## **Shadow Health and Wellbeing Board**

Friday, 1st February, 2013 in Cabinet Room 'C' - County Hall, Preston, at 2.00 pm

## Agenda

## **TEA, COFFEE AND BISCUITS**

Available from 1.45pm

- 1. Welcome from the Chair and overview of the agenda
- 2. Apologies for absence
- 3. Minutes of the meeting held on 18 October 2012 (Pages 1 8)

To agree the minutes of the meeting held on 18 October 2012 as an accurate record

4. Feedback & Recommendations from 1:1s (Pages 9 - 18)

Report attached

5. Health & Wellbeing Board Regulations

Verbal update

6. Third Sector approach to Health & Wellbeing (Pages 19 - 26)

Report attached

7. Living Well with Dementia - Health Scrutiny Committee Response

(Pages 27 - 58)

Report attached

8. Children & Young Peoples response to Health & Wellbeing Strategy

(PULSE) (Pages 59 - 78)

- 9. Any Other Urgent Business
- 10. Date of Next Meeting

The next meeting of the Shadow Health and Wellbeing Board will take place on Thursday 25 April 2013, 2pm at Woodlands Conference Centre, Chorley.

## **Shadow Health and Wellbeing Board**

Minutes of the Meeting held on Thursday, 18th October, 2012 at 2.00 pm in Oak Room - Woodlands Conference Centre

#### **Present:**

#### Chair

County Councillor Mrs Val Wilson, Cabinet Member for Health and Wellbeing (LCC)

#### **Committee Members**

County Councillor Mike Calvert, Cabinet Member for Adult and Community Services (LCC) County Councillor Mrs Susie Charles, Cabinet Member for Children and Schools (LCC)

Richard Jones, Executive Director for Adult and Community Services (LCC)

Helen Denton, Executive Director for Children and Young People (LCC)

Maggi Morris, Director of Public Health (LCC / PCT)

Dr Simon Frampton, West Lancashire Clinical Commissioning Group (CCG)

Dr Jimmy Reid, Fylde and Wyre Clinical Commissioning Group (CCG)

Peter Kenyon, Chair of Lancashire PCT Cluster Board

Janet Soo-Chung, Chief Executive of Lancashire PCT Cluster Board

Councillor Julie Cooper, East Lancashire District Councils

Councillor Bridget Hilton, Central Lancashire District Councils

Councillor Cheryl Little, Fylde District Councils

Lorraine Norris, Lancashire District Councils (Preston City Council)

Michael Wedgeworth, Chair of Third Sector Lancashire

Walter D Park, Chair of Lancashire LINk

Karen Partington, Chief Executive of Lancashire Teaching Hospitals Foundation Trust

Dave Tomlinson, Finance Director - Lancashire Care NHS Foundation Trust

#### **Officers**

Sakthi Karunanithi, Director of Population Healthcare, Public Health Lancashire Mike Leaf, Director of Health Improvement, Public Health Lancashire Habib Patel, Lancashire County Council

## **Apologies**

Dr Peter Williams, East Lancashire Clinical Commissioning Group (CCG)

Dr David Wrigley, Lancaster Clinical Commissioning Group (CCG)

Dr Robert Bennett, Chorley and South Ribble Clinical Commissioning Group (CCG)

Dr Ann Bowman, Greater Preston Clinical Commissioning Group (CCG)

Deborah Harkins, Director of Health Protection and Policy, Public Health Lancashire

## 1. Apologies for absence

Apologies for absence were received from Dr Peter Williams, Dr David Wrigley, Dr Bob Bennett and Dr Ann Bowman. Professor Heather Tierney-Moore submitted apologies with Dave Tomlinson attending in her place as a substitute.

## 2. Minutes of the meeting held on 4 September 2012

**Resolved:** The minutes of the Board meeting held on 4 September 2012 were agreed as correct.

## 3. Role and Function of the Shadow Health and Wellbeing Board

Habib Patel, Lancashire County Council, gave a presentation on the Role and Function of the Shadow Health and Wellbeing Board and the Strategy and Interventions, therefore Items 3 and 4 were considered together as a joint item.

Habib recapped what the Board brief to date has been:

## **Statutory Responsibilities:**

- To undertake a Joint Strategic Needs Assessment (JSNA) of health and social care needs.
- To use the JSNA to develop a joint high-level Health and Wellbeing Strategy ensuring public involvement in its development.
- To co-ordinate NHS, social care and public health commissioning plans.
- To promote integration between the NHS, public health and social care.

#### The Board also included:

- Hold to account (performance manage).
- Voice on behalf of the people of Lancashire on Health & Wellbeing related issues.

Habib stated that the next stage for the Board is to make the shift from the "thinking" stage to the "doing" stage.

Habib discussed the Health and Wellbeing Strategy for 2012 – 2020 and explained that criteria from the Strategy has been used to assess the 10 Interventions that the Board chose to target. Meetings have taken place since the last Board meeting with individuals to discuss which of the 10 Interventions chosen would be selected as the main Interventions for the Board to initially focus on. From this the following four Interventions were chosen:

- Loneliness in older people
- Support for Carers
- Affordable Warmth
- Early response to domestic violence

The next stage for all partners is to look at their ways of working and determine what they can put forward, or offer, to support how the Board can make a difference to the four chosen Interventions.

Habib also stated that the outcomes for the Board to achieve by January 2013 are:

- To ensure the role, function and leadership of the Board is understood by Board members (in the context of delivery of the strategy).
- To ensure that Board members understand and are committed to the Health and Wellbeing strategy (what contribution the sector you represent will make and what contribution your organisation will make).

• To ensure that the Health and Wellbeing interventions are underway and are delivering early results, (again what contribution board members will make to their success).

Habib also discussed the next steps for the Board as follows:

- Dialogue with Board members to take place during December 2012 to discuss:
  - Leadership role in the delivery of the strategy
  - Understanding of role & responsibility
  - Commitment from your sector/organisation
  - Strategy
  - H&WB interventions
  - o Commitment to holding the system to account

Board members discussed and clarified what they see as their individual roles on the Board. Board members made some comments regarding work that is taking place to align District Council functions to the Health and Wellbeing Strategy which the Board welcomed.

Board members also discussed what they would like to see included in the discussions scheduled to take place in December and how this will shape the direction of the Board going forward:

- Clear links between Commissioning Plans and the Boards Health and Wellbeing Strategy.
- Utilising the various skills mix of the Board.
- Assessment of needs and targeting of support where needed.
- How the Board aligns itself around the four chosen Interventions.
- Move from high level documentation to specific detail about each Intervention and how the Board is making a difference.
- Move towards action that the Board can see is taking effect.

**Resolved:** The Board noted the presentation, agreed to support the four chosen Interventions as detailed and welcomed the opportunity to engage in further dialogue through a series of individual meetings to be held in December 2012.

## 4. Strategy and Interventions

This item was considered jointly with Item 3.

## 5. Shadow Health and Wellbeing Board Conference - 16th November 2012

Habib Patel presented the report (circulated) outlining the proposals for the Shadow Health and Wellbeing Board Conference to be held on 16<sup>th</sup> November 2012.

It was noted by the Board that the Police and Crime Commissioner elections are also taking place on 16<sup>th</sup> November 2012 which will have an impact on District Council Chief Executives and other staff as they will be required to manage the voting that takes place, this may have an impact on the availability of officers from the District Councils attending the Conference. The Board noted the comment raised.

**Resolved:** The Shadow Health and Wellbeing Board discussed the proposal and agreed to the format and content of the event as circulated in the report.

## 6. Health and Social Care Reform 2012 - Update report

Janet Soo-Chung, Chief Executive – NHS Lancashire, presented the report (circulated).

Janet gave an update on the implementation of the Health and Social Care Act 2012 and provided updates on the following:

## **NHS Commissioning Board**

The NHS Commissioning Board has been set up. The overarching role of the Commissioning Board is to ensure that the NHS delivers better outcomes for patients within its available resources. Its responsibilities will include supporting, developing and holding to account an effective and comprehensive system of clinical commissioning groups. The Board will ensure that the new system architecture is cohesive, coordinated and efficient.

The Board has is now in place and has been recruiting to its structure for some months beginning with Director level appointments to the nine Directorates. This national machinery is supported by four sub-national regions and a network of 27 local offices.

The Local Area Office for Lancashire will sit within the North of England region and is similar to the current configuration of the PCT Cluster (I\JHS Lancashire) and the SHA North. It was noted that Richard Barker has been appointed as the Regional Director for the North of England.

A number of key appointments at functional Director level have been confirmed in the last two weeks as follows:

- Medical Director Dr Jim Gardner
- Finance Director John Critchley
- Director of Commissioning Martin Clayton
- Director of Operations and Delivery Jane Higgs

The post of Director of Nursing is currently out to advert and an appointment is expected by the end of October.

Each Local Area will be responsible for the direct commissioning of primary care services, performance management of the Lancashire local health system by holding Clinical Commissioning Groups to account and a range of specialised NHS services. In the case of the Lancashire Local Area Team, it will take on the lead role for commissioning health services for Offenders for the whole of the North West.

It is envisaged that the Local Area Office will be based in Preston which has good transport links to the rest of Lancashire and is more convenient for enhancing the opportunities for more integrated working with partner organisations. Approximately 80 staff are expected to be based in the Local Area Office and posts are currently being filled.

## **Clinical Commissioning Groups (CCGs)**

The eight CCGs (six of which fall within the County Council's administrative boundaries) are already operating with delegated budgets and are increasingly taking on the day-to-day commissioning and contract management/performance responsibilities on behalf of their local PCTs. This transition will move even faster as 31 March 2013 gets closer.

In order to become a statutory organisation in its own right each CCG has to go through a nationally managed authorisation process between now and 31 March 2013. The content of the authorisation process is built around six domains and has been developed through a wide range of stakeholder involvement including patients, carers, clinicians and partner organisations.

The timetable for assessment has been set out in four waves and all the CCGs across Lancashire have opted for Waves 1-3 which means they will have a decision about their state of readiness and further development needs by 31 January 2013.

## **Commissioning Support Units (CSU)**

A key feature of both the eight CCGs and the NHS Commissioning Board local area office is that the staffing structures will be kept to a minimum and they will be expected to acquire additional services (back office and specialist) from the CSU by way of an agreed contract. The Lancashire CSU has been developing a joint venture approach with Cumbria but this work has now been stopped as the Cumbria CCG has determined to purchase its support service from the North East. This is in line with the decision to include Cumbria within a Local Area Office which comprises Northumbria, Newcastle and Cumbria.

Derek Kitchen has been appointed Managing Director of the Lancashire CSU. Derek has been leading the Staffordshire CSU since 2011 and in his new role he will lead the two CSUs. The two CSUs will remain independent and will be hosted by the NHSCB from 1 April 2013 pending further decisions about their future shape and degree of commercial expertise.

#### **Public Health Lancashire**

From 1 April 2013 the responsibility for a range of public health services will transfer to the upper tier local authorities. A Steering Group has been working to ensure that this transition works smoothly and effectively for the last few months.

As yet no appointment has been made to the post of Executive Director of Public Health. However appointments have been made to the three posts which will report directly to this post.

#### These are:

- Director of Public Health Improvement Mike Leaf
- Director of Health Policy and Protection Deborah Harkins
- Director of Population Healthcare Sakthi Karunanithi

A process of re-shaping and rationalising the structures is now underway to bring the three existing teams across the Lancashire PCTs together with the LCC team into one. A further presentation regarding Public Health Lancashire was also presented at Item 7 during this meeting.

## New leadership arrangements through transition

The NHS Chief Executive David Nicholson has written to all NHS Leaders setting out the steps in the transition to the new health and social care system. In the letter he describes arrangements to ensure stability and resilience for the current system through to the new health and care system from April 2013.

This means that anyone appointed to regional and local leadership roles in NHS Commissioning Board will take on responsibility both for teams managing operational delivery in 2012/13 and planning the new system for 2013/14.

The Clinical Commissioning Group Board members commented that work was being undertaken on new pathways and some joint work with the County Council has already been undertaken, for example a project has been running since July regarding Health and Respiratory Issues. A number of other new pathways are also up and running.

**Resolved:** The Shadow Health and Wellbeing Board noted the report and the progress made to date on the Health and Social Care Reform 2012.

## 7. Public Health Update

Sakthi Karunanithi, Director of Population Health Care and Mike Leaf, Director of Public Health Improvement gave a presentation on Public Health Lancashire.

Sakthi begin the presentation by talking about the previous Health Care system and how it has changed over the previous years. Sakthi explained that the new Health and Care System from April 2013 will put people and communities at the heart of the system and that the new Public Health Lancashire team will be the middle ring of influence which can directly commission public health services.

There will be Public Health teams in:

- Lancashire County Council
- Public Health England (Cumbria and Lancashire)
- NHS Commissioning Board Local Area Team (pan-Lancashire)

The five main contributions of the team will be:

- To directly commission public health services.
- To provide public health leadership and support to NHS Commissioners, LCC, Districts, the Third Sector and other partners.
- To be the interface between the Health and Wellbeing Board, the District level partnerships and the rest of the health system.
- To develop new relationships with CCGs, NCB LAT, PHE, CSU and LCC Directorates to improve health and well being outcomes.
- To contribute to develop national policies.

Mike continued the presentation by explaining that there will be a "One Team" approach – Local Health – Lancashire Wide.

This will include a number of County wide functions:

- County-wide support services.
- System wide workforce and organisational development for Public Health.
- Enable consistent, co-ordinated, systematic approach to:
  - working with partners
  - Influencing national policy
- Provide critical mass.
- Support delivery of public health in localities.
- Intelligence and knowledge management.
- Health protection.
- Business management, planning and governance.
- Influencing county based wider determinants of health.
- Commissioning of health improvement and wellbeing services.
- Clinical leadership and governance.
- Performance management and improvement.
- Locality development.
- Liaison with LCC Cabinet/ Executive and other LCC Directorates.
- Workforce development and training.
- Communication and marketing.

Mike also explained that Public Health Lancashire will work within Localities:

- By providing Public Health Leadership and support to CCGs, District Level Partnerships and District Councils.
- Multi-disciplinary teams reflecting the three domains of public health (matrix working)
  - Supported by locality staff taking on county-wide areas of responsibility.
- · Reflecting health economies.
- Align with Lancashire County Council locality footprints.

Public Health Lancashire will provide new approaches, including:

- Use of assets.
- Integrated commissioning.
- Generic skills with matrix working on public health priorities.
- Greater focus on wider determinants, delivering improved outcomes and reducing inequalities.
- Aligned with the shifts envisaged in the Health and Wellbeing strategy.

**Resolved:** The Shadow Health and Wellbeing Board noted presentation and progress made regarding Public Health Lancashire.

## 8. Any Other Urgent Business

None.

## 9. Date of Next Meeting

The Board noted that the next meeting would be the Shadow Health and Wellbeing Board Conference, to be held on Friday 16<sup>th</sup> November 2012, starting at 12.45pm at the Gujarat Centre, Preston.

Andy Milroy Principal Executive Support Officer

Lancashire County Council County Hall Preston

# Agenda Item 4

## 1.Introduction

The Lancashire Shadow Health and Wellbeing Board has now been meeting for a year. The shadow Board agreed that its first priority was to clarify its priorities within a Health and Wellbeing Strategy. The strategy has now been developed and launched and needs to move to the delivery phase. In April 2013 the Shadow Health and Wellbeing Board will emerge from its shadow form and will become a substantive functioning Board. It is therefore a good time for Board members to reflect on its work to date, ensure lessons from the shadow period are translated into the statutory phase and agree how the strategy will be delivered.

During January discussions were held with members of the Health and Wellbeing Board. During these discussions questions were posed to Board members regarding their role on the Board. They were also asked to suggest any recommendations that are required to be made to the strategy, how the strategy should be delivered and how they can help to contribute to support the delivery of the strategy. They were also asked how they can help support the four chosen interventions.

These discussions highlighted a number of challenges for the Board both in delivering the strategy and in exercising its other roles. This report outlines these challenges and offers recommendations to address them.

### 2. Role of the Board

The core purpose of the Lancashire Health and Wellbeing Board is to provide collaborative leadership for the health and wellbeing of the population of the county. Its four functions are:

- To identify the health and wellbeing needs of the population through the Joint Strategic Needs Assessment (JSNA)
- To set out priorities to meet these needs within a Health and Wellbeing Strategy
- To co-ordinate the commissioning plans of Health and Wellbeing Board partners
- To promote integrated commissioning and provision of services

## 3. Developing the Health and Wellbeing Board

Board members recognised that they have a leadership role to play for health and wellbeing. They saw their role as 'to hold the ring' on health and wellbeing in the county. Board members were however, unclear about how they will hold each other to account for their actions and provide challenge in relation to decisions affecting the health and wellbeing system. A number of Board members stated that the Board had not yet had the opportunity to explore some of the significant challenges facing the health, care and wellbeing system.

## Recommendation

- Hold a facilitated development session for Board members to work through a number of scenarios providing opportunities to challenge in a safe environment and to agree how Board members will hold each other to account.
- Develop a process by which the "knotty issues" that need discussion are identified and a programme of work to take these forward

## 4. Key challenges for the Board

## 4.1 Features of an effective Health and Wellbeing system

An effective Health and Wellbeing system has three goals:

- Improvement of health outcomes
- Improvement of public and patient experience of the system
- Increased sustainability

Although the health and wellbeing strategy sets out priority health and wellbeing outcomes it does not fully establish how public and patient experience will be improved or how the system will be sustainable with an ageing population and increasing demand on the resources available. Several Board members perceived sustainability challenges as a critical issue for the Board to grapple with, however most viewed these issues as outside of the health and wellbeing strategy. It could be argued that the 'shifts' within the strategy aim to highlight some of the public experience and sustainability issues but this was not recognised by a number of Board members.

#### Recommendation

 The strategy narrative should be explicit about the three goals of an effective health and wellbeing system and how the strategy shifts contribute to improving citizen's experience and the sustainability of the system.

#### 4.2 What success looks like

Health and Wellbeing Board members were asked how the strategy could be strengthened and how we can ensure it is implemented. In response to these questions a number of Board members mentioned the need for the strategy to be more explicit about what success would look like, to ensure the Board is able to oversee its implementation. However there were mixed views about whether measures should be placed against the outcomes, interventions and shifts. Some members felt that success measures would be essential and others were concerned that there could be a perception that not reaching the success measures would be seen as failure.

It will be difficult for the Board to hold itself and its constituent members to account for delivery and to identify ongoing improvement priorities without explicit success measures. It is therefore suggested that the strategy needs to articulate what success will look like and to specifically state how Lancashire would be different if the strategy was successfully implemented.

#### Recommendations

- An overarching measurable goal for the strategy should be set focused around narrowing the gap in healthy life expectancy
- SMART (specific, measurable, attainable, realistic and time sensitive) success measures should be set for each outcome, shift and intervention and progress should be reported to the Board.

## 4.3 Delivery

A number of Board members felt that the Board should have strategic oversight of the delivery of the strategy. Some felt that further consideration was needed to understand how the action of each constituent organisation would contribute to the measurable delivery of the outcomes and shifts.

Some Board members said that they were not clear why the Board had selected four interventions of the ten to drive forward and on what basis those particular four had been selected. Some of the CCG Board members felt that the four interventions chosen required social care rather than healthcare intervention. It was suggested that a clear rationale for why these have been chosen should be included in the strategy narrative.

## Recommendations

- The Board should review its decision to focus on the four specific interventions and be clear of the rationale for this
- The Board should consider developing a three-year strategic plan to specify
  how the strategy will be delivered, specifically, how partners will contribute to
  the outcomes, shifts and interventions. It is suggested that Board members
  could nominate a representative from their organisation who could form a
  multi-agency team and work together to develop the three-year strategic plan.

## 4.4 Co-ordinating commissioning plans

One of the roles of the Health and Wellbeing Board is to co-ordinate the commissioning plans of partner organisations so that they contribute to the health and wellbeing strategy. A number of Board members were unsure as to how that co-ordination would happen in practice. Others felt that the Board needed to develop some clear expectations with regard to how and when commissioning plans are shared with, and co-ordinated by, the Board and discussion about how to ensure constructive challenge is provided.

A number of Board members were not sure how the strategy would be reflected in their own organisation's commissioning plan. Some of the CCG Health and Wellbeing Board members offered to present any business case for investment in the health and wellbeing strategy priorities to their CCG Board, whether or not that particular priority was reflected in the commissioning plan. Although this is very positive, there is a risk that this approach would make co-ordinating commissioning plans very difficult for the Board. One Board member suggested that the Board's role is to ensure that the pieces of the individual plans come together to achieve the strategy's goals so that members can understand the specific contribution each makes and agree how to address gaps.

## Recommendations

- The Board should make explicit its expectations about how and when it would like to receive partner's commissioning plans and about what should be included in them in order for them to co-ordinate as effectively as possible with health and wellbeing strategy priorities
- The Board needs to give consideration to how it will undertake the coordination of commissioning plans to ensure that any gaps can be identified
  and proposals developed for them to be filled. Once these plans have been
  discussed by the Board they could be considered in more detail by a multi
  agency team who could co-ordinate the plans across the partners.

## 4.5 Integration

Integration of the commissioning and provision of interventions and services was rarely mentioned by Board members during this process. It was clear from the discussions that many Board members are not considering how they can move towards joining up services and interventions across sectors with other Health and Wellbeing Board partners at this stage even though the pooling and sharing financial and other resources is one of the strategy shifts. This is understandable at a time when new organisations are forming and/or learning about their new responsibilities. However, as the Board moves into statutory form, Board members will need to explore the need and appetite for joint commissioning and provision and how this could add value to the strategy outcomes.

#### Recommendation

 The Board's approach to co-ordinating commissioning plans should include the identification of opportunities for integrating in the commissioning and delivery of services and these should be highlighted to the Board.

#### Appendix - Summary of Discussions with Health and Wellbeing Board Members

#### Introduction

During January 2013, members of the Health and Wellbeing Board discussed on an individual basis their organisation's contribution to the Health and Wellbeing Strategy. This report will summarise the main findings from these discussions.

#### **Role on the Board**

Many of the Board members recognised that their role on the Board was to provide a link between their own organisation and the Health and Wellbeing Board. They considered this as essential to facilitate communication. Board members also acknowledged that they need show leadership, one member commented it was like 'sitting at the top of the mountain where you can talk about the health economy and mould it into a different place'. A number of Board members also noted that they have a role to play by influencing and challenging others.

## Recommendations to improve the strategy

### Length of the strategy

Some Board members commented on the length of the strategy. Some considered this to be the right length while others considered it needed to be simplified and be concise. One suggestion was that it should be amended to read 'we aim' rather than 'we will'. A proposal was made for a user friendly flier to be produced that includes a summary of the strategy.

#### Shifts, priorities and outcomes

Suggestions in relation to the shifts, priorities and outcomes require:

- Further explanations of the shifts, priorities and interventions
- Better linkages between the four outcomes
- The strategy to clearly spell out why the strategy is different and needs to be different in the shifts, including measures of success for the shifts
- The strategy needs to pull out the wellbeing element
- The interventions need to capture the shifts more radically

#### Success measures

It was proposed that success measures need to be developed for the outcomes, interventions and shifts. The strategy needs to specifically state how Lancashire would be different or in what ways it will have improved when the shifts and outcomes have been achieved. This would give the strategy more credibility and commissioners would know what is expected of them.

However, it was noted that the Health and Wellbeing Board should not become a performance management system and it was suggested by one Board member that targets should be avoided as failure to achieve the targets may be seen as failure.

#### The four chosen interventions

Some Board members questioned why the four interventions were chosen as they considered that the chosen interventions were all social care related. They felt it would have been beneficial if more balance had been given to the chosen interventions. They suggested it would have been more relevant to them if, for example, vulnerable families and healthy weight were chosen, as these would have more buy in from CCGs.

#### How the strategy should be delivered

#### By Board members reporting back progress to the Board

It was suggested that there needs be an on-going process whereby Board members report back to the Board on their progress and that they are held accountable for their actions in implementing the strategy.

It was also suggested that 6 monthly progress reports could be submitted to the Board. The Board would also benefit from a Lancashire dashboard being developed to measure performance.

#### Aligning commissioning plans with the strategy

It was suggested that the strategy could be delivered by aligning the strategy with Board member's commissioning plans, strategies and intentions.

#### Developing a plan for how the strategy will be achieved

It was proposed that a three year plan should be devised on what the Board would have expected CCGs, hospital services, social care and public health to have achieved.

#### Commitment to the shifts

In order to ensure that the shifts are achieved it was felt commitment from Board members was needed and this should be reinforced at every opportunity. Partners will also need to demonstrate how they will deliver the shifts in their commissioning plans.

#### Others

Some of the elected members of the Board already regularly brief Cabinet Members within their local authorities and those they represent to keep them up-to-date with the strategy and developments and others suggested that they will do so from now on.

#### **Delivery of the strategy**

A number of suggestions were identified as to how Board members can help support the delivery of the strategy. These include:

 CCG Members said they would keep their CCG up to speed with the Strategy and Board and work to ensure that the commissioning plans reflect the strategy

- Development and monitoring of tactical plans to deliver the strategy and commissioning plans
- Promote an understanding of the strategy throughout their organisation
- Ensure that young people have a voice focus on social issues, strong advocacy, contribute by changing CYP trust and ensure that children and young people have a voice
- Use Large Scale Change methods to deliver
- Bring skills of change, energy, passion and accountability
- Build confidence and trust in the Board

#### Interventions

#### 1. Loneliness in Older People Intervention

Recommendations made to the loneliness in older people intervention are as follows:

- A single point of access is needed possibly locating Help Direct in the surgery
- A good neighbour scheme should be developed
- The third sector should be involved
- There should be an investment in culture change and asset identification rather than services
- Increase the awareness of services such as faith groups and luncheon clubs
- Educational sessions for CCGs and GPs to make them aware of the services available
- Community nursing teams should be involved in sharing information
- An asset based approach needs to be developed. A model approach should be developed of what a community asset based support network should look like
- Finally, one suggestion was that no additional funding should be required to carry out this intervention.

The following are suggestions made by Board members on how they can contribute to the loneliness intervention:

- GPs can contribute by identifying people who are lonely and signposting them
- Raise the issue of loneliness in older people at the Third Sector working group
- Support an asset based approach
- Commission and undertake community asset mapping and development
- Explore the role of the third sector mobilise and grow the voluntary sector
- Schools could open up their facilities for older people. In order for older people to engage with schools they could have hot meals in schools.

To carry out the loneliness intervention resources were suggested as follows:

- Interest in commissioning a service for people to be referred to
- Attends older people's networks and Parish Council liaison meetings and make loneliness in older people as a standing item on the agendas
- Take business cases for investment in the intervention to CCG Board.

#### 2. Support for Carers' Intervention

Recommendations made to the support for carers' intervention are as follows:

- Develop a LES for the carers' register
- To involve the third sector groups in providing support for carers
- Links need to be made with young carers

It was mentioned that GPs already carry out carers' awareness training and CCGs have already carried out work in this area at a Carer Conference.

There were concerns that the one hour training course for staff was unrealistic

The following are suggestions made by Board members on how they can contribute to the support for carers' intervention:

- GPs can screen carers for depression and identify the support that they can promote
- A LES could be developed for the carers' register
- Go out and reach with carers
- To look at the impact on commission and de-commissioning

To carry out the support for carers' intervention resources were suggested as follows:

- Carer support into the workplace
- Take business cases for investment in the intervention to CCG Board.

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#### 3. Affordable Warmth Intervention

Recommendations made to the affordable warmth intervention are as follows:

- Link to flu vaccination –distribute warmth packs
- Publicise existing programmes widely
- Identify people and signpost them to the appropriate support

One Board member identified concerns about using disease registers to support the targeting of this intervention for reasons of confidentiality

The following are suggestions made by Board members on how they can contribute to the affordable warmth intervention:

- Integrate identification and measures into assessment and discharge
- Make connections to districts through PH locality teams

To carry out the affordable warmth intervention resources were suggested as follows:

- To put the identification of vulnerable as a LES on COPD and CVD registers
- To share commitment for a standard of response to overcome confidentiality issues

#### 4. Early response to domestic abuse

Recommendations made to the early response to domestic abuse intervention are as follows:

- Health visitor input health visitors are the greatest source of awareness and would appreciate being given updates
- A database to be developed regarding domestic abuse for use across hospitals
- Single point of access

The following are suggestions made by Board members on how they can contribute to the early response to domestic abuse intervention:

- Training for A and E staff
- Undertaking of Domestic Abuse awareness training if all Lancashire CCGs would undertake this training
- Public health programmes to prevent injury

To carry out the early response to domestic abuse intervention the resources were suggested as follows:

• There is no harm in writing into the contract the requirement for A and E staff to ask partners to leave during examination when a person presents with 'accidental' injury.

It was felt by one of the CCGs that it would be difficult to say what CCGs could do to make a difference. Victims and perpetrators of domestic abuse rarely disclose to GPs.

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# Agenda Item 6

# Introducing the 3<sup>rd</sup> Sector Health and Wellbeing Group

The Group consists of key leaders from across the 3<sup>rd</sup> Sector in Lancashire. It was established, through the ONE Lancashire initiative, via a survey and mapping exercise of infrastructure organisations, with the express intention of working collaboratively. It has been advised by an external specialist consultant.

We believe we are stronger together, offering the best prospects for our Sector's contribution to the health and wellbeing of the people, of Lancashire.

All involved are focused on leadership on behalf of the Sector. We believe that we can offer to the Lancashire Health and Wellbeing Board a vehicle by which crucial aspects of its strategy can be achieved, by doing work commissioned by its members.

These, we believe, are the benefits:

Benefits for Commissioners	Benefits for the Third Sector		
Reduced transaction costs	Overcoming the barriers to small local VCF organisations securing and		
Efficiency savings	delivering public service contracts by		
Development of a commissioning-ready provider base	building critical mass and delivery capacity		
Overcoming fragmentation within service delivery arrangements through better coordinated and streamlined provision	Protecting and consolidating the unique selling points that small, independent and niche providers offer		
Single point of contracting	Material net reductions in indirect/overheads expenditure within frontline providers		
Effective channelling of any bundling of			
existing, small-scale, multiple contracts/SLA's/grants through the consortium's intermediary infrastructure	Driving up standards and continuously improving quality		
More effective management of escalating community demand, especially amongst disadvantaged and vulnerable service users	Increased capacity to leverage social investment and community development finance		
Strengthening localism by ensuring that local services are safeguarded and sustained	More efficient use of resources and reduction in duplication Less confusion about where to go for		
Capitalisation on the sector's capacity for	infrastructure support		
added value through, e.g. the 'volunteer dividend' and utilisation of wider charitable resources	Joined up back office functions (including support for frontline consortia); and,		
A focus on <u>social value</u> and opportunity to work in partnership on co-commissioning.	Better quality support outcomes		

The Group, which currently consists of 10 founding member local charities, has, by establishing at the outset clear terms of reference, over the past 4 months agreed a clear statement of purpose, signed a memorandum of understanding and produced a Business case.

The Group's statement of purpose is that as 3<sup>rd</sup> Sector organisations we jointly recognise the need for a health and wellbeing (HWB) Group for Lancashire, which enables the 3rd Sector to get the best opportunity to shape and design commissioned services and contract with the public sector. And that this Group will extend the reach and impact of existing consortia and other health and wellbeing providers through collaborative working.

And we would now like to ask the Lancashire HWB Board for the following fourthings:

- Endorsement for this approach and its continuing development
- A commitment to work in partnership
- A commitment to recognising social value in all commissioned work
- The opportunity to engage in the development of the Board's strategy and its outworking

In making this request the founding members; Age Concern Central Lancashire, Age UK Lancashire, Greater Together, Insight Network, Lancashire Association of CVS, Lancashire Mind, Lancashire Sport Partnership, The Family, Health and Wellbeing Consortium, Third Sector Lancashire and Young Lancashire, are keen to highlight a summary of their combined collaborative offer and potential reach which is:

- Coverage: Lancashire wide
- Range: Children, Families, Adults from 'cradle to grave'
- Contracting Experience: in excess of £10 million
- Workforce: Paid: over 500 employees. Volunteers: over 10,000 volunteers
- Partnerships: Four Consortia in excess of 160 quality assured providers
- Reach: in excess of 6,000 local 3<sup>rd</sup> Sector bodies, from community groups to charities and social enterprises.
- Service Users: over 100,000
- Services: wide and extensive range from capacity building, specialist, and service user led.
- Offices: in excess of 20 offices

Bringing these resources together; organisations recognise the opportunity to develop and provide new services, jointly across the breath and diversity across Lancashire and further details of individual organisations offers are included below.

Summary of founder members:

## **Age Concern Central Lancashire**

Our mission is to promote the wellbeing of all older people and help make later life a fulfilling and enjoyable experience. Primarily supporting people over the age of 55 or their carers we provide a wide range of services

These are funded through a mix of commissioned contracts, grant funded projects or self- generated income, with several delivered in partnership with voluntary, community or public sector partners. Incoming resources in 2011/12 were £2.4million.

The charity employs 140 staff on a mix of permanent and zero hours contracts and is supported by over 275 volunteers, engaged in every aspect of our operations.

### Age UK Lancashire

Age UK Lancashire's mission is to promote the relief of elderly people in any manner which is deemed by law to be charitable in and around Lancashire.

Our aim is to enable all older people to make more of life. Our services enhance well being, decrease isolation and enable older people to remain independent and involved in the decisions which affect them.

We primarily support people aged 50+ but have built up expertise to deliver services to all adults, through our commissioned services such as Help Direct, Caring Neighbourhood schemes and Hospital After Care.

We also run a Trading Company which runs many charged- for services which are open to all adults. These include a Personal Assistant/ Home Help service and Foot Care provision.

We strive to work with hard-to-reach groups and ensure we deliver services which are appropriate for older people from diverse cultural and ethnic backgrounds.

We currently employ 255 permanent staff along with 37 casual employees and are supported by 900 volunteers. Together we reach over 55,000 older people annually. From our 12 local offices across the county we are dedicated to providing local services which are easy to access.

#### **Lancashire Mind**

Covering the whole of the County and unitary areas of Lancashire, the organisation has a turnover of £1m and employs 40+ staff supported by over 50 volunteers. We provide support to over 700 service users and carers at any one time. Our service is accessed by some 8,000 people every year.

Our specialist and targeted service aims to improve mental wellbeing, increase awareness and reduce the stigma so often faced by people who experience a mental health need. We offer user- led services, commissioned services, pilot projects and grant funded provisions to support people in innovative ways to attain and sustain mental wellbeing.

We have extensive experience of managing external funding and grants including; LCC Multi-agency day services, Community Restart, Supported Housing, and Floating Tenancy support. MH Training, Corporate advice, signposting referral agents, income generation projects, The Eco Centre and volunteer opportunities. We also offer Counselling interventions and Targeted Youth Support

## Lancashire Association of Councils for Voluntary Service (LACVS)

LACVS represents 6 district and multi-district Councils for Voluntary Service which offer a comprehensive range of practical services to frontline voluntary, community, faith and social enterprise (VCFS) groups across Lancashire.

We work with organisations across the sector from small, informal and volunteer ledgroups to larger, staffed, service providers across rural and urban areas.

We have extensive experience of providing one to one support, information and training in areas such as start-up, governance, becoming commissioning ready, funding advice, good practice and quality standards, business planning, volunteer development, personnel and accounting.

LACVS includes CVS with experience of successfully delivering frontline services e.g. support for carers, volunteer centres, health champions, families health and wellbeing.

We reach out to over 4,000 VCFS groups through effective communication channels and networks with strong roots in local communities.

LACVS has a collective annual income in excess of £4 million and more than 70 staff. It has extensive experience of contract and project management both collaboratively and as individual CVS.

## **Lancashire Sport**

Lancashire Sport Partnership is one of 49 sub-regional sport partnerships operating across England. We are funded by Sport England, by agencies to deliver specific projects on their behalf, by local government and by private sponsorship.

County Sports Partnerships are an integral part of the Government's drive to develop a 'single sports delivery system' across England, and we are the key bridge between local and regional networks. Lancashire Sport has access to a network of 2,000 sports club in Lancashire

## **Young Lancashire**

Our aim is to support and develop high quality voluntary youth work and educational opportunities for all young people in Lancashire. We help voluntary youth services and groups to achieve the highest standards of practice and effectiveness.

Services include: development of financial and personnel procedures, fundraising support, bid writing, business and strategic planning, quality standards, guidance materials and support, access to an AQA moderation service to accredit participation and learning, support on safeguarding and access to CRB checks.

Currently Young Lancashire supports a network of 250 organisations working with over 80,000 children and young people, supported by 9,000 volunteers and over 500 paid staff.

Additionally four independently incorporated consortia are working together as part of the 3rd Sector Health and Well-Being Group – They are: Greater Together, the Families Health and Well Being Consortium the Insight Network and Third Sector Lancashire. These consortia alone bring a further 160 'quality assured' front line voluntary organisations to the mix.

## **Greater Together**

Our purpose is to promote efficiency and effectiveness in the charitable activities of not-for-profit organisations, voluntary groups and charities working with children, young people and families for the benefit of the public, and, to advance the education of those involved with voluntary and not-for-profit sector organisations working with children, young people and families.

The company was formed in 2011 and now has over 60 organisations in membership, committed to working in partnership with an agreed vision statement below:

"We believe that together we can learn more, progress faster and deliver better than we can apart and therefore have a duty to collaborate for the benefit of those we serve. The result will be a thriving local community in which all children, young people and families, including the most disadvantaged and vulnerable, are able to achieve their full potential"

Member organisations offer a wide range of services including targeted youth support; family intervention; therapy; domestic violence; diversionary and prevention; employability and supported employment, work with disability, drug advice etc. This membership is from a broad range of organisations, but especially local grass roots organisations (circa 88%) but also large national organisations (circa 12%) that have operated in Lancashire for at least three years.

The company's business plan is focused on winning appropriate tenders: to date the consortium has secured a tender for the provision of Targeted Youth Support and Youth Services for the County Council and has secured a significant amount of working capital to realise and complete the businesses start up phase.

## **Families Health and Wellbeing Consortium**

The primary goal of the Consortium is to improve the quality of life of local people, especially those who are most in need, through the provision of high quality, responsive, generalist, specialist and innovative services and initiatives. The focus of the consortium is building on the capacity and track records of existing civil society partners to deliver, collaboratively, a range of holistic and bespoke services for children, young people, families and their communities.

The Consortium, which has membership in excess of 20 organisations, aims to achieve this by securing funding for the delivery of services and will manage the ensuing revenue through a joint approach.

## **Insight Network**

The Insight Network for Mental Health is a registered charity comprising 70 plus members drawn from across Lancashire. The members range from large to small organisations and local community agencies to those with a national footprint, together with service users and carers and other interested parties. The Network acts as a united body to develop the capability and capacity of its members. In so doing they aim to ensure that the mental health services in Lancashire meet the stated needs of Service Users and Carers.

The Network acts as a single point of contact for the sector and harnesses the views of the sector.

It has been in existence since 2005 and over that time it has established positive relationships with many parts of the statutory services. In particular it works in partnership with the Lancashire Mental Health Commissioning Network and has worked with them on several collaborative activities.

#### **Third Sector Lancashire**

Third Sector Lancashire is a consortium of Lancashire-wide infrastructure bodies. We have specialised over the past 18 months on the Health and Well-Being agenda, with a series of hearings and consultations for infrastructure and front-line organisations with experts in the field.

A similar programme is planned for 2013.

The aim is both to help the sector keep abreast of developments, and to feed into the policies and programmes of public sector providers, so that the sector is better able to make its contribution to the developing agenda.

Thus we act as a 'voice' and representative of the third sector, a process made more active by the position of the Chair of TSL sitting on the Health and Well-Being Board to represent the sector. We do not aspire to deliver services directly, but to act as an independent broker with public sector commissioners and our sector.

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## Executive Summary for the 'Living Well with Dementia' in Lancashire Report

At the Health Scrutiny Committee on the 12 July 2011 a report on the mental health inpatient reconfiguration proposals was discussed. Elected Members decided to set a task group to review the services and support available to dementia patients with a particular focus on respite provision.

The task group focused on the following stages:

- Prevention and early diagnosis
- Home and community based provision
- Residential care
- End of life care

The task group conducted their research by carrying out discussions with relevant professionals, carrying out care home visits and considering a range of documentary evidence.

The task group arrived at the following conclusions:

## Early diagnosis

- Remove the stigma and raise the awareness of dementia
- Enable people to live well with dementia
- Education about dementia is needed
- Increase the exposure of positive experiences
- GP's could be encouraged to add a simple memory test to the periodical health checks
- Planning needs to be undertaken for what services will be required in the next 5/10/15 years due to the predicted increase in the number of people with dementia by 2025.

## Home/community base support

- The Alzheimer's website has useful advice and guidance
- It was acknowledged that due to the small numbers of patients under 65 years with dementia, the commissioning of specialist services was difficult. However it was felt that Help Direct would be able to signpost patients and carers and offer advice and guidance.
- The topic needs to be NHS driven in terms of commissioning services. However, there is unlikely to be additional funding to deliver more services so a different approach is needed. With the Cabinet Member for Adult and Community Services and Cabinet Member for Health and Wellbeing sitting on the Health and Wellbeing Board they will be in a position to request that issues, such as dementia services, are added to the agenda.

- A good business case is needed to justify initial investment of training 'front-line' staff.
- E-learning could be a cost effective way of delivering basic awareness training.
- The Communications Team could promote positive messages of living with dementia

## Residential and nursing homes

- Adequate training for all residential and nursing home workers would enable a greater understanding of the condition and how to cater for the needs of the residents.
- The PP list could provide more meaningful information

## End of Life Care

 Opportunities to discuss end of life care could be incorporated into the overall care plans.

## Recommendation from Overview & Scrutiny Task Group

The task group have recommended that the Health and Wellbeing Board consider how dementia services will be planned over the next 5-15 years to meet the predicted increase in demand.

#### RECOMMENDATION

The HWB are asked to note the report and consider the report in more detail at a future HWB meeting.

# 'Living Well with Dementia' in Lancashire

**Overview & Scrutiny Review** 

For further information about this report please contact
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# Background to the review

At the Health Scrutiny Committee on 12 July 2011, members considered a report on the mental health inpatient reconfiguration proposals. The Chair noted that there was a lot of concern about dementia care and respite provision and suggested that a task group be established to consider those concerns and look at the timeline of services and support available to dementia patients and their carers. Members acknowledged the work already undertaken in the development of the Lancashire Dementia QIPP Strategy, which identified key integrated opportunities for improving the health and social care for those affected by dementia in Lancashire, and concluded that many of the services were already at a good standard and met the requirements of the National Strategy. However, they welcomed the identification of areas in which services could be further improved and co-ordinated and made more consistent across the county.

Members therefore agreed that a task group be established to review the services and support available to dementia patients with a particular focus on respite provision.

The Scrutiny Committee approved the request for a task group at its meeting on 16 September 2011.

# Membership of the task group

The Task group was made up of the following County Councillors:-

- Fabian Craig-Wilson (Chair)
- Terry Aldridge
- Renee Blow
- Margaret Brindle
- Carolyn Evans
- Misfar Hassan

# Scope of the Scrutiny exercise

The original scope of the task group was to review the services and support available to dementia patients with a particular focus on respite provision. Due to the range and complexity of services and support available for dementia patients the task group decided to break down the review into individual sections of the overall pathway of care. Therefore the scope of the exercise was to look at each of the following stages in detail:

- Prevention and early diagnosis
- Home and community based provision
- Residential care
- End of life care

Whilst the review would be broken down into individual topics it was agreed that cross cutting themes of training and communication would be addressed at each stage.

Members felt that the issue of respite care was a significant topic in its own right, and to enable a robust review of the related services and support agreed that they would briefly examine the issue in relation to dementia patients but would recommend that a further, separate task group be established to undertake a comprehensive review of all respite care services.

## Methodology

#### Witnesses

The Task Group carried out a series of information and evidence gathering sessions. Discussions took place with a number of witnesses.

- Julia Pither Integration Project Manager (Older Adult Network)
- Clare Evans Social Worker
- Liz Wordsworth Social Worker
- CC Mike Calvert Cabinet Member for Adult & Community Services
- Dawn Butterfield Head of Commissioning (North)
- Dr Ian Leonard Associate Medical Director and Memory Assessment Lead Clinician
- Barbara Lowe Professional Lead for Occupational Therapy
- Rebekah Proctor Consultant Clinical Psychologist
- Rebecca Davies Network Director, Mental Health Commissioning
- Debbie Nixon Strategic Director, Mental Health Commissioning
- Beverley Page-Banks Support Services Manager, Alzheimer's Society Central Lancashire
- Peter Sullivan Adult Carer Support Officer, Preston & District Carers Centre
- Graham Towers Carer
- Iain Pearson Help Direct Manager (Help Direct Preston & South Ribble delivered by Age Concern)
- Barbara Rimmer Dementia Advisor

## **Site Visits**

Members visited a number of care homes in their own divisions to establish what specific services and activities are available for dementia residents; what training the care home staff receive to effectively understand the condition; and whether the physical environment aided orientation. Members produced a brief questionnaire with which to assist their investigations. (Annex A).

The homes visited included:

- The Broadway Nursing Home, South Shore, Blackpool
- The Victoria Residential Home, Burnley
- Dove Court, Burnley
- Lady Elsie Finney Care Home, Ingol

Penwortham Grange Residential Care Home, Penwortham

## **Documents**

The task group considered a range of documentary evidence including:

- Health Scrutiny Committee 12 July 2011, Item 7: Mental Health Inpatient Reconfiguration
   Transitional Arrangements
- Minutes of Health Scrutiny Committee 12 July 2011
- Lancashire Dementia QIPP initiative A Case for Change (Jan 2012)
- Centre for Public Scrutiny Ten questions to ask if scrutinising services for people with dementia
- Department of Health Case for Change: community based services for people living with dementia (2011)
- Department of Health Case for Change: memory service for people with dementia (2011)
- Department of Health Living well with Dementia: A National Dementia Strategy (Feb 2009)
- Department of Health Quality Outcomes for People with Dementia: building on the work of the National Dementia Strategy (Sept 2010)
- Dementia Advocacy Network Taking their side: fighting their corner.(Jan 2012)
- Alzheimer's Society Dementia 2012: A National Challenge (March 2012)
- Alzheimer's Society Worried about your Memory?
- Department of Health End of Life Care for People with Dementia (2010)
- Lancashire County Council & Helen Sanderson Associates Living well thinking and planning for the end of your life (June 2010)

A range of information on websites was considered which included:

- www.dh.gov.uk
- www.alzheimers.org.uk
- www.cqc.org.uk
- www.lancashirecare.nhs.uk
- www.lancashire.gov.uk

#### **Findings**

#### What does the term dementia mean?

The term 'dementia' describes 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 and 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 individual way. It is often the case that the person's family and friends are more concerned about the symptoms than the person may be themselves.

Symptoms of dementia may include the following:

- Loss of memory this particularly affects short-term memory, for example forgetting what happened earlier in the day, not being able to recall conversations, being repetitive or forgetting the way home from the shops. Long-term memory is usually still quite good.
- Mood changes people with dementia may be withdrawn, sad, frightened or angry about what is happening to them.
- Communication problems including problems finding the right words for things, for example describing the function of an item instead of naming it.

In the later stages of dementia, the person affected will have problems carrying out everyday tasks and will become increasingly dependent on other people.

#### The current picture

There are currently estimated to be around 17,600 people aged 65 and over in Lancashire with dementia, and these numbers are expected to rise to more than 25,600 by 2025. This increase is linked to the predicted rise in the number of people who will be aged over 85. There are also at least 317 people aged 64 and under who have dementia. Numbers in the 'under 65' age group are only predicted to increase by a very small amount.

However the Task Group were off the opinion that there may be many more people affected, who simply remain un-diagnosed.

<u>Living well with Dementia: National Dementia Strategy</u> was published by the Department of Health in February 2009. The vision set out in the National Dementia Strategy is for people with dementia and their family and carers to be helped to live well, no matter what the stage of their illness or where they are in the health and social care system. It seeks to:

- encourage help-seeking and help-offering (referral for diagnosis) by changing public and professional attitudes, understanding and behaviour;
- make early diagnosis and treatment the rule rather than the exception; and
- enable people with dementia and their carers to live well with dementia by the provision of good-quality care for all with dementia from diagnosis to the end of life, in the community, in hospitals and in care homes.

To support implementation of the strategy, £150 million was allocated to primary care trusts as part of their annual revenue allocation to fund the first 2 years of the national strategy. However, the funding was not ring-fenced and across the county little, if any, was directly used to implement the dementia strategy.

Subsequently, in September 2010, the coalition government updated the dementia strategy with the publication of <u>Quality Outcomes for People with Dementia: building on the work of the National Dementia Strategy</u>. This set out four national priority objectives:

- improved early diagnosis and intervention
- improved quality of care in general hospitals
- living well with dementia in care homes
- reduced use of anti-psychotic medication

In response to the National Dementia Strategy, Lancashire County Council, NHS North Lancashire, NHS Central Lancashire, NHS East Lancashire, NHS Blackpool, NHS Blackburn with Darwen, Blackburn with Darwen Borough Council, Blackpool Borough Council, Lancashire Care NHS Foundation Trust and the Alzheimer's Society have worked in partnership to develop the Lancashire Outcomes Framework for Dementia. This framework provides a set of user and carer defined outcomes. The agencies that are partners to this agreement have all adopted these outcomes and used them as the foundation for development of local joint commissioning strategies for dementia. This ensures that delivery of the National Dementia Strategy across Lancashire is firmly rooted in the expectations and aspirations of local people who are affected by

dementia, either as sufferers themselves or as family members, friends or carers. In addition, a range of indicative outcome measures have been included in the framework to assist partners in developing local measures to track progress and improvement, as part of their dementia commissioning strategies.

A diagram identifying the different stages of the pathway is provided as Annex B

#### **Training**

Dementia training is one of the key objectives within the National Dementia Strategy and as such is an area of common interest for all agencies involved in supporting people with dementia. Therefore, as part of the work undertaken together to develop the Lancashire Outcomes framework, partners agreed to establish a time-limited multi-agency task group to consider whether there may be scope for collaboration and economies of scale in relation to dementia training. Partners involved in this project included LCC Commissioning, Personal Social Care, Training, Lancashire County Commercial Group, Lancashire Workforce Development Partnership, NHS North, Central and East Lancashire, Lancashire Care Foundation Trust and the Alzheimer's Society. The outcome of the work of this group was a set of dementia workforce competencies mapped against the types and numbers of staff across agencies who work in a role supporting people with dementia and the appropriate types, levels and costs of training required to meet the competencies identified. Due to the impact of the Comprehensive Spending Review on training budgets across partner agencies limited progress in terms of implementation has been made.

#### Improving Service Quality

In 2011 the Department of Health published the Dementia Commissioning Pack which included a set of contract inserts for a range of services. These contracts inserts set out best practice and practical actions that providers can take to ensure that their services and staff are responsive to the needs of people with dementia and their carers. The inserts are relevant to both generic and specialist services since the majority of people with dementia are undiagnosed and are therefore likely to be accessing non-specialist services.

As part of the recent review of the Council's generic contract with domiciliary care providers the DoH contract inserts for domiciliary care have been included. Plans are in development to review and update the generic care homes contract which will also in future incorporate the DoH dementia contract inserts. These measures will help to drive up quality within the care sector

with all service users benefitting from the improved standards of care and in particular those with dementia.

Many people with dementia have co-morbid physical health problems that often prove challenging in general health and social care settings. Acute hospitals and care and nursing homes are key settings where people with dementia receive support. However, evidence across the country suggests this support and the support to those working with these people could be improved and developed to greater effect.

As part of the Quality Innovation Productivity and Prevention (QIPP) this project, led by the Lancashire Mental Health Partnership Team, is seeking to provide a basis for service and system redesign in order to support people more effectively, innovatively and at reduced cost to the health and social care economy of Lancashire. It has focused on the benefits of a coordinated approach, Lancashire wide variations and how a standardised approach in key areas will deliver improved quality and better performance. The Case for Change has four key areas of focus:

- Reviewing and reducing the use of anti-psychotic medication for people with dementia
- Acute General Hospital Care
- Memory Assessment Services and ongoing support following diagnosis
- Care/Nursing Homes and Community Support

#### **Dementia Inpatient Facilities - Consultation**

Evidence suggests that it is better to care for people with dementia in their own homes or community settings rather than residential care or hospital. In Lancashire, decreasing demand for inpatient services for people with dementia (in terms of both numbers of admissions and lengths of stay) has correlated with the work to develop community services over the past few years such that increasing numbers of patients with dementia are receiving treatment and assistance through local community services. During the last year approximately 93% of dementia care contacts were in the community, supported by specialist teams. Whilst the overall numbers of people with dementia is increasing as the population ages, the further development of a comprehensive range of community supports will mean that far fewer will require an inpatient admission. In the future, dementia inpatient services will be a very specialised service mainly for patients who require intensive care and support, whose behaviour cannot be managed in the

community. Most people with dementia will receive the care and support they need in their local community.

Lancashire Care Foundation Trust have worked with partners to develop a set of consultation proposals around the future provision of specialist dementia inpatient facilities and the parallel development of a comprehensive provision of community based dementia services in every locality across Lancashire.

This public consultation exercise will commence in early December

#### Area based examples of achievements and best practice:

#### North Lancashire

- Monthly drop-in sessions run by Memory Assessment Services and the Alzheimer's Society for people with dementia and their carers held in public venues during the day/evening.
- Early diagnosis: systems established to monitor numbers with dementia on dementia registers in primary care.
- Recovery-focussed care plans in place.
- The Intermediate Support Team are working with Care Homes to ensure residents with dementia are appropriately supported, offering advice, training and support.

#### East Lancashire

- Developed a bi-monthly 'Memory Matters' newsletter.
- Development of awareness raising toolkit including DVD for South Asian Communities.
- Advice and support given to several care homes around good practice re; environments for people with Dementia.
- Development of an Easy Read Dementia website.

#### Central Lancashire

- The dementia advisor service is now well established and the hours of the service have been extended.
- A DVD has been produced together with easy read literature to compliment the dementia advisor service.
- Establishing a risk share arrangement with general acute hospitals and local GPs to best manage the physical health needs of people with high level dementia care needs

Brookside a development for enhanced care – 111 apartments with 24 hour support. Within
Brookside there is Memory Assessment Service, the West Lancashire Dementia Advisors are
based there, some Lancashire Care Foundation Trust are based there plus other community
and carer focused activities and amenities such as a Bistro, Community Choir, 'Singing For
The Brain' and music therapy.

The investigations of the task group were broken down into the key stages of the overall dementia care pathway. They spoke to a number of different stakeholders at each stage and their findings are detailed below

#### **Early Diagnosis**

There are many different types of dementia, although some are far more common than others and they are often named according to the condition that has caused the dementia

Alzheimer's disease is the most common cause of dementia. During the course of the disease, the chemistry and structure of the brain changes, leading to the death of brain cells. It is a progressive disease, which means that gradually, over time, more parts of the brain are damaged. As this happens, the symptoms become more severe.

Vascular dementia is the second most common form of dementia after Alzheimer's disease. It is caused by problems in the supply of blood to the brain. Vascular dementia affects different people in different ways and the speed of the progression varies from person to person.

Typically, the symptoms of vascular dementia begin suddenly, for example after a stroke.

Vascular dementia often follows a 'stepped' progression, with symptoms remaining at a constant level for a time and then suddenly deteriorating

#### Other types include:

Dementia with Lewy bodies Fronto-temporal dementia Korsakoff's syndrome Creutzfeldt-Jakob disease

Further information on all these different types of dementia can be found on the <u>Alzheimer's</u> <u>Society</u> website.

Dementia comes into play when memory problems begin to effect the day to day live and cause problems with judgements and understanding, lack of concentration. When these areas start to change it has an enormous impact on day to day life.

The milder part of the spectrum has not been recognised until quite recently and people with dementia (mild forms) are still able to hold down a job etc. All dementias affect different people in different ways; but it is a progressive disease.

The difficulty in diagnosis is recognised as it can often be mistaken for depression. Blood tests can be done to eliminate other factors such as anaemia and, in the case of vascular dementia, high blood pressure and high cholesterol increases the likelihood.

There is a fear of diagnosis, and better communication of support and services may address this as often the public 'fear' it more than getting cancer. Strategy development has taken place in this area both at a national and local level and recent TV campaigns will hopefully start people talking about the subject as awareness raising helps to de-stigmatise the condition. Hope needs to be promoted through the management of the condition as currently there is no known cure.

In Lancashire, GPs are now more knowledgeable than they were a few years ago and the number of referrals has increased. They have a clear understanding of dementia in the context of all the other illness they deal with and they don't all need to be dementia experts, however it would help if GP practices had a dementia specialist but it's not a mandatory requirement. The wider Clinical Commissioning Groups will have a mental health specialist under which dementia will be included.

The people who tend to remain un-diagnosed are always the people with the milder forms of the disease and some people come to the memory clinics too late to make use of the support. The more information about what can be done, the more likely it is that people will seek help and that support can be provided for those going through diagnosis. We need to increase exposure to positive examples of living with dementia in families and communities.

#### Can medication help?

Some medication can improve the quality of life but there is a clear drive to reduce the amount of anti-psychotic prescribing nationally. The benefits of medication can be significant but they also have side effects. Evidence suggests that if the drugs work for the individual they will function better with them and it slows down the progression of the illness. However towards the later

stages they become less effective not because they've become immune to them but because the illness has become worse.

Aricept is used to treat mild to moderate dementia caused by Alzheimer's disease. It improves the function of nerve cells in the brain and works by preventing the breakdown of a chemical called acetylcholine. People with dementia usually have lower levels of this chemical, which is important for the processes of memory, thinking, and reasoning. The spend on Aricept by Lancashire Care Foundation Trust on has increased over recent years.

Medication is reviewed in the first instance and evidence has shown if it has worked for the first 3 months it will help for longer periods.

#### What can be done to prevent the onset of dementia?

Whilst it is not possible to prevent all cases of dementia, there are some measures that can help prevent vascular dementia, as well as cardiovascular diseases, such as strokes and heart attacks.

The best ways to prevent vascular dementia are eating a healthy diet, maintaining a healthy weight, getting regular exercise, drink in moderation, don't smoke and make sure that the blood pressure is checked and controlled

Alcohol has never improved anyone's memory and alcohol abuse is a factor in dementia onset – particularly if someone is drinking more than recommended into middle and old age.

There is some evidence that rates of dementia are lower in people who remain as mentally and physically active as possible throughout their lives, and have a wide range of different activities and hobbies. Evidence supports cognitive stimulation techniques – methods to aid the memory, such as regularly doing crossword puzzles. Support can be provided to help people choose things that suit them.

Physical activity helps due to increased oxygen to the brain, and dancing is another example as a routine is something that has to be learnt and remembered. Music is also very evocative in terms of recalling the time/place when a song or melody was first heard and the words of songs.

The key is to help people to help themselves – enabling people to manage their own lives.

#### **Home/Community based support**

Many people with dementia are supported by non-specialist community based services and that, in terms of helping people with dementia and their carers to live well with dementia means all services must be well equipped to understand and respond positively to the needs of people with dementia. The majority of care delivered to people with dementia at home and in the community is provided by family carers

A broad range of services are available to patients and their carers within Lancashire and some examples of these include:

#### **Memory Assessment**

Memory assessment services support the early identification and care of people with dementia. They offer a comprehensive assessment of an individual's current memory abilities and attempts to determine whether they have experienced a greater memory impairment than would be expected for their age.

Charnley Fold in South Ribble is an open access resource centre within a specifically designed environment for the needs of people with dementia. It provides a hub for memory assessment services, community mental health teams (older adults), consultant clinics, enhanced day support services, dementia adviser services, flexible outreach — community support to people with dementia, peer support meetings and carers groups and an open access information and advice centre for people with memory concerns, including a drop in café.

#### Help Direct

The Help Direct Advisors are aware of the issues surrounding dementia – but signpost to appropriate agency as they don't receive specific training in dementia or other memory conditions; however all staff attend 'safeguarding adults' training which covers all vulnerable adults. Guidelines are produced that advisors go through to filter which callers need additional support. It is a very hands on approach as visits are made if felt that they are needed.

Specific training would be beneficial. If trained it would help the advisors increase their ability to recognise certain subtleties of the condition.

A 'Well being measures' tool is used to determine how people are coping with their daily life. They measure this score at the beginning and end of their intervention so they can find out the level of increased resilience through the activities and support suggested.

Help Direct also signpost carers to various organisations and services that can provide the relevant respite care support.

#### Alzheimer's Society

<u>Dementia 2012: A national challenge</u>. This updates the national dementia strategy that was produced in 2009 and looks at what is the actual experience of families and patients. It has three main areas of focus

- Driving improvements in health and care
- Creating dementia friendly communities that understand how to help creating awareness
- Better research it's been low on the financial agenda. Whilst there isn't yet a cure there have been great improvements in the care and support available.

CRISP – Carers Information and Support Programme. – This is an early stage 5 wk programme for people supporting a family member or friend with dementia. The friendly, confidential group sessions provide the opportunity for discussion about the experience of caring and provide information about dementia, legal and money matters, ways of coping day to day and getting help from local services. The Programme doesn't provide all the information all at once so the patient is not overwhelmed. Often once someone has been diagnosed people are then left alone, if they don't need any drugs or intense support at that stage. A lot of work has been done to contact people at the early stages and accompany them on their journey.

#### **Dementia Advisor Service**

Dementia Advisor Service (DAS) came out of the National Dementia Strategy. They visit people in their homes or can visit at a centre (e.g. Charnley Fold) – they are linked to a memory assessment centre. They can be with the patient for the whole journey and don't bombard them with all the available information at the point of diagnosis but take them through the stages as they get to them. Positive feedback has been received from patients who state that the DAS is very helpful.

The national campaign <u>Worried About Your Memory?</u> provides a range of guidance, one of which is a booklet that is designed to help people have a greater understanding of memory loss and the information and support that is available

There are definite gaps in services for people under 65 but the DAS however are able to try many different avenues to seek support. They also signpost to advice for benefits available, such as council tax rebate, disability living allowance, or carers funding.

Transport is a major issue in terms of gaps in service provision – often people are advised not to drive but many services are only efficiently accessed with a car.

#### <u>Carers</u>

A diagnosis can affect relationships – strain can be put on them especially if there is resistance to seeking help. The needs of carers of patients can be the same but they can also be very different.

Carers suffer higher than average instances of depression which in some instances may result in the dementia patient requiring alternative care. Problems can arise if the carer gets ill – there is an assumption by health and social care professionals that other family members will take over the care

It was felt there is a lack of suitable respite care and out of hours provision, particularly during weekend nights. A problem is that if a dementia carer wants to arrange respite care the actual patient doesn't want to deal with anyone else or let anyone else into the house. Dementia friendly care at home needs to be explored and needs to be far more intuitive and skilled rather than just task driven.

The financial strain also takes its toll on the family as the understanding of reduced financial income doesn't always register with the patient themselves.

It was acknowledged that it doesn't always help to meet with other carers of dementia sufferers as it can be too emotionally upsetting to discuss the future outlook for a person progressing through the illness. Instead it can be more beneficial to talk to carers of people with other conditions instead so they understand the issues of caring for someone without dwelling on the specific characteristics of the condition.

#### **Residential & Nursing Care**

With the provision of community based support and services, the aim is to keep people based in their own home as long as possible. However, it may get to stage where people with dementia need to go into a residential or nursing home. Many people with dementia move into a care home once their dementia progresses to a certain stage and some people with dementia have other illnesses or disabilities that make it difficult for them to remain at home

Good quality care that preserves dignity, treats people with respect and promotes independence can improve the lives of care home residents with dementia.

Challenges include finding good placements which offer the required skills, acknowledging the variable quality and availability of places and having to move long distances away from their families, which can be the case when people have very challenging behaviour

Choosing the right care home is, therefore, very important but it can be difficult.

#### Different types of care home

There are two categories of homes that are specifically registered to care for people with dementia. These are EMI (Elderly Mentally Infirm) homes offering nursing level care and EMD (Elderly Mental Dementia) which offers residential level support.

The type of home that the person requires will depend on their general health and care needs. Everyone with dementia is different. For some people with dementia the main problems that they experience will be dementia-related, whereas for other people with dementia their main problems may be caused by a different condition, such as a stroke.

Residential care homes provide help with personal care such as washing, dressing and eating. In some residential care homes staff have had specialist training in dementia care. Nursing homes provide personal care but also have a qualified nurse on duty 24 hours a day.

It is quite likely that dementia and non-dementia patients live in the same home.

All social, residential and nursing care providers must be registered with the Care Quality Commission, the independent regulator of all health and social care services in England.

#### Finding care homes in your local area

Lancashire County Council offer impartial advice and information to help families make the choice that is right for the person with dementia. Further information is available by telephoning Care Connect, the social care contact centre on **0845 053 0009**.

A social worker assessment can be carried out to determine the most suitable type of care required by the person and a directory of care homes in their local area can be provided. This is known as the County Council's 'Preferred Provider' (PP) list.

All homes included on the PP list are regularly checked and monitored by the County Council to ensure they provide high quality and personalised services, but the dementia patient and their family need to be aware that if they choose residential or nursing care from a non preferred provider that the County Council do not carry out any checks on these agencies.

Lists of local care homes and inspection reports are available from the <u>Care Quality Commission</u> (CQC) Their website provides the facility to specifically search for homes that specifically cater for dementia patients and details the latest results of inspections carried out to determine whether the home is meeting the required government standards.

Currently the PP list does not provide any detailed information on the standard or availability of care available and is generally just a list of names and contact details for a specific locality.

Many families of dementia patients have limited knowledge of the financial issues to be considered when a person needs residential or nursing home care and the social work team can assist with this aspect. Social Workers have financial knowledge of the benefits and assistance available and can arrange for council officers to do home visits for financial assessment.

Social workers are also based in hospitals and can support dementia patients and their families through the discharge process.

Not all social workers have dementia experience and additional training would potentially be able to address this. A mentoring system is in place and teams share knowledge and best practice through the discussion of individual cases but further staff development would be beneficial.

Greater integration of health and social care services could also help to address the promotion of good practice and develop bespoke 'dementia awareness' training opportunities.

A professional such as a doctor, or a voluntary organisation such as a local Alzheimer's Society, may also be able to give advice on the type of home that may be suitable for someone with dementia.

Examples of good practice in a care home include:

- Following the principles of person-centred care. This approach aims to see the person with dementia as an individual, rather than focusing on their illness or on abilities they may have lost.
- Creating opportunities for residents to spend time together and get to know each other through a wide variety of social opportunities.
- Encouraging people with dementia to maintain relationships with people outside the care home.
- People with dementia often need to have things to stimulate their interest and so an overly tidy environment is not always helpful.
- Spaces should be clearly signed and laid out to minimise any of the confusion or distress that people with dementia may sometimes feel.

It is estimated nationally that the number of places for people with cognitive impairment in institutions would need to rise by 63%, from 224,000 in 1998 to 365,000 in 2031, in order to keep pace with demographic pressures.

The tables below were taken from Lancashire Dementia QIPP initiative – A Case for Change Table A shows the number of people with dementia supported by Lancashire County Council in care homes as at August 2011.

Table A

Lancashire County Council	North	Central	East	TOTAL for LCC
Number of people with dementia	293	347	336	976
supported in care home places	293	347	330	970

The cost of a dementia residential care home place in 2010/11 was £466.50 per week and the cost of a nursing care home place for someone with dementia was £595.50 per week. Table B shows all spend on people in care homes who have dementia over the full year 2010/11

Table B

Lancashire County Council	North	Central	East	TOTAL
Annual expenditure on people	£7,033,849	£9,009,98	£7,644,873	£23,688,70
with dementia supported in a		5		7
care home places (non				
nursing)				
Annual expenditure on people	£1,717,667	£3,762,23	£2,063,703	£7,543,607
with dementia supported in		7		
nursing care places				
Total annual expenditure on	£8,751,516	£12,772,2	£9,708,576	£31,232,31
people with dementia		22		4
supported in care homes				
as a % of all care homes	51%	51%	43%	48%
expenditure				

#### Hospital based care

In Lancashire specialist dementia beds sit with the mental health trust which is <u>Lancashire Care</u> <u>NHS Foundation Trust</u>, but this is not always the case across the rest of the country. Often it is the responsibility of the acute trusts instead.

Patients often end up in hospital as dementia means that the carer or residential home struggle to cope with their behaviour

Wherever possible, people with dementia in Lancashire are supported in their homes and in their local community through the provision of a range of good quality community services and support and over the last three years significant progress has been made towards achieving this aim.

These developments have resulted in decreasing use of inpatient services for people with dementia (in terms of both numbers of admissions and lengths of stay).

During the last year approximately 93% of dementia care contacts were in the community, supported by specialist teams. Consequently current usage of the existing 65 specialist dementia inpatient beds across 4 sites is operating at an average of 46 beds (70%). This suggests that further work is needed to re-invest this unused resource in the development of additional community resources, to ensure that more people can be supported at home and in their own community.

In the future dementia inpatient services will need to become highly specialised to meet the needs of a much smaller group of people who will generally have very complex needs and are likely to be detained under the Mental Health Act. The predicted numbers of people needing this type of service are very small – up to 30 people at any one time.

One example of the community resource provided by the Trust is the Nursing Home Liaison

Team who respond to referrals from any nursing home that has a concern about a patient with a

mental health condition. They provide advice and support on the management of patients.

They also provide on-going support and education to help staff become more knowledgeable in delivering person centred care, looking at alternatives to anti-psychotic medication to find alternative ways of managing challenging behaviour to provide a better outcome for the service user.

This service currently does not operate consistently across the county but following the wider mental health inpatient reconfiguration proposals consultation, due to start in early December, the intention is that by 2016, the Nursing Home Liaison Team will be able to deliver support and advice right across Lancashire.

#### Feedback on visits to residential and nursing homes

To establish what specific services and activities are currently available for dementia residents in Lancashire members of the task group visited a number of care homes.

The key findings included:

Much evidence of best practice such as

- induction packages for staff which included training on recognising and coping with dementia symptoms
- showing and treating residents with kindness, dignity, respect, understanding and empathy.
- o promoting independence
- 'Getting to know you' booklets completed by families
- Singing and music as reminiscence therapy used to stimulate and in some cases distract residents
- Using a variety of techniques to deal with challenging behaviour such as a short nap, diversion, distraction and the calming influence of specific staff members.
- ensuring knowledge and current best practice is updated.
- Support from GPs, fast referrals to local mental health teams.

#### End of life care (EoLC)

End of life care is normally defined as the care needed during the last year of life. Dementia presents challenges to this definition given the slow progression of most types of dementia, and identifying the time for a transition to EoLC will often be difficult.

Consequently, carers of people with dementia commonly underestimate the likelihood that a person will die in the next few months.

A particular feature of dementia, however, is that the individual's communication skills deteriorate so that the ability to express their views and wishes and to make choices is lost at an earlier stage than with other life limiting conditions.

In the future, Clinical Commissioning Groups will commission NHS services on behalf of individuals; therefore a real opportunity exists for GPs to be at the forefront of commissioning high quality EoLC services for people with dementia across the whole system and the care pathway. The National End of Life Care Programme has worked in partnership with the National Institute for Health and Clinical Excellence (NICE) to produce a commissioning guide for EoLC for people with dementia.

The majority of dementia patients in a residential or nursing home would remain there for the end of their life. Unless they are in significant pain there wouldn't be much benefit of moving them out

of the residential home to a hospice or hospital as it could be very distressing for them to be in unfamiliar surroundings.

Dementia patients should be encouraged to plan as early as possible before they are unable to decide for themselves and the County Council's social work team can again help with an assessment of a person's needs as they enter the final stages of their life.

This palliative care is the active holistic care of patients with advanced progressive illness, including the management of pain and other symptoms, and the provision of psychological, social and spiritual support. The goal of palliative care is achievement of the best quality of life for patients and their families.

Lancashire County Council have produced, jointly with partners, a guide called 'Living well - Thinking and planning for the end of your life', based on the work in Central Lancashire by a group of people who were supporting family members, or working with people in residential care at the end of their lives. The guide is to help people think about and record what is important to them now, and what they want in the future when planning for the end of their life.

#### **Conclusions**

The Task Group reflected on the information and evidence they had considered throughout the review and arrived at the following conclusions:

#### Early diagnosis:

- Removing stigma and raising awareness would make it less scary and increase confidence in help available.
- Enable people to live well with dementia and help people to comes to terms with their condition.
- Education about dementia is needed, skilling up the workforce across GP practices and other front line staff.
- Increase exposure of positive experiences.
- GPs could be encouraged to add a simple memory test to the periodical health checks already undertaken for blood pressure, cholesterol etc.
- Need to be planning now for what services will be required for the next 5/10/15 years due to predicted increase in number of people with dementia by 2025.

#### Home/community based support

- Alzheimer's website has a great deal of useful advice and guidance.
- It was acknowledged that due to the small numbers of patients under 65 (currently approx 317 in Lancashire) with dementia, the commissioning of specialist services was difficult.
   However it was felt that Help Direct would be able to signpost patients and carers and offer advice and guidance.
- The topic needs to be NHS driven in terms of commissioning services however, it's unlikely there's going to be any additional funding to deliver more services so a different approach is needed. However, as the Cabinet Member for Adult & Community Services and the Cabinet Member for Health & Well Being both sit on the Health & Well Being Board they are in a position to request that issues, such as dementia services, are added to the agenda.
- Need a good business case to justify initial investment of training 'front-line' staff.
- E-learning could be a cost effective way of delivering basic awareness training.
- The Communications Team could promote positive messages of living with dementia and it might be useful to do some promotional work around myth busting.

#### Residential and nursing home care

- Adequate training for all residential and nursing home workers would enable a greater
  understanding of the condition and how to cater for the needs of the residents. The
  incentive to providers is that the training of their staff could be one of the criteria for the
  inclusion on the County Council's Preferred Provider list.
- The PP list could provide more meaningful information e.g. whether psychiatric nursing is available.

#### End of Life Care

Opportunities to discuss end of life care could be incorporated into the overall care plans
when a person moves into a residential or nursing home to ensure that the dementia
patients' wishes are respected if they lose the ability to communicate clearly.

#### Recommendations

The Task Group therefore recommended that:

- The Health & Wellbeing Board is asked to consider how dementia services will be planned over the next 5 – 15 years to meet the predicted increase in demand.
- The Cabinet Member for Adult & Community Services is asked to consider an investment in basic training for all front line staff dealing with dementia in Lancashire.
- The Cabinet Member for Adult & Community Services is asked to consider the promotion of positive messages of 'living well with dementia' in Lancashire to encourage people to seek early support.
- The Cabinet Member for Adult & Community Services is asked to review the information provided on the Preferred Provider (PP) list and consider what improvements could be made to enable people to make informed choices about residential and nursing home provision.
- The Clinical Commissioning Groups consider a periodical memory test to be carried out at the same time as other health checks.

# Acknowledgements

The task group would like to thank all those who gave their time and help to this investigation.

#### Questions to ask when visiting a Care Home

taken from the CfPS document "10 Questions to ask if you are scrutinising services for people with dementia")

Although being supported to remain at home or in a housing facility such as extra care housing is the preference for most people with dementia, in some situations this will not be possible. For some, living in a care home provides the right balance between safety and independence, and access to activity and an understanding community. Unfortunately, good quality care is far from the norm – failure to communicate, over-use of antipsychotic medication to manage behaviour, lack of stimulation, inadequate nutrition, and lack of support from specialist mental health teams – is well documented.

A third of people with dementia live in care homes; up to 75% of people in non specialist homes have dementia, rising to 90-95% in homes for the elderly mentally infirm. That increase in the population with dementia means that although a greater proportion of people will be supported at home, the number of those requiring a care home placement is likely to remain similar to the current position. There is a considerable body of evidence for homes to draw on to provide excellent support. However, individual homes can only do so much to provide good quality care. They need to be supported within the wider system of the NHS, council and the voluntary sector. In particular, homes need to be supported by specialist mental health services that provide regular interventions rather than ad hoc or crisis support.

- 1. What measures are in place to improve training and education of staff to recognise and better deal with residents with dementia?
- 2. How do you ensure best practice in dementia care?
- 3. Do you provide regular activities to stimulate people with dementia such as art, music and Life story work? Examples?
- 4. Is there a rich physical environment to aid orientation with assistive technology for prompts, reminders and communication?
- 5. Do you routinely use non pharmacological behaviour management strategies?
- 6. To what extent is there a local system of specialist mental health support for care homes?

   e.g. does Lancashire Care Foundation Trust offer any nursing liaison service. (at present this type of service is only available in the east of the county)

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# YOUNG PEOPLE'S VIEWS ON THE LANCASHIRE HEALTH AND WELLBEING STRATEGY

January 2013







#### What is PULSE?

**We are** young people representatives (aged between 12 – 22 years) from different groups across Lancashire (e.g. Youth Council, Health Action Groups, Young Carers, Long Term Health Conditions, CAMHS, Children in Care Council) who have come together to form a new county group to look at young people's health and wellbeing issues.

**We believe** that children and young people's views about health and wellbeing are important and should be gathered, shared, listened to and acted upon.

#### We aim to:

- make a positive difference to children and young people's health and wellbeing.
- make sure the voice of children and young people is heard by decision makers.
- advise these decision makers on how to make health services and health education more children and young people friendly.

#### To do this, we will:

- meet together monthly and bring information from our groups and take information back out from the meeting. For example: we have asked our groups about health priorities for young people and what they think about the Health and Wellbeing Strategy. In this way we can gain the views of a larger number of young people from different backgrounds across the county;
- provide opportunities to hear the voice of other children and young people who do not come to our meetings;
- focus on a few health issues identified as priorities by young people and those relevant to young people included in key plans and strategies;

#### Our current priorities are:

- Emotional Health and Wellbeing
- Substance Misuse (including alcohol and tobacco)
- Access to health information
- get consultations out widely to young people if they link with our priorities;
- invite decision makers to our meetings, to our presentations and go to their meetings to listen to them, be listened to and challenge them to make changes based on what young people are saying;
- run our own projects that support our priorities.

Our group is open to anyone. It is really good the way we all mix together and have fun, while learning new things and looking at health issues. Although we all have different opinions, we all listen to each other and at the end we come to an agreed decision.



#### Aims of the Report

- To give young people's views on the Lancashire Health and Wellbeing Strategy
- Promote the work of PULSE
- Explore how the Lancashire Health and Wellbeing Board and PULSE could work together in the future

Throughout this report there are questions, in speech bubbles, for the Health and Wellbeing Board from PULSE. We have also used thought bubbles to share our thinking or put forward suggestions for the Health and Wellbeing Board to consider.

PULSE would like to request feedback from the Health and Wellbeing Board on our questions and suggestions. We would also like to know how our views have influenced the work that is happening as part of the strategy.

#### **Background to the Report**

Two of the new Public Health Directors, Debs Harkins and Mike Leaf, came to a PULSE meeting on the 25<sup>th</sup> October 2012 to talk to us about the Lancashire Health and Wellbeing Board and to find out our views on the Health and Wellbeing Strategy.

Following a presentation, we worked in three groups to decide which parts of the Strategy were most important to young people. We were given 14 cards, one for each different part of the Strategy. Each group placed the cards onto a continuum according to how important or not important they felt each issue was for young people.

At the next meeting we looked at where the different groups had placed each card and discussed:

- how each issue impacts on young people;
- why we thought the groups had placed the cards where they had;
- any ideas we had for what should be done in each area that would help make a difference to young people.

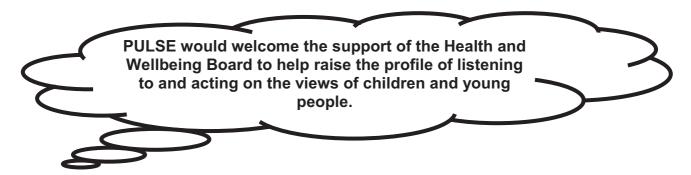
We carried out the same activity with some of our participation groups and brought the results back to our next meeting. Seven groups of young people (50 in total) took part in this activity. All of these views have been included in this report. Some of the priorities/ actions do not have seven dots on the continuum as some groups did not give a response to this part of the strategy.

A small group of young people from PULSE worked with Annette McNeil and Nicki Turner, from Lancashire County Council's Children and Young People's Integrated Health Service, to decide the layout and content of the report. Annette and Nicki used our words and views to help create a first draft, which they sent out to us to



read and suggest changes. We met again to discuss the final content which we then shared with the full PULSE group. Final amendments were made after this meeting.

In addition to this report, seven members of PULSE attended the Health and Wellbeing Strategy Event on the 16<sup>th</sup> November. We were very keen to be involved in this event and put our views forward. Although it was very positive that we had been invited and supported to attend, our feedback from the event is that we didn't feel that some of the adults valued our input because they saw us as 'just a young person' with little to offer. One of our young people reported that when they were eventually given the chance to make their point, the group of adults in their workshop rated their point as one of the most important that had been made. We feel that this example does help to show that there is still work to be done on helping some adults to see the importance and value of listening to the views of children and young people.





## Young People's Views on the Health and Wellbeing Strategy

In her presentation, Debs Harkins explained that the Lancashire Health and Wellbeing Strategy has identified four priority areas: Maternal and Child Health, Mental Health and Wellbeing, Long Term Health Conditions and Improving the Health and Independence of Older People. We will give our views on these first, including where each group placed each priority on the continuum, according to how important they felt they were to young people.

KEY:



= the position on the continuum where each group placed priority/ action



#### **Mental Health and Wellbeing**

Not	Quite	Important	Most
Important	Important		Important

All groups placed this priority as most important to children and young people. PULSE agrees that this should be a high priority. Emotional health and wellbeing has already been identified by PULSE members and wider groups of young people as a really important issue and has been selected as one of the key priorities for PULSE. Many members of PULSE are also involved with other groups of young people that are working on improving the mental health and wellbeing of children and young people.

We feel that lots of young people are affected badly by mental health and wellbeing issues which can have an impact on everything, including day to day activities. This doesn't just affect the individual but may impact on the whole family.

There are lots of pressures that young people are under which might affect how we feel about ourselves and how we cope. A consultation carried out by the North Lancashire Health Action Groups (which involved over 1,000 young people) found that there are a range of issues that could affect young people's emotional health and wellbeing e.g. family splits/divorce; family deaths/ illness; bullying; stress due to school or college work; boyfriend/girlfriend/ friendship problems; weight issues; depression; sexual assault; domestic violence; eating disorder; self harm. Low self-esteem, or a lack of self-confidence can be caused by, or be a result of, any of these. The North Lancashire Health Action Groups found that this figure was higher in schools with young people from wards with high deprivation scores.

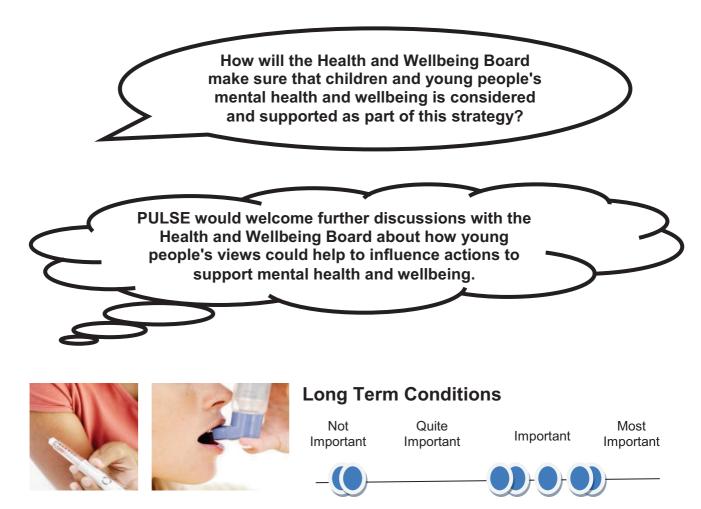
Out of those who had a problem, 66% of young people recognised there was a change in their behaviour which included getting angry; behaving badly/getting in trouble; isolating self/withdraw from social life; letting self go; giving up on school work; no motivation; less confidence; depression; self harm; over-eating/undereating; smoking/alcohol/drugs.

When asked what strategies they used to help them cope, young people reported a range of ways which included not thinking about their problem; talking with people; medication; and counselling. However the most popular answer was simply that they



did not cope, or used negative ways of coping such as alcohol/drugs, fighting, not going to school or self harm.

Young people involved in this consultation don't feel that this issue is talked about enough. We don't feel that there is enough education about emotional health and there aren't enough people who are around who can help us. We would like teachers and other adults who work with children and young people to have training so they can recognise the signs, ask if we are OK and be able to refer us for help. There should be lessons in school to help children and young people recognise symptoms, learn how to deal with issues and find out where we could get help. We would also like information on where to get support (e.g. leaflets, posters, talks in assemblies and lessons, Facebook, radio) and confidential help available at school and other places where young people go.



Some of the members of PULSE have long term health conditions so we know how important this can be for young people. Everyone has the right to have a happy life and the chance to reach their full potential, no matter what conditions they have.

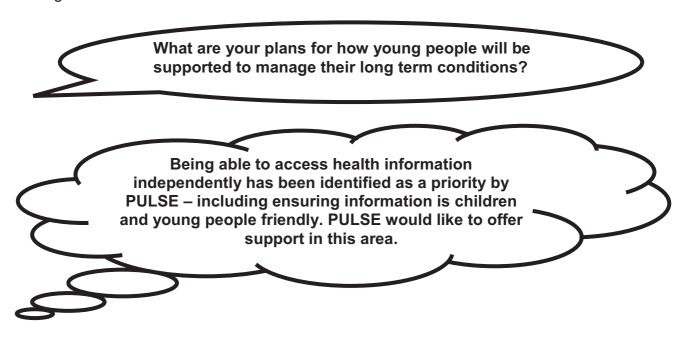
We recognise that having the right equipment and correct medication will help to ensure that young people with long term conditions can do the things that they want to and that other young people can do.

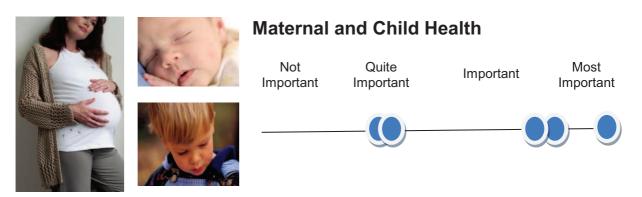


It is important that young people are supported to manage their long term conditions themselves, as much as possible, to help them both now and in the future. To do this they need to be able to access health information independently, which is written in a young person friendly way and is available in places where young people go. In a consultation on the Public Health White Paper, young people referred to the importance of being able to access interesting, engaging, accurate and high quality information that could help us understand how to be and stay healthy.

It is also important that the right support is in place for when young people become adults. As well as supporting the young person with their long term conditions, it is important to offer help with any mental health and wellbeing needs, including emotional needs, they may have. Living with a long term condition can be emotionally straining and it is important that this aspect is not forgotten.

The two groups that placed this priority as not important did this because they felt that a lot is already being done and that these conditions are generally well managed.





At first some groups from PULSE placed this as less important to young people. However, when we discussed it further we realised that this will support and have an



impact on young people in the future. We recognise that acting early will help to prevent health issues in teenage years and later on. For example, it's important that strong bonds are developed between mother and child as early as possible because this will help reduce other problems, e.g. emotional health and wellbeing issues, later in life. We also recognise that this priority could offer support to teenage mothers; to young carers who may need to support relatives who have health issues, both physical and emotional; and to young people who are in families who have, or are expecting, a baby. It is good that the focus will be to improve the health and wellbeing of all children and young people as well.

Lots of our discussions focused on the importance of helping to make young people fully aware of the consequences of having a baby and becoming a teen mum. Some girls are saying they want to get pregnant and more should be done to educate them on the impact that this decision can have. When young people talk about what health issues are important to them, Sex and Relationships Education (SRE) comes up time and time again.

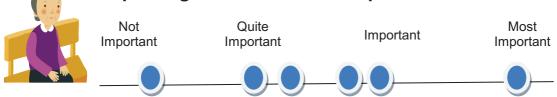
Lots of consultations show that young people do not think SRE is adequate. We feel more information and knowledge about sex would help us to delay having sex for longer and make it more likely we would practice safe sex. Building self esteem and self confidence would help us cope better with the many pressures to become sexually active. More time and a higher priority should be given to Personal, Social and Health Education (PSHE) in schools, which includes SRE. There should also be better training for teachers so they feel more confident to deliver this in the classroom. Although SRE was identified as an important priority for young people, PULSE chose not to have this as a main priority because there is already another young people's group championing this, namely the SRE Campaign Group, as part of the Youth Council. This group is working hard to develop a SRE Charter for Schools to help make sure that this important subject meets the needs of young people in Lancashire.

As well as having better SRE, young people want more widely available, better quality and accessible local sexual health services. However, many worry about being seen using these services and being labelled for doing so. Some are put off from going as they worry about being judged by the staff for using them. Making sure services, such as access to contraception, are easily accessible, based in places that young people already go and are young people friendly, is key.

How will you make sure that the services and support that is going to be offered as part of this action will be young people friendly e.g. age appropriate and easy to access?



## Improving the Health and Independence of Older People



Not surprisingly this issue was seen as being less important than other issues for young people. However, PULSE recognises the link between this priority and the action around Loneliness in Older People and Mental Health and Wellbeing.

The groups that placed this higher up the continuum felt that older people do not have a voice, just like young people. They are a vulnerable group in our communities and so need help and support to be healthy and independent. When you get older, your health and independence can easily change.

#### **Ten Actions**

In her presentation, Debs also explained that ten actions have been identified. Early response to domestic violence and support for carers were seen as being of higher importance to young people. However, all of the remaining actions were identified as being important to young people by at least one of the groups.



Stopping domestic violence early was felt to be very important to young people of PULSE and the other groups who took part in this activity. We recognise that domestic violence isn't always about physical, violent behaviour but can be emotional and/or sexual abuse as well. This issue is often hidden away and not spoken about. There is a concern that children and young people can get overlooked if the focus for support is mainly on the adult who is affected. It was felt that not supporting children and young people who have experienced or witnessed domestic abuse would have a long term effect on emotional health and wellbeing such as trust issues in future relationships, shyness, anger management issues and a belief that violence is right.

We feel that it is really important to make sure that young people are supported as well as the 'victim'. It is also important that this issue is discussed in PSHE lessons to help raise awareness with young people. We also feel that there should be training for staff so they can spot the signs and offer support/ signpost to help. Offering



counselling/ support to young people, so we can talk to people to help them to cope with this issue, is also important.

We feel that it is important to encourage everyone to talk about domestic violence rather than turning a blind eye to opportunities to intervene.

How will you consider young people's thoughts and feelings on the subject to make sure children and young people don't get forgotten in this important area?

How will support be offered to children and young people through this strategy?



#### **Support for Carers**

Not Quite Important Important Most Important

All groups rated this as important or very important. Some members of PULSE are young carers themselves, or know people who are, and therefore are very aware of the impact that this can have on young people who have caring responsibilities. Carers need support to enable them to keep physically and emotionally healthy as caring for someone can be stressful, hard work and can lead to feelings of guilt on both sides. Being a young carer can also mean that young people miss out on some of the usual teenage things.

We feel strongly that the needs of young carers should be considered as part of this strategy as well as the needs of adults who are carers. This includes more support for young carers to stay in education whilst caring for relatives and more opportunities for young carers to have fun doing the things that their friends are doing. In some cases there may be a need for financial support and support to make their accommodation suitable.

The Health and Wellbeing Board may wish to seek the views of how things could be improved for young carers through the Young Carers Forum which is commissioned by Lancashire County Council and coordinated by Barnardos.





# Identify those who are at risk of admission into hospital and provide appropriate intervention

Not	Quite	Important	Most
Important	Important		Important

This was considered to be of high importance to young people by two groups. Reasons given included young people missing out on school (and impact that this might have on their future) and missing out on their social life through the need to keep going into hospital.

For older young people, one group felt that the children's ward is not always most appropriate for them and this may affect how they feel about being in hospital. This may impact on their emotional health and may even result in them refusing to go back in because the care they receive doesn't meet their needs. One possible suggestion put forward was to have separate teenager wards (14 – 19 years and up to 25 year olds if young person has additional needs) or give young people the choice at 16 for the young person to decide whether they want to go on the children's ward or adult ward.

One group felt that there are other more important areas for development than this at present.

How will you make sure that the appropriate interventions within this part of the strategy meet the needs of children and young people?

How will you identify children and young people that are at risk of admission into hospital?





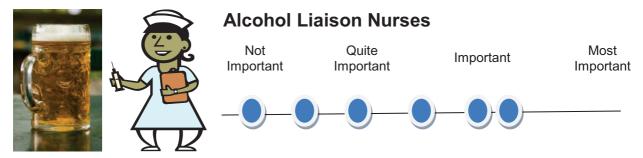
Most of the young people in PULSE felt that this action was important; recognising the impact that smoking in pregnancy has on the future health of the unborn baby. It was felt that the group who placed this lower down had probably not considered the wider picture and recognised this link. It was felt that when tackling this issue it was important to consider teenage parents and the issue of other adults smoking in the home around a pregnant mother. Awareness needs to be raised of the impact of smoking in pregnancy. We also want this action to include not just tobacco but other substances, such as cannabis.

PULSE is concerned that many people, particularly teenage mums, may be reluctant to admit that they smoke due to a fear of being judged. It is important that professionals working in clinics are not judgemental and that services are young people friendly. Training on working with young people should be delivered to members of the CYP Workforce.

Early intervention and prevention was felt to be important by the young people which includes more drugs, alcohol and tobacco education in schools, starting at an earlier age and smoking cessation sessions available for young people to help them stop smoking before they become pregnant.

PULSE has identified substance misuse, including tobacco, as one of their priorities so would like to offer to support the Health and Wellbeing Board with this action.





Although this action wasn't placed as high as other issues on the continuum, we recognise that lots of young people are drinking, with binge drinking identified as a particular problem. Young people in the group said they knew other young people who have been taken to hospital because they have drunk too much alcohol.

It was felt that some groups placed it lower down because they didn't know much about alcohol liaison nurses. Another group felt that this action was not important because alcohol liaison nurses would not be much use or that there are already services out there to support with alcohol issues.



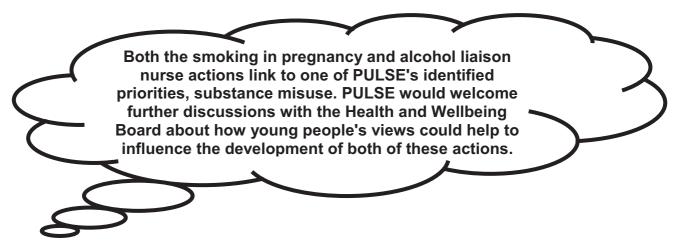
It was suggested that alcohol liaison nurses should have a preventative, early intervention role specific to children and young people. This could include working in schools and linking to hospital A&Es to identify those young people who are attending and step in to offer support. It would also be a good idea for the alcohol liaison nurses to link with GPs and pastoral care teams in schools, (based on the idea that young people may speak to GPs and teacher before anyone else) and deliver information about their service as part of the PSHE curriculum or through assemblies. It was also felt that, to make sure that the service is young people friendly, there should be training to support the alcohol liaison nurses to work effectively with young people.

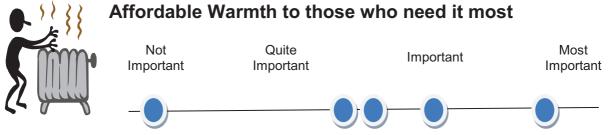
The messages given to young people about their drinking shouldn't focus entirely on 'Don't do it' – information should be given about how to keep safe when drinking and how to reduce any harm caused as a result of unsafe drinking.

Relevant information for young people should highlight the impact of unsafe drinking.

How will you make sure that children and young people's needs and views are used to help influence the development of the smoking in pregnancy and alcohol liaison nurse actions?



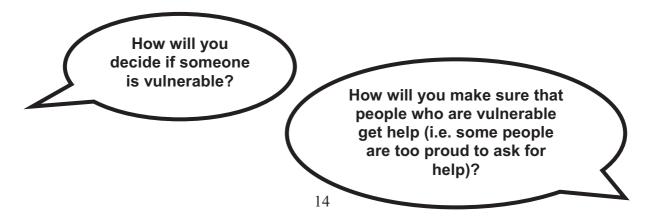




The young people of PULSE recognise that this is an issue that affects young people and not just the very old and very young. We feel that long term conditions such as asthma would be impacted on and living in a cold house could mean that young people may be more at risk of developing respiratory illnesses and other more serious illnesses. We also recognise that living in a cold, damp atmosphere may lead young people to develop depression/ mental health issues. It may also mean that young people are less able to concentrate on their homework and lead to them falling behind with studies, affecting their future career prospects.

Suggestions put forward included providing alternative heating sources for those most vulnerable (e.g. calor gas and halogen heaters); providing warm clothes for vulnerable people (e.g. free jumpers and onesies); and supporting people to properly insulate their homes. This includes giving them information and help so then they know how to properly insulate their homes. It was also felt that some people might not trust the people who ring up offering them free insulation because they think it might cost them money and it's a trick.

One group of young people felt that this action requires a multi agency approach and isn't necessarily an important priority for health services.







# Joined Up Support for Vulnerable Families (First Pregnancy)

Not Quite Important Most Important Important Important

It was felt that the group from PULSE that placed this lower down on the continuum had perhaps not thought about how this impacts on children and young people. Young parents were felt to be vulnerable and should be included for this joined up support. Getting help early was seen to be important and would help support children and young people's physical and mental health now and in the future. Providing help early was also felt to lead to less, more expensive, support in the future.

As with the discussions that took place around Maternal and Child Health, we feel that things need to be put in place to address young people having babies very early. Some young people suggested that shocking young people into not wanting a baby by sharing the reality of having a baby (e.g. using real care babies and films showing the reality of looking after a baby). This would help to challenge media images that tend to glamorise teenage pregnancy. Again, better SRE was suggested as a way of helping to address this.

Why is this only for first time pregnancies? What happens if diagnosis of mental health issues/ long term conditions, which may make a family vulnerable, comes after the first pregnancy (i.e. post natal depression)?



## **Healthy Weight Environmental Measures**

Not Quite Important Important Important Important

Being a healthy weight, particularly eating healthily, was recognised as an important issue for young people by most groups.

Being an unhealthy weight has an impact on body image, confidence and mental health. It can also lead to bullying. More support is needed to help obese young people to make healthier choices to try and prevent their long term health being affected.

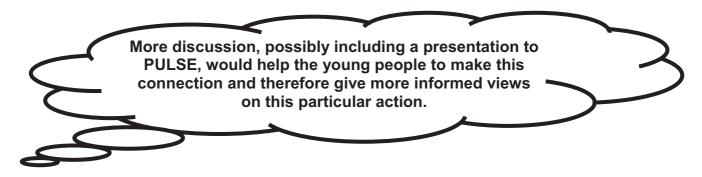


Young people recognised the influence that the media and food advertising has on encouraging them to make less healthy choices. It was also felt that some young people prefer junk food instead of meals and fill themselves up on food full of sugar, fat and calories. There was also the suggestion that some young people don't realise or care about the impact that over eating and not doing enough exercise has on their future health.

A comment was also made that the focus of this action shouldn't just be about over eating but should also focus on not eating enough.

As with many of the other actions, better education and information designed specifically at young people were put forward as suggestions. Another suggestion was to ensure that good healthy food and more opportunities for exercise were offered in schools.

We recognise that many of the groups failed to see the connection between the choices they make and the lack of choice that might exist due to the environment around them, which is the focus of this action.





# **Self Care – Encouraging People to Take Control of their own Health and Wellbeing**

Not	Quite	Important	Most	
Important	Important		Important	

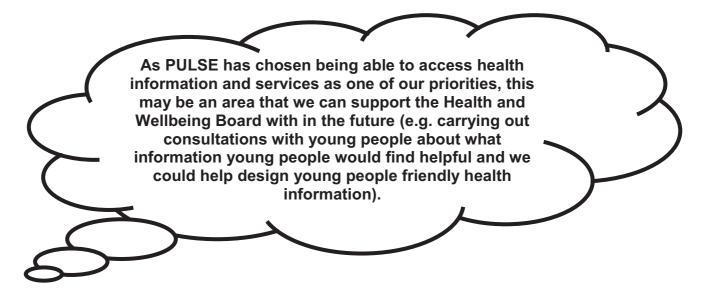
Many of the groups placed this lower on the continuum than other issues. However, although it might not seem important to young people at the moment, we recognise that encouraging people to take control of their own health and wellbeing will help them in both the short and long term. For young people it will also help them to become more independent.

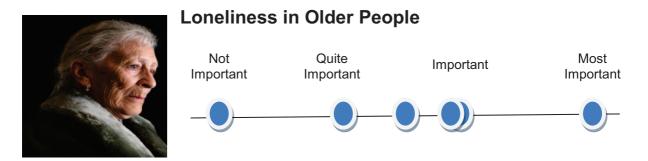
It is natural for young people to take risks and live for the moment. We do not always fully understand the importance of looking after our health and wellbeing now for our future health. There is also a danger that telling us not to do something may make it more likely that we will take part in risk taking behaviour.



We feel that we don't get enough health information and what we do get is often not written in a young person friendly way. Some of us don't have the confidence to access health services or the knowledge about where to go for help. Another barrier for us accessing services is that we don't want to be seen, by our friends or people that know us, when we are accessing specialist services.

Information for young people on how to look after our health and wellbeing needs to be more accessible and needs to be presented in a young people friendly way (e.g. bright, colourful, fun and designed by young people). Listening to Children's Views on Health Provision – a Rapid Review (National Children's Bureau, May 2012) shows that children and young people acknowledge the importance of being healthy and having a healthy lifestyle, but do not always feel they have access to the information and advice that would enable them to make healthier choices.





Two groups thought this was the least important part of the Health and Wellbeing Strategy for young people because it doesn't really affect us at the moment. However, other groups recognised that it might do when we are older as it could lead to depression and other conditions. Others felt that it could impact on some young people if they have an older relative.

Young people have a part to play in helping to stop older people feeling lonely by spending more time with them.



## In addition to the questions above, PULSE would like to know:

How much of what is being planned to be done in the strategy will be about children and young people? How will you work out how you will spend your budget and how much will be for children and young people? How will you find out about what children and young people need? What do you think about **PULSE?** What would be the best way for us to communicate with each other? How could PULSE best help support the Health and Wellbeing Board and Strategy? How can PULSE and the Health and Wellbeing Board best work together?



#### Our suggestions for how we could work together in the future

- PULSE would like to support the Health and Wellbeing Board and other decision makers with any of our identified priorities of emotional health and wellbeing; substance misuse and access to health information and services. This could include providing views on proposed actions; carrying out further consultations with a wider number of young people to gain their views on specific related issues to inform future actions; helping to produce children and young people friendly materials and resources etc.
- PULSE would like to support the areas on the Strategy which we feel are most important to young people i.e. domestic violence and long term conditions.
- Representatives from PULSE would like to attend specific Health and Wellbeing Board meetings and would like to invite members of Health and Wellbeing Board to attend specific PULSE meetings.
- Discussions need to take place to work out the best way for:
  - a) PULSE to be kept updated on the work of the Health and Wellbeing Board and Strategy;
  - b) the Health and Wellbeing Board to be kept updated on the work of PULSE;
  - c) children and young people's views to be shared with the Board and wider groups.
- PULSE would like the Health and Wellbeing Board to help them champion the views of children and young people and encourage other decision makers to listen to and act upon their views.

#### Conclusion

PULSE have highlighted a number of areas from the Health and Wellbeing Strategy that are important to young people.

PULSE was established to:

- make a positive difference to children and young people's health and wellbeing.
- make sure the voice of children and young people is heard by decision makers.
- advise these decision makers on how to make health services and health education more children and young people friendly.

In this report, opportunities have been identified where PULSE feel they can offer additional support to the Health and Wellbeing Board. PULSE would welcome a response to the questions and opportunities identified for joint working.

We would welcome a written response and would like to invite you to attend a future PULSE meeting to present this.

