshire NHS Foundation Trust and so too does this response to the Inquiry. However, we know that many of the messages from the Inquiry are equally relevant to other health and care settings. Issues such as the culture of care and the vital importance of listening to and being open with patients, their families and advocates apply across the health and care system. These sorts of problems were identified not just in Mid Staffordshire NHS Foundation Trust but also in the terrible failures of care at the independent sector assessment and treatment unit, Winterbourne View.1

A. Preventing Problems

7.

Together the changes set out in this document will help to secure a consistent culture of compassionate care with patients' interests at its very heart. At local level, commissioners will work with hospitals to identify and tackle poor care. A Chief Inspector of Hospitals will shine a powerful light on the culture of hospitals, driving change through fundamental standards and national ratings which put the experience of patients at the centre of what the NHS does and the way in which its success is judged.

8.

The measures in this document – radical transparency, excellence in leadership, clarity of accountability, consequences for failure and rewards for the very best – will together put in place the action needed to revitalise the

culture of the NHS around a consistent focus on the needs of the patients it serves.

Time to Care

9. But to do so, leaders need time to lead and staff need time to care. In a busier NHS, we will ensure that paperwork, box ticking and duplicatory regulation and information burdens are reduced by at least one third. With a single version of the truth in the Chief Inspector's balanced assessment, there will be a single national hub – the Health and Social Care Information Centre – for collecting information, and it will have a duty to seek to reduce the information burden on the service year on year.

Safety in the DNA of the NHS – The Berwick Review

10. Professor Don Berwick, former adviser to President Obama, will be working with the NHS Commissioning Board to ensure a robust safety culture and a zero tolerance of avoidable harm is embedded in the DNA of the NHS.

B. Detecting Problems Quickly

Chief Inspector of Hospitals Making Assessments Based on Judgement as Well as Data

11. The Care Quality Commission will appoint a powerful Chief Inspector of Hospitals later this year. Armed with a sophisticated battery of information about hospitals from across the system, but, crucially, informed by expert judgements of inspectors who have walked the wards, spoken to patients and staff, and looked the board in the eye, the Chief Inspector will make an assessment of every NHS hospital's performance, drawing on the views of commissioners, local patients and the public. The Care Quality Commission will be supported by local Quality Surveillance

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Groups, encompassing all the key players in the system, so that there are effective arrangements in place to identify rapidly those hospitals where there is a risk or reality of poor patient care.

Expert Inspectors, not Generalists

12.

We will bring an end to the days of generalist inspectors briefly visiting organisations who often have little specialist insight into the organisations they visit. From this year, new and thorough expert-led inspections will get to the heart of how hospitals are serving their patients, exposing the poor, spurring on the complacent and celebrating the achievements of the good and the excellent. Just as OFSTED acts as a credible, respected and independent arbiter of the best and the worst in our schools, the Chief Inspector will shine a light on how our hospitals are serving our patients. The Chief Inspector will become the nation's whistleblower – naming poor care without fear or favour from politicians, institutional vested interests or through loyalty to the system rather than the patients that it serves.

13.

A ‘comply or explain’ approach to known good practices will be used in inspections. So, where there are well-established practices that benefit patients (for example nursing rounds, supervisory ward sisters, evidence-based staffing levels, and independent collection of patient experience data), inspectors will expect to see these being used across hospitals, or a valid explanation given if this is not the case.

Ratings – A Single Balanced Version of the Truth

14. We intend to give the Care Quality Commission the power to conduct ratings at the earliest opportunity and will work with the Nuffield Trust to develop these proposals further. Until now there has been a confusing welter of information about hospitals and the public cannot easily tell how well their local hospital is doing. In the future the Chief Inspector will ensure that there is a single version of the truth about how their hospitals are performing, not just on finance and targets, but on a single assessment that fully reflects what matters to patients. As in education, the Chief Inspector will make a balanced assessment of hospitals and give them a single, clear rating, which could be “outstanding”, “good”, “requiring improvement” or “poor”. Outstanding hospitals will be given greater freedom from regulatory bureaucracy. The Friends and Family Test for both patients and staff will be a vital component of the rating. Everyone in the system, whether regulator or commissioner, will use the same single set of data to judge success.

Chief Inspector of Social Care

15. There will be a new Chief Inspector of Social Care who will adopt a similar approach to social care and will be charged with rating care homes and other local care services, promoting excellence and identifying problems.

Publication of Individual Speciality Outcomes

16. A new spirit of candour and transparency will be essential for exposing poor care. In line with the Nuffield Trust recommendations, information about hospitals will not be limited to aggregated ratings but it will be possible to drill down to information at a department, specialty, care group and condition-specific level. As a starting point, the NHS Commissioning Board will extend the transparency on surgical outcomes from heart surgery, which has been hugely successful, to cardiology, vascular surgery, upper gastro intestinal surgery, colorectal surgery, orthopaedic surgery, bariatric surgery, urological surgery,

head and neck surgery and thyroid and endocrine surgery.

Penalties for Disinformation, and a Statutory Duty of Candour

17. Mortality data must be interpreted with care, but it must also be accurate so that the public and patients can trust that they are hearing an honest and fair account. So there will be tough penalties and we will consider the introduction of additional legal sanctions at corporate level for organisations that are found to be massaging figures or concealing the truth about their performance. A statutory duty of candour on providers to inform people if they believe treatment of

care has caused death or serious injury, and to provide an explanation, will reinforce the existing contractual duty.

A Ban on Clauses Intended to Prevent Public Interest Disclosures

18. Contractual clauses that seek to prevent NHS staff from speaking out on issues like patient safety, death rates and poor care will come to a halt. Staff who disclose such problems should be supported, not vilified.

Complaints Review

19. A review of best practice on complaints will ensure that when problems are raised, they are heard, addressed and acted upon, and seen as vital information for improvement rather than irritations to be managed defensively.

C. Taking Action Promptly

Fundamental Standards

20. The Care Quality Commission, working with NICE, commissioners, professionals, patients and the public, will draw up a new set of simpler fundamental standards which make explicit the basic standards beneath which care should never fall. This will be in language that both the public and professionals can easily understand.

Time Limited Failure Regime for Quality as Well as Finance

21.

In the past, when poor care was detected, it was too often put in a “too difficult” pile. Patients have been left with no one acting with urgency on their behalf to ensure a decent standard of care. This inaction must and will stop.

22.

The Chief Inspector will identify poor care in public, a call to action to the hospital itself, its commissioners and the organisations responsible for their oversight. Where normal commissioner engagement with local hospitals has been unable to address significant concerns about patient care, a new time-limited three stage failure regime, encompassing not just finance, but for the first time quality, will ensure that where fundamental standards of care are being breached, firm action is taken until they are properly and promptly resolved.

23.

In the first stage, the Chief Inspector will require the hospital board to work with its commissioners to improve, within a fixed time period, but the Care Quality Commission will not be responsible for making improvement happen. That will first be a task for the Board of the hospital, working with its commissioners. In the second stage, if the hospital with commissioners is unable to resolve its own problems, then the Care Quality Commission would call in Monitor or the NHS Trust Development Authority to take action. In the final stage, where fundamental problems in the hospital mean that

its problems have not been resolved, the Chief Inspector will initiate a failure regime, in which the Board could be suspended or the hospital put into administration, whilst ensuring continuity of care.

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24. The Care Quality Commission, the NHS Commissioning Board, Monitor and the NHS Trust Development Authority will be required to agree together the data and methodology for assessing hospitals. This will ensure a single set of expectations on hospitals of what is required of them which are aligned with the way in which commissioners, led by clinicians and guided by the views of local patients, ensure high quality care in the hospitals for which they are responsible. Providers will demonstrate, through annual Quality Accounts, how well they are meeting that single set of expectations.

D. Ensuring Robust Accountability

Health and Safety Executive to use Criminal Sanctions

25. Where the Chief Inspector identifies criminally negligent practice in hospitals, the Care Quality Commission will refer the matter to the Health and Safety Executive to consider whether criminal prosecution of providers or individuals is necessary. The Department of Health will ensure sufficient resources are available to the Health and Safety Executive for this role.

Faster and More Proactive Professional Regulation

26. The General Medical Council, the Nursing and Midwifery Council and the other professional regulators are hampered by an outdated legislative framework that is too slow and reactive in tackling poor care by individual professionals. As part of the implementation of the Law Commission's review, we will seek to legislate at the earliest possible opportunity to overhaul radically 150 years of complex legislation into a single Act that will enable faster and more proactive action on individual professional failings.

Barring Failed NHS Managers

27. To deal with the small numbers of managers who let their patients and the NHS down through gross misconduct, and prevent them from moving to new jobs in the NHS, we will introduce a national barring list for unfit managers, based on the barring scheme for teachers.

Clear Responsibilities for Tackling Failure

28. At a national level, these proposals, taken together, will resolve the confusion of roles and responsibilities in the system, so it is clear where the buck stops on poor care beyond the action that providers and commissioners take themselves. The Chief Inspector will identify failing standards in NHS Trusts and Foundation Trusts. Where necessary, Monitor and the NHS Trust Development Authority will resolve them with hospitals and their commissioners. The Department of Health will ensure that everyone plays their part on patients' behalf.

E. Ensuring Staff are Trained and Motivated

HCA Training before Nursing and other Degrees

29. Starting with pilots, every student who seeks NHS funding for nursing degrees should first serve up to a year as a healthcare assistant, to promote frontline caring experience and values, as well as academic strength. They will also provide students with helpful experience for managing healthcare assistants when they qualify and enter practice. The scheme will need to be tested and implemented carefully to ensure that it is neutral in terms of costs. Health Education England will work with the Nursing and Midwifery Council, professional leaders and trade unions in developing the pilots. We will

explore whether there is merit in extending this principle to other NHS trainees.

Revalidation for Nurses

30. Building on the historic introduction of medical revalidation, which offers proactive assurance of individual doctors, when the Nursing and Midwifery Council turns around its current poor performance we will work with them to introduce a proportionate and affordable national scheme to ensure all practising nurses are up to date and fit to practise.

Code of Conduct and Minimum Training for Health and Care Assistants

31. Camilla Cavendish is reviewing how best to ensure healthcare assistants can provide safe and compassionate care to patients. We are today publishing standards of conduct and training for all care assistants. The Chief Inspectors will ensure that employers meet their registration requirements that all health and care support workers are properly trained and inducted before they care for people.

Barring System for Healthcare Assistants

32. The Chief Inspector of Hospitals will assure, as part of inspections, that all hospitals are meeting their legal obligations to ensure that unsuitable healthcare assistants are barred from future patient care by properly and consistently applying the Home Office's barring regime.

Attracting Professional and External Leaders to Senior Management Roles

33. The NHS Leadership Academy, in addition to its existing work to ensure that top leaders have the right skills and the right values, will initiate a major programme to encourage new talent from clinical professionals and from outside the NHS into top leadership positions. From within existing resources, working with world class universities, we will develop an elite fast track programme for talented leaders outside the NHS to attract the brightest and best to top NHS jobs. In addition we will invest in MBA style programmes to ensure that clinicians with a talent for leadership are supported in becoming the clinical Chief Executives of tomorrow.

Frontline Experience for Department of Health Staff

34. At the centre of the system, the Department of Health will need to reconnect with the patients it serves. Within four years, every civil servant in the Department will have sustained and meaningful experience of the frontline with Senior Civil Service and Ministers leading the way.

Next Steps

35.

Key organisations across health and care will take the action needed to make this document a reality for patients and the Government will, as Robert Francis recommends, draw together a report on progress each year.

36.

In addition, all NHS hospitals should set out how they intend to respond to the Inquiry's conclusions before the end of 2013.

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Introduction

"Until the scandalous decline in standards is reversed, it is likely that unacceptable levels of care will persist and therefore it is an area requiring the highest priority. There is no excuse for not tackling it successfully. Much of what needs to be done does not require additional financial resources, but changes in attitudes, culture, values and behaviour."

Robert Francis QC

1.

This document sets out an initial response to Robert Francis' challenge to make patients 'the first and foremost consideration of the system and everyone who works in it'. It has been developed on behalf of the health and care system and in partnership with the signatories of the common statement of purpose above.

2.

The Inquiry's examination of the system's role in the appalling failures of care between 2005 and 2009 in Mid Staffordshire NHS Foundation Trust offers a stark, sobering and unpalatable analysis of a system failing to put patients first, a system that lost its way.

3.

At heart, Robert Francis' report2 is a powerful call to action on tackling invidious aspects of NHS culture that have arguably become more pronounced as the health service has become busier and the needs of patients more complex.

4.

Our NHS is rightly celebrated, performing incredible feats at the cutting edge of medicine and surgery. Its staff, in the vast majority of cases, are dedicated, skilled, kind and committed people. Yet in parts it is failing, sometimes atrociously, in the very basics of care: failing to ensure patients have food they can eat and water to drink; failing

to provide the correct dose of medicine or pain relief at the right time; too often failing vulnerable people; failing to listen to what patients and families say or to offer a kind word or hand when one is most needed.

5.

The essential diagnosis from the Inquiry is of an NHS that had veered, or was pushed, too far from its core humanitarian values and in too many places had its priorities wrong. Targets and performance management in places overwhelmed quality and compassion. Top down management instructions drowned out patient voices. Pressure to perform and fear of failure led to a controlling and defensive approach from organisations. Regulators, commissioners and others in the system became focused on their own roles and, in some cases, lost sight of the patients they were there to serve.

6.

The job now is to put the system back on track and to put in place sustainable measures to ensure that it continues to drive improvements. This means restating clearly our common purpose and binding principles – that quality is as important as finance, that patient interest comes before institutional interest, that we all work together in the interests of patients and are open and

transparent in our actions. Though Robert Francis' report focuses particularly on nursing and medicine, it is a call to action for the whole clinical workforce and everyone who works in health and care.

7.

Although the Inquiry and this response focus primarily on NHS hospitals the core messages are applicable to all staff working throughout the health and care system, whatever the setting. The failures of care identified at Winterbourne View Hospital – a hospital far away from Mid Staffordshire NHS Foundation Trust both geographically and in the nature of its services – demonstrated that the interests of patients need to be foremost, whatever their individual needs and wherever they are cared for. This call for action is as applicable to staff working in an independent hospital or treatment unit for patients with mental health problems or learning disability as it is for staff in an acute hospital.

8.

Robert Francis' report makes clear that changing organisational culture is pivotal to achieving meaningful change. Transforming the health and care system cannot be done from Whitehall and it cannot be done overnight. This response states a collective commitment to facilitate this transformation and early actions, but it is for every part of the health and care system to think, talk and act with drive and ambition to tackle avoidable harm and enable compassionate care. In supporting this transformation, each hospital in the country has been asked to hold listening events with its staff to reflect on Robert Francis' report and consider how to safeguard the core values of compassion and care in a busy NHS.

9.

Alongside his overarching critique of culture, Robert Francis has drawn out five key themes under which the majority of his recommendations sit: values and standards; openness, transparency and candour; leadership; compassion and care; and information.

Action Since the First Inquiry

10. The Department of Health and national agencies have acted on many of these areas both during the Inquiry and since it finished hearing evidence in December 2011. For example:

(a)

Values and standards – the NHS Constitution has been revised to give more prominence to values and the Care Quality Commission has increased its number of compliance inspectors, and improved their training. All inspections are now unannounced to strengthen the assessment process for essential standards. In addition, Patient Led Assessment of the Care Environment (PLACE) assessments will start in April 2013 with local people going into hospitals as part of teams to assess how the environment supports patients' privacy and dignity, food, cleanliness and general building maintenance.

(b)

Openness, transparency and candour

– actions include strengthening the protection and support available to whistleblowers, including a right to raise concerns within staff contracts; the amendment of the NHS Constitution to include explicit rights and pledges on whistleblowing; new guidance to employers; the extension of the national helpline to include staff in social care; the strengthening of the annual NHS Staff Survey, and making crystal clear that compromise agreements should not stop staff speaking out on matters of public interest. In addition, the NHS Standard Contract for 2013/14 will include a contractual duty of candour on all providers to be open and honest with patients when things go wrong with penalties for breaching this duty.

(c)

Leadership – the NHS Leadership Academy was established in 2012 and

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is already supporting system leaders through a range of programmes. In addition, the Professional Standards Authority for Health and Social Care has published standards for members of NHS boards and Clinical Commissioning Group's governing bodies that put respect, compassion and care for patients at the heart of leadership and good governance in the NHS.

(d)

Compassion and care – Compassion in Practice3 (the nursing, midwifery and care staff vision and strategy for England) was launched in December 2012. It is based on the values and behaviours of the "6Cs" – Care, Compassion, Competence, Communication, Courage and Commitment. Over the

last three months nurses, midwives and care staff, as well as stakeholders at national and organisational level, have developed implementation plans to support the delivery of the values and behaviours of the “6Cs”. In addition, the Government has announced a £13 million innovation fund for the training and education of unregulated health professionals and Skills for Health and Skills for Care have been developing minimum training standards and a code of conduct for healthcare support workers and adult social care workers in England.

(e)

Information – from April 2013, a network of local and regional Quality Surveillance Groups (QSGs) will bring together commissioners, regulators, local Healthwatch representatives and other bodies on a regular basis to share information and intelligence about quality across the system and proactively spot potential problems. Also from April 2013, Quality Accounts will include comparable data from a set of quality indicators linked to the NHS Outcomes Framework including the summary hospital-level

mortality indicator, infection rates and reported levels of patient safety incidents. More generally, the Power of Information4 sets out the Department’s ten-year framework for transforming information for health and care.

11.

In addition, we have published our response to the events at Winterbourne View in Transforming Care: a national response to Winterbourne View Hospital and a programme of transformation is underway including reviewing care placements and supporting everyone inappropriately in hospital to move to community-based support. A Joint Improvement Programme led by the Local Government Association and NHS Commissioning Board has been set up to support this transformation in care.

12.

There is much more to do under each of Robert Francis’ themes and most of the recommendations in Robert Francis’ report we accept, either in principle or in their entirety. This report, six weeks on, is not, and could not be, a full response to each and every one of Robert Francis’ 290 recommendations. As he notes ‘some recommendations are of necessity high level and will require considerable further detailed work to enable them to be implemented.’ To rush ahead would mean that they would not be given the full and collective consideration they deserve and would limit the clinical engagement and patient and public involvement that will be so important. The report, therefore, provides an overarching response, setting out key early priorities.

13.

We recognised also that there are vital questions implied by the report findings about how we ensure older people get excellent treatment care and support when they need it to help people stay in good health throughout their lives, maintain control and independence, and avoid or postpone needing hospital treatment or long-term

residential care. This response focuses particularly on urgent priorities to ensure safe, compassionate care in hospitals, and we will take forward further work later this year on improving prevention, integration and primary care to help keep more people out of hospitals.

14. Over the coming months, many of the organisations who have contributed to this response will produce their own action plans and we expect that everyone will respond to the Inquiry's first recommendation to set out how they will act on the Inquiry's recommendations. All NHS hospitals should also set out how they intend to respond to the Inquiry's conclusions before the end of 2013. This autumn, we will publish a document drawing this together into a system-wide update on progress and next steps. We will continue to ensure Robert Francis' report drives real change, reporting annually on our progress and where we need to take further action.

Leeds Health & Wellbeing Board

Report author: Colin Mawhinney
Tel: 0113 3781150

Report of: **Leeds and Partners**

Report to: **Leeds Health and Well Being Board**

Date: **22nd May 2013**

Subject: **Leeds Innovation Health Hub**

Are there implications for equality and diversity and cohesion and integration?	☐ Yes	☐ No
Is the decision eligible for Call-In?	☐ Yes	☐ No
Does the report contain confidential or exempt information? If relevant, Access to Information Procedure Rule number: Appendix number:	☐ Yes	√☐ No

Summary

1. Key partners in the health sector have been working to establish Leeds as a leading city for health and innovation. Success could significantly improve the health and wealth of the city by improving services and increasing jobs and investment.

2. In the short time since its creation the Leeds Innovation Health Hub under the leadership of Leeds and Partners has, in seeking to safeguard and improve patient outcomes, sought to understand the best means to draw investment into the city and has produced some early wins in doing so.

3. The next stages of the work will be crucial to building further momentum to deliver real transformation in the City's record and reputation as leading in health and innovation. In shaping these messages for audiences both inside and external to the city it will also be crucial for partners to speak together in support for the direction and pace of travel.

Recommendations

The Health and Wellbeing Board is asked to:

- Note the contents of this report and support the core proposition of the Leeds Innovation Health Hub to establish the City as a leading international centre for health and innovation.

1 Purpose of this report

1.1 Key Partners in the health and care sector have been working to establish Leeds as a leading city for health innovation. Success could significantly improve the health and wealth of the city by improving services and increasing jobs and investment.

1.2 This report provides an update on progress and an overview of the key opportunities being developed. The report then goes on to explain how the city's ambition will be achieved.

2 Background information

2.1 The city's Growth Strategy, a framework for driving economic growth and jobs, identified the health sector as having untapped potential based on its assets and opportunities in relation to the Health and Social Care Act 2012. A sector group was formed, the Leeds Innovation Health Hub (LIHH), to develop good working relationships with both private and public sector organisations.

2.2 Leeds and Partners joined the LIHH group in June 2012 and have since been asked to act as chair. Leeds and Partners was established by partners in Leeds to promote and raise awareness of the city and attract foreign direct investment and increase trade to support economic growth. It will do this by targeting sectors with greatest potential for growth including Health. Leeds and Partners provide the lead in shaping the work of the Leeds Innovation Health Hub and in facilitating its engagement with investors.

2.3 The LIHH has, in seeking to safeguard and improve patient outcomes, sought to understand the best means to draw investment into the city and has produced some early wins in doing so.

2.4 In August 2012 the group commissioned a report from Ernst and Young to map key assets in the health sector and to define the points of differentiation upon which its leadership in health innovation could be established. This work has been essential to the development of a credible sector proposition and has clearly identified four areas where Leeds has a competitive advantage, these are: health informatics, medical technology, engaging communities and leadership of change.

2.5 These advantages could confer benefits both separately and together as a platform for investment in the city. Feedback from investors indicates that no other city is as well placed to offer such widely distributed strengths across the 'care continuum' connecting pre-treatment health prevention , treatment and post treatment activities and making the emerging programme much more than simply technical or social driven innovation but a powerful blend of both to effect significant improvements in outcomes

2.6 The emerging LIHH vision can be realised both by the establishment of a network of stakeholders across a 'health ecosystem', working collectively to deliver health and wealth outcomes. The health ecosystem is to be understood as commissioners, providers, patients and their communities, but also including companies and investors servicing the health sector. These may be based in other 'priority' sectors such as finance, professional services, digital and advanced manufacturing. Their inclusion in the health ecosystem reflects the interdependent structure of the Leeds economy.

3 Main issues

3.1 LIHH is continuing to gain traction and momentum across both public and private sectors and includes Leeds City Council, the Leeds Teaching Hospitals NHS Trust, Universities, the Community Healthcare NHS Trust , the three Clinical Commissioning Groups, the NHS Commissioning Board and the NHS Information Centre, EMIS (representing Health Informatics sector) and Surgical Innovations representing the medical technology sector. The LIHH Executive Group is facilitated by Leeds and Partners has formed two working groups:

3.2 **The Health Informatics Working Group:** Led by Jason Broch, Chair of Leeds Health Informatics Board, and working to the Board's mandate the working group includes commissioners, providers and representation from local private sector companies. This group is working towards the creation of a single electronic patient record by end 2014 and, using this technology, aim to lever maximum benefits and value for patients, the City Council and the NHS. This would be over one year earlier than the pledge given for this target to be delivered nationally by 2016 by the Secretary of State. An announcement is expected in respect of progress towards this milestone by July 2013.

This work is being developed within the clear guiding principle that patient records will remain confidential and therefore secure.

3.3 **The Medical Technology Group:** Working with emerging technologies and engaging closely with the Health Informatics Working Group, the University of Leeds and a range of stakeholders this group are facilitating expansion and relocation space for companies in the medical technology sector sector.

3.4 **A Community Engagement Working Group** is currently being established and with be supported through the URBACT 4D Cities project. This, emerging, working group includes representation from Leeds City Council, Leeds Community Healthcare NHS Trust and Health Watch (Leeds) and will focus on ensuring opportunities for participation (including jobs) and benefits arising from growth in Health Informatics and Medical Technology sectors feed through to local communities.

3.5 A further key finding of the Ernst and Young study indicated that achieving the Vision at scale and at pace in a sector currently marked by fragmentation and uncertainty will require the development of a 'special purpose vehicle' together with a Programme Director and supporting team. This will provide the flexibility needed to respond quickly to investment opportunities and also provide a mechanism to draw funding down from government grant programmes.

3.6 Emerging Opportunities

3.7 This activity is already attracting interest of a number of potential inward investors and influential stakeholders, including specifically:

3.8 **Hosting visits from a major health informatics and diagnostic systems provider, investor and manufacturer of diagnostic instruments**. They are based in the US and have expressed an interest in coming to Leeds (with both systems services and manufacturing) and are still considering the city in the context of other options.

3.9 **NHS England – Award for Pilot Status for interoperable patient record systems**. The delivery of a Single electronic patient record is a priority for NHS England. They will be announcing a selection process in the next few weeks to choose up to six towns and cities in England to host pilots which would assess systems for interoperability. The Health Informatics Working Group will be submitting a bid for the City to be selected as one of the hosts.

3.10 **Surgical Innovations:** with support from the Leeds Innovation Health Hub Group have secured funding from RGF2 which will see the firm catalysing a health technologies hub for the city and create 300 new jobs. The company have committed to establishing this facility in Leeds thus creating further opportunities for the city to host a cluster of similar medical technology companies.

3.11 **Depuy Synthes**: have recently been successful with an application for RGF 3 to support investment in a Product Development Centre in Leeds. Whilst the programme is not directed towards an overall increase in the Company's 500+ workforce in Leeds it will open opportunities to expand the number of apprentices through normal levels of staff turnover.

3.12 **EMIS and TPP:** both Leeds based companies with leading market shares in patient records have been rapidly expanding over recent years and creating hundreds of new jobs. Engagement with EMIS and TPP has, in turn, led to deepening collaboration with public sector commissioners of health services based in the city resulting in the formation of the Health Informatics Working Group referred to above. Taken together these companies have a key role in supporting delivery of the Leeds Care Record based on the creation of open standards to facilitate integration of information. EMIS and TPP have both agreed

to work to these standards and will work in partnership with commissioners to deliver other leading edge projects to improve services to patients.

3.13 **The NHS National Leadership Centre:** the NHS Leadership Academy has already established its headquarters in Leeds and is proposing a further investment for a National Centre for Leadership in the city centre. The proposal is for a major facility providing leadership courses for visitors from across the UK. The forecast includes 25,000 delegate training days and giving a major boost to the city centre economy if the proposal is approved by the NHS England. Leeds and Partners are providing a lead is supporting the proposal.

3.14 **Health Education England**: a new Leeds-based NHS national organisation, responsible for £5bn of health spending and employing about 1800 people across the UK with numbers of jobs still to be finalised for Leeds. They are interested in emerging proposals for a virtual hub and co-locating on a new ' health' park.

3.15 **Health Watch England**: have confirmed that they will have as yet (unconfirmed) number of staff based in Leeds. These staff may be small in number but will have significant influence and could play a part in the development of the health ecosystem.

3.16 **BIS Regional Growth Fund**: A bid has been submitted for £8.5 m funding support from the Department of Business Innovation and Skills to deliver a portfolio of innovative health related projects valued at £52m. These projects will be undertaken to attract inward investors to establish new operations in Leeds. Taken together the projects will deliver 680 new jobs in the health sector

3.17 Working with the UKTI in the US Leeds and Partners are working with Anne Avidon, US Sector Lead, Healthcare Vice Consul and the local Y&H UKTI team on a programme of activity for 2013-14 for this sector. This will include a 'webinar' to raise awareness of the Leeds health sector proposition in the US with input from members of LIHH, the hosting of a delegation of Medical Technology businesses from Massachusetts in Leeds, a US road show led by Leeds and Partners with key stakeholders and businesses which will target other US destinations with strengths in this sector.

3.18 Next Steps for the Leeds innovation Health Hub Group

3.19 A Delivery Framework including an application for RGF4 is to be completed by end June 2013. This plan will define the networks, structures (including a proposal for Special Purpose Vehicle), facilities, investment funds, a programme of activities and outcomes required to realise the Vision. The work will also feed a separate application and bid to deliver an Advanced Health and Medical Leadership Network including services to be located in the city's Aire Valley Enterprise Zone.

3.20 A Conference and Events Programme supporting our work to establish the city as a centre for new thinking and policy on the future of health and applies those ideas to transform its own health system. such as:

- An International Symposium on 'Cities, Health and Wealth' a conference planned for September in partnership with the NHS Confederation of Employers
- A Leeds presence at AdvaMed 2013, Washington: the premier inward investment exhibition and 'showcasing' event for international Life Sciences
- An international seminar on Community Engagement in Leeds Eco system Funded by EU URBACT programme and organised by the URBACT 'Local Support Group'

4 Health and Wellbeing Board Governance

4.1 Consultation and Engagement

4.1.1 Consultations to date have been conducted directly with partners on a project by project basis. However the following consultations are planned to discuss the Leeds Innovations Health Hub's Delivery Framework

- 1st May Virtua (USA)– Demonstration of Interoperable systems in operation
- 23th May Leeds and Partner's Board
- 10th June CCG Leads
- 20th June LCC Leadership Management Team & Executive Leads
- On-going – regular consultations with UKTI

4.2 Equality and Diversity / Cohesion and Integration

4.2.1 The Leeds Health and Well Being Board's Terms of Reference include a commitment to promote integration and it is in this respect that the emerging programme of LIHH could make the most significant contribution to the Joint Health and Wellbeing Strategy going forward.

4.2.2 The objectives of the LIHH include the overall aim of the Health Hub is "To improve the health and wealth of all the people who live and work in Leeds"

4.2.3 The priorities are:

- To achieve improved health and social care outcomes for the population of Leeds

- To maintain and further enhance the international reputation for Leeds as a centre of excellence for innovation in health and medical technology

- To attract inward investment and encourage local enterprise and business opportunities through innovation in health and medical technology

4.2.4 It should be expected that realisation of these objectives will contribute significantly to the reduction of health inequality in the city

4.3 Resources and value for money

4.3.1 As indicated above Leeds and Partners will be submitting bids for further funding from the Department of Business, Innovation and Skills to support its programme of work. This will provide the basis for further match funding from public and private sectors.

4.4 Legal Implications, Access to Information and Call In

4.4.1 There are no legal implications for the Health and Wellbeing Board arising from this briefing.

4.5 Risk Management

4.5.1 A initial risk assessment will be undertaken on as part of the emerging Delivery Framework and will be reported through the appropriate channels. A summary of the key risks and key issues has been provided below.

Risk	**Issues**
Governance	It is critical that the work and priorities of LIHH remains aligned to those of both the City Council and Partners involved. This will be picked up separately at a meeting of the Council's Leadership Management Team on 20th June
Inability to identify appropriate leadership and sponsorship of programmes of work	Adoption of Innovation is identified in the Health and Social Care Act and in policy documents published by BIS and Department of Health as critical to changes going forward. Success will be determined by the degree to which Partners provide commitment and leadership in support of this.
Safeguarding Patient Data	New Technologies may alter the use and flow of information including patient records It is essential that safeguarding data at the level of the individual should be hard wired into the design and implementation of any new systems.
Giving away proposition value and revenue rights,	Similarly as new investors, or partners become involved in the delivery of innovative new systems it is essential that the commercial value of knowledge generated should be protected in the interests of the city and its communities.
Pace. Too slow Involving large and complex range of stakeholders slows down delivery or Too fast and loses support	Following new legislation and the threat of budgetary pressure on services it will be important to set the pace of innovation and change at a level that will deliver investment timed and at a level that will safeguard and improve patient outcomes

5 Conclusions

5.1 The Health and Social Care Act 2012 provides for a new emphasis on the importance of innovation in delivering better health services offering improved value for money. In this respect innovation has a key role to play in plugging the investment gap emerging in different parts of our health service and which, in turn, may require new players with funding and expertise to come to the table.

5.2 In the short time since its creation the Leeds Innovation Health Hub under the leadership of Leeds and Partners has, in seeking to safeguard and improve patient outcomes, sought a focus on innovation in health and thereby leverage inward investment into the city

5.3 The next stages of the work will be crucial to building further momentum to deliver real transformation in the City's record and reputation as a leading one for health and innovation. As indicated in paragraph 2.5 and 2.6 the potential outcomes of investment in health are much greater than the sum of the parts. Advancement in Health Informatics is more than simply having the best in IT equipment and literacy but will provide the first step towards a larger ambition to deliver a city and population that is digitally enabled across a wider range of services including transport and education. In shaping these messages for audiences both inside and external to the city it will also be crucial for partners to speak together in support for the direction and pace of travel.

6 Recommendations

6.1 The Health and Wellbeing Board is asked to:

- Note the contents of this report and support the core proposition of the Leeds Innovation Health Hub to establish the City as a leading international centre for health and Innovation.

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