Dementia in Oldham

Overview and Scrutiny Board

Sangita Patel (Scrutiny and Improvement Officer)

11 June 2013
Crompton Suite, Civic Centre, Oldham

A PURPOSE OF THE REPORT

To provide the Overview and Scrutiny (O&S) Board of the outcome from the Dementia workshop that took place on 25 April 2013.

B BACKGROUND

The dementia needs assessment had been previously considered by O&S Members, which led to a dementia workshop being organised. This was to enable Members and representatives of Oldham Healthwatch, Clinical Commissioning Group, Council, voluntary, community and organisations and residents groups in Oldham, to share best practices and have an input in the work of dementia. The notes of information and discussions shared are attached to this report.

D RESEARCH

The Department of Health on 15 May 2013 produced a report that marks progress in the first year of the dementia challenge. The report highlighted the key responsibilities for Council, which included:

- Contribute to an increase in diagnosis rates through health checks for 65-74 year old. The information provided at health checks to raise awareness for people experiencing memory difficulties e.g. training tools, leaflets;
- To meet carers eligible need for support in response to Care and Support Bill;
- To make a national dementia declaration;
- Form a Local Dementia Action Alliance which would be responsible for improving the lives of people with dementia in the local area;
- To provide sufficient funding to meet the needs of people with dementia and their families in response to the Dilnot review;
- Integrate care and support for people with dementia and that the Health and Wellbeing Boards lead on this; and
- Create the right environment to help people with the condition to have an improved quality of life (£50m worth of capital funding for 2013-2014 was made available by Government to do this).

E FINDINGS
Information relayed at the workshop clearly demonstrated that dementia was both a national and local priority. In Oldham, it was apparent that this was a priority for the Health and Wellbeing Board and various groups such as the Dementia Commissioning Group, Integrated Commissioning Partnership and Oldham Dementia Partnership. Dementia was also included the Joint Strategic Needs Assessment from April 2012, whilst a Dementia Commissioning Plan had been produced. Work was underway for the delivery of the new memory service in Oldham.

The vision for Dementia in Oldham is:

To enable people with dementia to lead as full and active life as possible:
- To receive an early and accurate diagnosis
- To receive the information and support they need to make decisions about their life and for their carers to feel well supported.

People with dementia will:
- Have their individual needs assessed
- Receive coordinated services throughout the dementia care pathway
- From well trained and skilled practitioners
- Who treat them with dignity and respect

The work had been complemented by a dementia needs assessment that had been undertaken jointly, which looked at all stages of the care pathway from early diagnosis to end of life care. This work began in April 2012 where dementia evidence base and national policies had been reviewed, over 30 key stakeholders had been interviewed and a series of workshops of over 100 people had taken place. Age UK had helped to find out what people with dementia in Oldham thought about the services available in Oldham and how dementia was affecting them. Part one of the needs assessment was completed and focused on early diagnosis and post diagnostic support. This had led to the development of a new model for memory services that will lead to quicker diagnosis, with shorter waiting times and more information and support or people once they have had a diagnosis of dementia confirmed. Oldham Council and Oldham Clinical Commissioning Group have committed nearly £400k new investment for this. Discussions were currently taking place with the providers of the new service.

**Key points from workshop discussions**

a) Training
- Staff working in care homes should regularly attend dementia awareness training sessions and that they should share this with their colleagues to ensure consistency in approach.
- All key professionals who regularly come into contact with patients who have/or may have dementia, have regular specialised training such as GPs, nurses and social workers.
- Dementia Champions should be recruited in Oldham who regularly come into contact with the public e.g. staff working at banks, supermarkets, post offices, corner shops, postal workers, plumbers. These individuals should be trained on identifying symptoms of dementia and the process of reporting.
- Any training delivered should be integrated across health and social care and that carers should have an input in the design and delivery of dementia training.
b) Signposting and Information

- Information should be made easily available and accessible in various formats, which should include a pack with a fact sheet, flow chart of the process and contact details of key organisations.
- Discussions would need to take place to agree the terminology that was consistent and appropriate for all communities in Oldham.
- The roles of Community Development Workers at each District should be utilised to promote the work and develop links with local communities.

c) Learning from others

- Rochdale’s Mental Health charity provides support for people with dementia and their carers through a range of activities such as taking people out with dementia on outings to reduce social isolation. All staff working at the charity was fully trained and that this work could be rolled out across Oldham.
- The work undertaken by Saddleworth Carers Group could be replicated in other areas in Oldham who worked closely with patients and local GPs.

d) Involving the person with dementia in planning, design, implementation and evaluation of services.

e) Care Management

- Emphasis should be placed on caring and reducing social isolation and loneliness for those undertaking roles that involves working with a person with dementia.
- Role of carers should be enhanced that requires them to write up brief notes of visits and to be consistently proactive in dealing with issues.
- Discussions would need to take place with Chemists who could dispense pills and fill the dispensers.
- Assessment processes should be evaluated to determine social and health needs as well as providing opportunities for individuals and their carers to have confidential conversations separately.

The key points highlighted at the workshop complements evidence already in existence and work is already in progress that addresses some of the issues highlighted at the workshop.

E  RECOMMENDATIONS

It is recommended that the O&S Board notes and makes any suggestions on the information contained within this report.

F  CONSULTATION UNDERTAKEN

Legal  □  Finance  □  Other  □
N/A

G IMPACT ON COMMUNITY STRATEGY & COMMUNITY COHESION
N/A

H IMPACT ON EQUALITIES
N/A

I MONITORING PERIOD (monthly/quarterly/6 monthly)
N/A

J REVIEW PERIOD (6 months/1 year)
N/A

K APPENDICES
Appendix 1 – Notes from Dementia workshop
OVERVIEW AND SCRUTINY DEMENTIA WORKSHOP NOTES

25 APRIL 2013

Background

The Overview and Scrutiny Health Task and finish Group at its meeting on 12 March 2013 agreed to organise a Dementia workshop to review future plans for the future. The workshop was also an opportunity to have an input in the future delivery of dementia services in Oldham. The notes include the discussions that took place at the workshop.
## Participants

<table>
<thead>
<tr>
<th>Name</th>
<th>Organisation</th>
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<tr>
<td>Councillor Colin McLaren</td>
<td>Oldham Council</td>
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<td>Councillor Derek Heffernan</td>
<td>Oldham Council</td>
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<tr>
<td>Councillor Susan Dearden</td>
<td>Oldham Council</td>
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<tr>
<td>Olwen Fish</td>
<td>Healthwatch</td>
</tr>
<tr>
<td>Averil Cunnington</td>
<td>Priest and Carer - Saddleworth</td>
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<tr>
<td>Rubina Malik</td>
<td>Pennine Care</td>
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<tr>
<td>Sarah Dodgson</td>
<td>British Red Cross</td>
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<tr>
<td>Christine Wilson</td>
<td>Oldham Council</td>
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<tr>
<td>Paul Rainford</td>
<td>Community Voice Ltd</td>
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<td>Julie Radcliffe</td>
<td>Together</td>
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<td>Sarah Taylor</td>
<td>Together</td>
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<tr>
<td>Christine Dennis</td>
<td>Finwood and Districts Residents Association</td>
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<tr>
<td>Wynn Sharp</td>
<td>Finwood and Districts Residents Association</td>
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<tr>
<td>Gary Rowbottom</td>
<td>Healthwatch</td>
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<tr>
<td>Anna Sidebottom</td>
<td>Healthwatch</td>
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<tr>
<td>Peter Sidebottom</td>
<td>Healthwatch</td>
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<tr>
<td>Debbie Fricker</td>
<td>Crossroads Care in Greater Manchester</td>
</tr>
<tr>
<td>Alison O’Brien</td>
<td>Saddleworth Patient Participation Group</td>
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<tr>
<td>Sylvia Parkington</td>
<td>Healthwatch</td>
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<tr>
<td>Helen Morris</td>
<td>Dementia Friends Champion</td>
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<tr>
<td>Debra Sparks</td>
<td>Home Instead Domiciliary Care</td>
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<td>Dallas Baker</td>
<td>PA to Gary Rowbottom</td>
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<td>Jade Czuba</td>
<td>Healthwatch</td>
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<td>Fiona Hague</td>
<td>Crosswards</td>
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<td>Yvonne Lee</td>
<td>Age UK Oldham</td>
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<tr>
<td>Hayley Misell</td>
<td>Alzheimer’s Society</td>
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<tr>
<td>Ratilal Chohan</td>
<td>Carer</td>
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<tr>
<td>Diane Pleasant</td>
<td>Public</td>
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<tr>
<td>Sue Neilson</td>
<td>Oldham Clinical Commissioning Group</td>
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<tr>
<td>Paul Smithies</td>
<td>Carer</td>
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<tr>
<td>Dr Keith Jeffery</td>
<td>Clinical Director for Mental Health - Oldham Clinical Commissioning Group</td>
</tr>
<tr>
<td>Dr Lisa Wilkins</td>
<td>Oldham Council - Consultant in Public Health Medicine</td>
</tr>
<tr>
<td>Jonathan Sutton</td>
<td>Oldham Council - Joint Commissioning Manager - Adults</td>
</tr>
<tr>
<td>Michelle Bradley</td>
<td>Oldham Council - Associate Assistant Director - Integrated Commissioning &amp; Partnerships</td>
</tr>
<tr>
<td>Koser Khan</td>
<td>Oldham Council - Research &amp; Engagement Specialist</td>
</tr>
<tr>
<td>Jo Charlan</td>
<td>Oldham Council - Scrutiny and Improvement Officer</td>
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<tr>
<td>Sangita Patel</td>
<td>Oldham Council - Scrutiny and Improvement Officer</td>
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Improving Services for People with Dementia and their Carers

Overview and Scrutiny Committee Workshop
April 25th 2013

Today

2.00 Welcome
Colin McLaren, Chair Overview and Scrutiny Committee

2.05 Overview of the workshop
Dr Keith Jeffery, Clinical Director for Mental Health, Oldham CCG

2.10 Introduction to Dementia and the Oldham Dementia Programme
Dr Lisa Wilkins, Consultant in Public Health Medicine

2.35 Living with dementia in Oldham - Carers/patients stories
Paul Smitten

Today Cont

3.00 The Dementia Pathway – Experience of the Committee member’s constituents
Facilitators –
- Group one: Jonathan Sutton and Michelle Bradley
- Group two: Lisa Wilkins and Keith Jeffery

3.50 – 4pm Summing up and next steps
Colin McLaren and Jonathan Sutton

Introduction to Dementia and the Oldham Dementia Programme

Dr Lisa Wilkins
Consultant in Public Health Medicine

National priority

- NICE guidelines - 2004/2006
- National Audit Office report - 2007
- National Dementia Strategy - 2009
- Quality Outcomes for People with Dementia - Coalition update - 2010
- PM’s Challenge on Dementia – 2012
- NHS Operating Framework priority – 2012/13
- NICE Quality Standards
- RCP National Dementia Audit – 2011
- CQC reports

Local Priority

H&WBS - Ageing well
- Improving support for people with dementia
- Improving support for carers
- Decreasing loneliness and isolation
- Preventing falls
- LTC
But younger people have dementia too
What is dementia?

'Dementia' is a term used to describe a syndrome that may be caused by a number of illnesses in which there is progressive decline in multiple areas of function, including decline in:
- Memory
- Reasoning
- Communication skills
- Ability to carry out daily activities

What is dementia? 2

Alongside this, individuals may develop behavioural and psychological symptoms in dementia (BPSD) such as:
- Agitation
- Aggression
- Wandering
- Shouting
- Repeated questioning
- Sleep disturbance
- Depression
- Psychosis

What are the causes of dementia?

- Alzheimer's disease (AD): 62%
- Vascular dementia (VaD): 17%
- Mixed dementia (AD and VaD): 10%
- Dementia with Lewy bodies: 4%
- Fronto-temporal dementia: 2%
- Parkinson's dementia: 2%
- Other dementias: 3%

How many people have dementia?

- 800,000 in England
- 17,000 under 65
- 1 in 3 people aged over 65 will have dementia before they die
- Double over next 30 years
- 80% care home residents

How many people have dementia in Oldham?

- Predicted prevalence – 2,300
- GP register size
  - Jan 2013 – 1,425 – 62% of PP
  - Ranked 195th best CCG out of 211
  - Predicted 4% increase per year
What are the national priorities?

- Living well with Dementia: A national Dementia Strategy? 2009 - 17 Objectives
- Quality Outcomes for people with dementia – 2010
  - Good quality diagnosis and intervention for all
  - Improved quality of care in general hospitals
  - Living well with dementia in care homes
  - Reduced use of antipsychotic medication
  - Underpinned by improvements of community personal support services

National priority 2

- PM Challenge – 2012, by 2015
  - Improvements in health and care
    - Improved diagnosis; CQUINs; Information on local services; Innovation fund
    - Dementia friendly communities that understand how to help
      - Dementia friendly communities
      - Awareness campaign
      - Pledges from businesses
    - Better research

What are we doing in Oldham?

- H&WBs priority
- JSNA – started April 2012
- Dementia Commissioning Group – June 2012
- Deep dive integrated Commissioning Partnership – August 2012 → POP
- Dementia Commissioning Plan
- Oldham Dementia Partnership – March 2013

Vision

To enable people with dementia to lead as full and active life as possible:
- To receive an early and accurate diagnosis
- To receive the information and support they need to make decisions about their life and for their carers to feel well supported.

People with dementia will:
- Have their individual needs assessed
- Receive coordinated services throughout the dementia care pathway
- Have well trained and skilled practitioners
- Be treated with dignity and respect.

Objectives

10 Objectives to improve health and patient/carer experience

2 Value for money:
- To increase focus on patient and carer support and early intervention to prevent costly crises occurring thus decrease avoidable hospital and care home admissions and readmissions.
- To enhance support to care homes in the management of inter-current acute illnesses and behaviour that challenges, decreasing the need for hospital admissions for care home residents.

Dementia Needs Assessment

- Started April 2012
- Policy and evidence base review
- Over 40 interviews so far
- Workshops >100 people

Completed
- Part one – Early diagnosis and post diagnostic support
- Part two – Experiences of Dementia Care and Services: The Views of Patients with Memory Problems and their Carers
- Part three – Antipsychotic and anti-dementia drug prescribing
Oldham Dementia Partnership

- Desire amongst everyone to improve quality of care they are giving
- Need for:
  - Coordination and collective action
  - Harness expertise and enthusiasm
  - Forum for people with dementia and their carers to influence service developments
- First priorities:
  - Carer and primary care training
  - Information pack and service guide
  - Public Awareness

Other Actions Being Taken

1. Memory service
2. RAID – Psychiatric Liaison Service to PAHT
3. Carers strategy
4. CQUINs
5. Primary care incentives and education
6. Speech and language therapy
7. Anti-psychotic prescribing

Actions Being Taken 2

- Reablement
- Respite care
- Intermediate care
- Healthcare support to care homes
- Dementia friendly communities
- Dementia champions and dementia training
- Community mental health teams

Group work

- High level pathway
- Highlight feedback from previous engagement
- Do the findings ring true with Member’s constituents’ experience of dementia care in Oldham?
- Is there anything that you would like to add?

Dementia Care Pathway 1/5

- Early diagnosis
- Initial post diagnostic support and information
- Maintaining skills
- Social activity & preventing isolation

- Public awareness
- Professional awareness
- Memory service diagnostic assessment
- CQUIN and RAID in hospital
- Memory/ liaison practitioners
- Care plan
- Information pack and service guide
- Structured group education programme
- Carer and peer support groups
- Care needs assessments
- Carer training
- Cognitive stimulation programme
- OT / psychology skills training and coping strategies
- SALT
- Reablement
- Facilitated group activities
- Volunteer support to access community activities / undertake usual activities

Groups

Group one:
- Support live at home
- Care homes
- Carer needs
- Safeguarding
- Staff development

Group two:
- Primary care
- Keeping out of hospital
- Hospital care
- Specialist mental health support
- End of life care
- Staff development
Key messages

- Similar to national picture
- Widespread problems throughout care pathway
- Mainly crisis intervention – focus must shift early and continuing regular support
- Navigating system problematic – need named key worker
- Inequities access
- Major staff development needs
- Dependent on carers but not supporting
- Nuggets of excellence – rapidly shifting baseline
- Desire for change
- Credibility established - Clinical leadership

OV&S Committee

- Recognition dementia:
  - High risk
  - Long term programme
  - Challenge of scale and complexity
  - Rapidly shifting baseline services
  - Most services not dementia specific
  - Majority not new services but better care and services

  - Huge opportunities to improve quality of life and care

Spare slides

Dementia Commissioning Plan Objectives

1. People with dementia receive care from staff trained in dementia care and are treated with respect and dignity.
2. People with suspected dementia receive an early and accurate diagnosis. People newly diagnosed with dementia and/or their carers receive information about their condition, treatment and the support options in their local area.
3. People with dementia have an assessment and an ongoing personalized care plan, agreed across health and social care that identifies a named care coordinator who addresses their individual needs.
4. People with dementia are supported to lead as active a life as possible and to maintain their independence.
5. People with dementia, while they have capacity, have the opportunity to discuss and make decisions about their future care.
6. Carers of people with dementia are offered an assessment of emotional, psychological and social needs and are well supported to meet those needs.

7. Carers of people with dementia have access to a comprehensive range of respite/short-break services.

8. People with suspected or known dementia using acute and general hospital inpatient services or emergency departments have high quality care and access to a liaison service that specialises in the diagnosis and management of dementia.

9. Care homes provide high quality care and treat all patients with dementia as individuals and provide a stimulating environment.

10. People in the later stages of dementia receive well planned and coordinated end of life care so that they die in the place and in the way that they have chosen.
Following the delivery of the presentation at the workshop, the following information was relayed in response to questions asked after the presentation was delivered:

- £0.5 million was being spent for the new memory service, which would be commissioned by Oldham Clinical Commissioning Group. There was a programme of 5 years work to implement.
- The proposals for preventative work included the NHS Health check programme, the memory clinic which would provide education and training for carers and the opportunity for the voluntary sector to tender for this contract. This would keep people active and reduce isolation and/or loneliness. There was also an opportunity to re-focus the money accordingly, enhancing schemes such as for reablement where the worker could spend up to an hour with the carer. This could also be opportunity where top tips on practical ways could be shared.
- There were a range of scores and tests in existence to determine whether an individual had dementia, depression or other reasons.

**Group One Discussion from a Social Care Perspective – Key points**

**Costs of care**
- It was difficult to define what a health problem was and what a social care problem was. This posed difficulty in who would pay for the associated costs. It was also emphasised that a health condition should not be means tested.

- Although dementia was a health condition, the related needs that arise were considered as social care needs “social needs are defined as getting up and getting dressed, the dementia is the health part”. The Group felt that this was not clear and needed clarity.

- Openness and transparency was needed as a nursing home could claim the money back, as they had people with dementia, but they did not tell anyone about it.

- When social care was delivered in one area, it felt like a ‘proper caring system’. The current climate has staff travelling miles leaving them minimum time to spend with the person with dementia and only having time to prepare their meal than actually spending time with the individuals. Affordability and distance that carers have to travel for support was also raised.

- Isolation was one of the causes of dementia and emphasised the importance taking people out of the house. ‘Caring is the most important thing rather than the cleaning’

**Referring and supporting individuals**
- Volunteers from luncheon clubs mentioned that they ‘come across awful lot of people that do not have any support or anyone’. It was difficult to get them to see their doctor as they could not refer them due to ‘no legal standing’. Those who were not family members could not help individuals who may have signs of dementia to get support from their GP’s. Other volunteers mentioned that they could not refer individuals, posing difficulties as statutory bodies would not accept referrals on their behalf.
The Memory Service was a good service but mentioned the difficulties around the assessment and the focus on re-aliment. The person with dementia did not want someone telling them what to do and it appeared that it was about making the person fit into the traditional assessment process when it may have not been what they wanted.

It must be acknowledged that people may not necessarily want care, but their families need care and are trying to get into the system.

**Medicines, care management**
- Administering medicines and getting dispensers filled was an issue that needed addressing particularly as some domiciliary care providers could not do this due to the risks. It was suggested that the role of chemists could be enhanced who could dispense pills and fill the dispensers.
- Assistive technology was not being utilised enough and that more that could be done
- Carers had an important role when they were going into homes and how they recorded information. Unfortunately, some carers did not always write notes when they visited people in their homes. More emphasis should be placed on carers to be more perceptive e.g. if food has gone off in the house and to remove it.
- Although there has been a lot of focus on carers, focus should really be on the person with dementia as they could have a real input. There were no individuals with dementia present at the workshop, but they should be approached for future consultations. They were an equal partner in and need to include the person with dementia. When people are newly diagnosed they have full capacity.
- Issue raised around the carer's assessment that sometimes joint assessments were not always appropriate. Need to look at assessment processes. Some carers did not want to say some things in front of the person they cared for.

**Terminology**
- Consideration needed to be given on recognising how a carer wanted to be addressed e.g. carer, husband, wife, family member. The person with dementia may not want to be referred as a sufferer.

**Accessing support**
- Individuals were not clear or understood what processes there were and how they could access support. This was important especially if an individual recognised the symptoms in others. Organisations existed who could provide information such as Alzheimer’s Society.

**Specialist services**
- There was a suggestion that specialist dementia services were needed, but to ensure individuals could access all services that were ‘dementia friendly services’. However, the need for specialist services depended on the stage that individuals were at, particularly those at later stages.
• Where an individual was at an early stage, accessing ordinary community services was reasonable. For example, sheltered accommodation had groups and activities that could be accessed by all, not just those with specific conditions.

Training
• Some GPs and professionals had limited knowledge dealing with people with dementia. Although, training was planned, it was emphasised that the role of all staff was important including those working at reception who could pick up symptoms and feed these to professions.

• There needed to be training for ‘dementia champions’ in care homes who could share their learning with others. However, it was recognised that there were issues releasing staff for training and costs associated with this. At present, the Council could not stipulate what training care homes provided for their staff.

• It was highlighted that a training manual had previously been developed by Department of Health project run by Polly Kaiser for care homes. Training in care homes was an area that needed further investigation.

Services
• There was a need for consistency of services and care provided. Tools such as life story and personal plans were considered to be low cost ways of working with individuals, which should be promoted.

• There was already a range of community groups in existence and resident groups could help identify people who were at an early stage with dementia. Each district partnership had a community development worker and these roles could be utilised to promote work being done as well as access to communities.

Stigma
• It was felt that stigma was still a big issue and a lot more could be done to raise awareness of dementia. Suggestions include more publicity, having a regular section in the Oldham Chronicle that could provide people with an update on what was going on.

• It was noted that ethnic minorities were not represented at the workshop and that there was a need to consider terminology as there was no equivalent word for dementia.

Charges
• The way complex services were charged and the role of home care was mentioned. It was suggested there needs to be different levels of charts that take into account basic needs and more complex needs at the later stages of dementia. A standard service delivery and consistency.

• The focus of dementia care pathway was on the first third of the pathway and focussed on the middle of the pathway a memory liaison officer would be the named contact for individuals in the care pathway. This would ensure the journey would be more co-ordinated.
Group Two Discussion from a Health Perspective – Key points

Communication
- There were clear communication problems, which needed to improve to ensure consistency in approach for patients, particularly in identifying the diagnosis by getting it right first time.

Carers Group
- The Saddleworth Carers Group model could be replicated in other areas across the Borough. It was a proactive group where they spoke to both the carer and the person with dementia and provided appropriate information. A representative of the Saddleworth Patient Group was also part of the Carers Group. The Group was a charity and was supported by local GPs. There was a new dementia champion who also delivered training.

Training
- Care in homes (residential and domiciliary) needed to be consistent. There were opportunities to raise concerns with Care Quality Commission, but this could be avoided if staff were trained adequately. For example, one staff from each care home should attend a training session who could then share their training with their colleagues.
- Training should be delivered jointly across health and social care rather than delivering short courses. Carers should have an input in the design and delivery of the dementia training. More dementia training should be delivered for GPs, nurses and social workers.

Information and Support
- The Mental Health charity currently working in Rochdale would like to extend their work into Oldham. Staff working for the charity was fully trained and would take people out who had dementia. This was to reduce social isolation.
- Support was also needed in social inclusion for people with dementia and their carers with particular emphasis in addressing this at an early stage.
- There should a pack of information available on dementia for carers and family members to read at their leisure. It should contain all relevant information including fact sheets and contact details of key organisations.
- Once the diagnosis had been confirmed, having a key worker or one co-ordinator who deals with the case eliminates the stress for the individual, carer and family.
- Having an integrated health and social care team that would encourage the completion of joint assessments. This would provide staff with access to patient medical information and be able to identify what services they have accessed from the health and social care system.
- Pennine Care would be delivering the new Memory Service where an additional five nurses would be appointed totalling to eight nurses, a part time psychologist and a part time occupational therapist. Links have been made with GPs, but this support should also be provided in care homes.
• Support should continue to be provided for a carer if the person with dementia had passed away.

Summary

The Chair had thanked everyone for their contribution at the workshop and explained that a report based on workshop discussions would be submitted to the Overview and Scrutiny Board for its consideration. Issues would be identified to what could be delivered within existing resources and where other resources could be found (capital and revenue) to address some issues. The role of the Overview and Scrutiny Board was explained in that they had no decision making power but could provide recommendations to Cabinet (decision making body) for their consideration.