Brighton & Hove
City Council

Overview & Scrutiny

Title:	**Health Overview & Scrutiny Committee**
Date:	**29 September 2010**
Time:	**4.00pm**
Venue	**Council Chamber, Hove Town Hall**
Members:	**Councillors:** Peltzer Dunn (Chairman), Allen (Deputy Chairman), Barnett, Deane, Harmer-Strange, Hawkes, Marsh, Rufus, Hazelgrove (Non-Voting Co-Optee) and Brown (Non-Voting Co-Optee)
Contact:	**Giles Rossington** **Acting Senior Scrutiny Officer** 29-1038 Giles.rossington@brighton-hove.gov.uk

♿	**The Town Hall has facilities for wheelchair users, including lifts and toilets**
	An Induction loop operates to enhance sound for anyone wearing a hearing aid or using a transmitter and infra red hearing aids are available for use during the meeting. If you require any further information or assistance, please contact the receptionist on arrival.

FIRE / EMERGENCY EVACUATION PROCEDURE

If the fire alarm sounds continuously, or if you are instructed to do so, you must leave the building by the nearest available exit. You will be directed to the nearest exit by council staff. It is vital that you follow their instructions:

- **You should proceed calmly; do not run and do not use the lifts;**
- **Do not stop to collect personal belongings;**
- **Once you are outside, please do not wait immediately next to the building, but move some distance away and await further instructions; and**
- **Do not re-enter the building until told that it is safe to do so.**

AGENDA

Part One **Page**

---

18. PROCEDURAL BUSINESS **1 - 2**

(copy attached)

19. MINUTES OF THE PREVIOUS MEETING **3 - 12**

Draft minutes of the meeting held on 14 April 2010 (copy attached)

20. CHAIRMAN'S COMMUNICATIONS

21. PUBLIC QUESTIONS

A public question has been received:

> "Does the committee agree that the government's plans for the NHS in its recent white paper, involve such a degree of reorganisation that it should be implemented only once adequate consultation with the medical profession and the wider public has taken place, and only when the policy has been proved effective by pilot schemes. Further, the timing of this policy, involving massive transitional costs when the government is planning extensive cuts in public spending, is ill advised."
>
> Mr Ken Kirk

22. NOTICES OF MOTION REFERRED FROM COUNCIL

No Notices of Motion have been received

23. WRITTEN QUESTIONS FROM COUNCILLORS

No questions have thus far been recieved

24. PUBLIC HEALTH: ANNUAL REPORT OF THE DIRECTOR OF PUBLIC HEALTH

Dr Tom Scanlon, Brighton & Hove Director of Public Health, will present his 2009 Annual Report (verbal)

25. HEALTHCARE FOR OLDER PEOPLE **13 - 58**

Report of the Brighton & Hove LINk on patient nutrition at the Royal Sussex County Hospital (copy attached).

Please note: the BHLINk report was commissioned by East Sussex

HOSC as part of a major review of nutrition in hospitals used by East Sussex patients. The full East Sussex HOSC report on Nutrition, Hydration and Feeding in Hospitals can be found on the East Sussex County Council website:
http://www.eastsussexhealth.org/news/NutritionFeeding.html

Officers from Brighton & Sussex University Hospital Trust will also be attending the meeting to talk to members about how older people are championed at the Royal Sussex County Hospital and to answer questions about older people's care and nutrition for older people in hospital.

26. DEPARTMENT OF HEALTH CONSULTATION: LOCAL DEMOCRATIC LEGITIMACY IN HEALTH **59 - 86**

(copy attached)

27. MENTAL HEALTH RECONFIGURATION: UPDATE **87 - 90**

28. 2009/2011 HOSC WORK PROGRAMME **91 - 96**

(copy attached)

29. FOR INFORMATION: REPORT OF THE SELECT COMMITTEE ON DEMENTIA **97 - 134**

(For Information) Report of the Scrutiny Select Committee on Dementia (copy attached)

30. FOR INFORMATION: LETTER FROM HOSC CHAIRMAN **135 - 136**

Letter from HOSC Chairman to Brighton & Sussex University Hospitals Trust in regard to car parking at the Royal Sussex County Hospital (copy attached)

31. ITEMS TO GO FORWARD TO CABINET OR THE RELEVANT CABINET MEMBER MEETING

To consider items to be submitted to the next available Cabinet or Cabinet Member meeting

32. ITEMS TO GO FORWARD TO COUNCIL

To consider items to be submitted to the next Council meeting for information

The City Council actively welcomes members of the public and the press to attend its meetings and holds as many of its meetings as possible in public. Provision is also made on the agendas for public questions to committees and details of how questions can be raised can be found on the website and/or on agendas for the meetings.

The closing date for receipt of public questions and deputations for the next meeting is 12 noon on the fifth working day before the meeting.

Agendas and minutes are published on the council's website www.brighton-hove.gov.uk. Agendas are available to view five working days prior to the meeting date.

Meeting papers can be provided, on request, in large print, in Braille, on audio tape or on disc, or translated into any other language as requested.

For further details and general enquiries about this meeting contact Giles Rossington, 01273 29-1038, email giles.rossington@brighton-hove.gov.uk) or email scrutiny@brighton-hove.gov.uk

Date of Publication - Tuesday, 21 September 2010

Agenda Item 18

To consider the following Procedural Business:

A. Declaration of Substitutes

Where a Member of the Commitee is unable to attend a meeting for whatever reason, a substitute Member (who is not a Cabinet Member) may attend and speak and vote in their place for that meeting. Substitutes are not allowed on Scrutiny Select Committees or Scrutiny Panels.

The substitute Member shall be a Member of the Council drawn from the same political group as the Member who is unable to attend the meeting, and must not already be a Member of the Committee. The substitute Member must declare themselves as a substitute, and be minuted as such, at the beginning of the meeting or as soon as they arrive.

B. Declarations of Interest

(1) To seek declarations of any personal or personal & prejudicial interests under Part 2 of the Code of Conduct for Members in relation to matters on the Agenda. Members who do declare such interests are required to clearly describe the nature of the interest.

(2) A Member of the Overview and Scrutiny Commission, an Overview and Scrutiny Committee or a Select Committee has a prejudicial interest in any business at a meeting of that Committee where –
(a) that business relates to a decision made (whether implemented or not) or action taken by the Executive or another of the Council's committees, sub-committees, joint committees or joint sub-committees; and
(b) at the time the decision was made or action was taken the Member was
(i) a Member of the Executive or that committee, sub-committee, joint committee or joint sub-committee and
(ii) was present when the decision was made or action taken.

(3) If the interest is a prejudicial interest, the Code requires the Member concerned:
  (a) to leave the room or chamber where the meeting takes place while the item in respect of which the declaration is made is under consideration. [There are three exceptions to this rule which are set out at paragraph (4) below].
  (b) not to exercise executive functions in relation to that business and

(c) not to seek improperly to influence a decision about that business.

(4) The circumstances in which a Member who has declared a prejudicial interest is permitted to remain while the item in respect of which the interest has been declared is under consideration are:

(a) for the purpose of making representations, answering questions or giving evidence relating to the item, provided that the public are also allowed to attend the meeting for the same purpose, whether under a statutory right or otherwise, BUT the Member must leave immediately after he/she has made the representations, answered the questions, or given the evidence;

(b) if the Member has obtained a dispensation from the Standards Committee; or

(c) if the Member is the Leader or a Cabinet Member and has been required to attend before an Overview and Scrutiny Committee or Sub-Committee to answer questions.

C. Declaration of Party Whip

To seek declarations of the existence and nature of any party whip in relation to any matter on the Agenda as set out at paragraph 8 of the Overview and Scrutiny Ways of Working.

D. Exclusion of Press and Public

To consider whether, in view of the nature of the business to be transacted, or the nature of the proceedings, the press and public should be excluded from the meeting when any of the following items are under consideration.

NOTE: Any item appearing in Part 2 of the Agenda states in its heading the category under which the information disclosed in the report is confidential and therefore not available to the public.

A list and description of the exempt categories is available for public inspection at Brighton and Hove Town Halls.

BRIGHTON & HOVE CITY COUNCIL

HEALTH OVERVIEW & SCRUTINY COMMITTEE

4.00PM 14 JULY 2010

COUNCIL CHAMBER, HOVE TOWN HALL

MINUTES

Present: Councillors Peltzer Dunn (Chairman); Allen (Deputy Chairman), Barnett, Harmer-Strange, Kitcat, Marsh and Rufus

Co-opted Members: Robert Brown (Brighton & Hove LINk)

PART ONE

1. PROCEDURAL BUSINESS

1A Declarations of Substitutes

1.1 There were none.

1B Declarations of Interest

1.2 Councillor Mo Marsh declared a personal and non-prejudicial interest in Item 12.

1C Declarations of Party Whip

1.3 There were none.

1D Exclusion of Press and Public

1.4 In accordance with section 100A(4) of the Local Government Act 1972, it was considered whether the press and public should be excluded from the meeting during the consideration of any items contained in the agenda, having regard to the nature of the business to be transacted and the nature of the proceedings and the likelihood as to whether, if members of the press and public were present, there would be disclosure to them of confidential or exempt information as defined in section 100I (1) of the said Act.

1.5 **RESOLVED** – That the Press and Public be not excluded from the meeting.

1.6 Apologies were received from Duncan Selbie, Chief Executive of Brighton & Sussex University Hospital Trust; Julian Lee, Chair of Brighton & Sussex University Hospital

Trust; Alan McCarthy, Chair of NHS Brighton & Hove; and Jack Hazelgrove, Representative of the Older People's Council.

2. MINUTES OF THE PREVIOUS MEETING

2.1 Cllr Harmer-Strange noted that the committee had not yet received information promised at the last meeting with regard to data on car parking at the Royal Sussex County Hospital. This will be followed up by officers.

2.2 Members discussed a resolution made at the last meeting to establish a working group to examine NHS Brighton & Hove's Annual Operating Plan. Cllrs Allen, Harmer-Strange and Rufus agreed to sit on the working group.

2.3 RESOLVED – That the minutes of the meeting held on 14 April 2010 be approved and signed by the Chairman.

3. CHAIRMAN'S COMMUNICATIONS

3.1 There were none.

4. PUBLIC QUESTIONS

4.1 There were none.

5. NOTICES OF MOTION REFERRED FROM COUNCIL

5.1 There were none.

6. WRITTEN QUESTIONS FROM COUNCILLORS

6.1 A written question was received from Cllr Kitcat. Beverly Thorp, Associate Director for Women and Children, responded to the question on behalf of Brighton & Sussex Universities Hospital Trust (BSUHT).

6.2 Ms Thorp told members that all wards at the Royal Alex Children's Hospital were currently open, although not every ward was operating at full capacity. The Alex had opened with approximately 50 beds, with the intention being to gradually step up to full capacity (100 beds). Current capacity is 70+ beds, and this is expected to grow as the Alex develops and as the trust is able to repatriate more patients from out-of-county placements. The relocation of children's A&E from the Royal Sussex County (RSCH) site is ongoing, with additional paediatric consultant and nurse posts being recruited.

6.3 In response to a further question from Cllr Kitcat, Ms Thorp informed members that the Alex has provision for 3 Intensive Care (IC) beds, although only one of these is currently operational. There are no immediate plans to bring more IC beds on-line, as the Alex could not readily rota the specialist staff required to run 3 beds without significantly expanding its general services (to the likely detriment of other providers in Sussex). The Alex has, however, concentrated on expanding its resource of High Dependency (HD) beds, and now has 7 in operation. These beds allow the hospital to cope with a wide range of conditions, although it may always be necessary to send some patients for very specialised care in London hospitals. Amanda Fadero, Chief Executive, NHS Brighton & Hove, added that the Sussex population was not large enough to support a full paediatric IC unit, but that the PCT was committed to developing the Alex as a tertiary resource for the whole of Sussex.

6.4 Robert Brown, LINk representative, informed members that the LINk was eager to promote the Royal Alex, and wanted to encourage BSUHT to invite children into the Alex in advance of elective procedures. Beverly Thorp confirmed that BSUHT had been involved in useful discussions with the LINk on these issues.

6.5 In response to a question from Mr Brown concerning children's cardiac surgery, Ms Thorp told members that there were no plans to perform this surgery in Brighton, but that BSUHT did have arrangements for a consultant cardiologist to visit the Alex to support families with cardiac issues.

6.6 In response to a question from Cllr Rufus regarding the cost implications of running the Alex below capacity, Ms Thorp told members that the Alex was not currently running at a loss. The trust's long term vision was to increase use of the Alex, particularly by moving services for children currently provided at RSCH (e.g. Audiology and ENT) to the Alex, and by promoting the Alex as the Sussex tertiary centre for children's care. Amanda Fadero added that the Alex operating at less than full capacity might be a reflection on recent developments in children's care, particularly in terms of greater emphasis on community-based services. Providing services in the most appropriate settings, even if this entailed under-utilisation of acute beds, should be welcomed.

6.7 Members thanked Ms Thorp for her contribution.

7. DELIVERING OUR VISION FOR THE NHS IN THE REGION IN ECONOMICALLY CHALLENGING TIMES

7.1 This item was presented by Amanda Fadero, Chief Executive, NHS Brighton & Hove. Ms Fadero told members that much of the NHS change required in coming years would be co-ordinated at a local level by NHS Brighton & Hove. However, it made sense to undertake some work across Sussex, with one or other of the Sussex PCTs leading on different work streams. For a number of work streams this would mean that NHS West Sussex was the lead PCT; however, in all instances, NHS Brighton & Hove would remain accountable to local residents.

7.2 The main pan-Sussex areas of priority are:

- Major trauma
- Pathology
- Dementia
- Rehabilitation
- Stroke Care
- Change Management

Details of many of the planned changes and the health ‘gains’ they may produce for local residents are contained in NHS Brighton & Hove’s Annual Operating Plan (AOP). The South East Coast Strategic Health Authority (SHA) has recently issued a ‘challenge’ to regional PCT AOPs (e.g. questioning whether planned improvements could be made more quickly etc), and NHS Brighton & Hove is currently examining its current AOP and its longer term Strategic Commissioning Plan in light of this challenge.

7.3 In response to a question from Cllr Kitcat on the recently announced plans to phase out Primary Care Trusts (PCTs), Ms Fadero told members that PCTs still had a good deal of work to accomplish, both in terms of continuing to commission high quality services and in terms of ensuring that GP commissioners were adequately prepared to take on commissioning roles. Although the immediate future would see a good deal of integrated working by regional PCTs (e.g. the Sussex Commissioning Unit), most commissioning activity would still take place at a local level.

7.4 Ms Fadero was thanked for her contribution.

8. AD HOC PANEL ON GP-LED HEALTH CENTRE: 1 YEAR UPDATE

8.1 This item was introduced by Juliet Warburton, Head of Primary and Community Care, NHS Brighton & Hove, and by Derek Witt, Care UK General Manager.

8.2 Members were told that the Centre had experienced a very successful first year, and had over-performed in terms of both patient registration and unregistered patient visits to the walk-in centre. Patient satisfaction was also very high. The Centre did have some ‘partly achieved’ scores in terms of its contract targets, but these were thought to be due to factors relating to the recent opening of the centre (e.g. some records re: patient satisfaction were incomplete, but this was because there were too few patients attending the centre in its first few months of operation to make data collection via the national Patient Survey tenable). NHS Brighton & Hove is confident that these standards will be met in the current year.

8.3 The committee was informed that work was ongoing to gauge what impact the opening of the Centre may have had on local A&E admissions.

8.4 In terms of any negative impact on neighbouring GP practices, members were told that there was no evidence thus far of any such issues.

8.5 In answer to a question relating to ‘continuity of care’ at the Centre, Mr Witt told members that Care UK employed a permanent team of salaried GPs to staff the Centre, and was therefore confident that continuity of care was good. Ms Warburton added that, if patients were unhappy with the continuity of care provided, this would be flagged up in patient satisfaction surveys – but currently survey data shows no such concern.

8.6 Ms Warburton told members that it had been necessary to sign-post some attendees away from the Centre’s walk-in service towards the end of the year, as the Centre had over-performed on this service and more costs would have been incurred by NHS Brighton & Hove had the walk-in service continued to see all patients who presented for treatment. The second year of the contract provides for an increase in walk-in patients, so this problem should not repeat itself. The diversion of patients was closely monitored, and all patients who required urgent treatment were dealt with promptly. There were no patient complaints arising from the diversion to other services.

8.7 In response to a question on the high number of unregistered patients visiting the Centre who did not reveal the identity of their own GP, Ms Warburton told members that many patients, particularly younger ones, simply did not know who their GP was, although some patients may actively have chosen to visit the Centre rather than their GP (e.g. to discuss issues they would have felt embarrassed to raise with their own doctor). Care UK and the PCT have worked hard to improve data collection in this respect, and results have improved considerably in recent months.

8.8 In reply to a question from the Chairman, Cllr Peltzer Dunn, concerning repeat prescriptions issued by the Centre, Mr Witt explained that the Centre would issue repeat prescriptions to people visiting the city, but would not do so for people already registered with a city GP. There is a degree of trust involved in issuing repeat prescriptions, as visitors who have forgotten their medicines are unlikely to have evidence of their eligibility for prescriptions to hand. However, the Centre will only ever provide a repeat prescription once, so there is limited scope for the system to be abused. When a repeat prescription is issued, this is flagged on the GP practice software system and the patient’s medical records are updated to show that the prescription has been issued

8.9 In response to a question from Cllr Allen about the impact of the Centre on neighbouring GP practices, Ms Warburton told members that there had to date been no negative feedback from local practice managers. The PCT continues to monitor this closely, particularly in terms of patients registering with the Centre (which might have an impact in the medium term had many people previously been registered with neighbouring practices).

8.10 In reply to a question from Mr Robert Brown concerning how the Centre was advertised to Travellers (many of whom seemingly eschew GP services, choosing to present for treatment at A&E), Ms Warburton told members that she would be happy to investigate what more could be done in terms of informing the Traveller community about the facilities offered by the Centre.

8.11 Ms Warburton and Mr Witt were thanked for their contributions.

8.12 RESOLVED – That the report be noted and an update report be requested in 12 months time.

9. SUSSEX ORTHOPAEDIC TREATMENT CENTRE (SOTC)

9.1 This item was introduced by Wendy Carberry, Deputy Director, Contracts, NHS Brighton & Hove and by Pamela Mackie, General Manager, Care UK.

9.2 In response to a question from Mr Robert Brown on Care UK’s criteria for selecting patients, members were told that specialist treatment centres were invariably unable to treat a small number of patients – i.e. those with co-morbidities which meant they could only be safely treated in a large acute hospital environment.

9.3 Cllr Kitcat went on to ask whether this had an adverse impact upon other areas of the local health economy (e.g. upon local acute NHS trusts which will typically pick up the complex co-morbidities inappropriate for treatment at a specialist centre). Amanda Fadero, Chief Executive, NHS Brighton & Hove, responded that it was important to focus on the totality of pathway management across the local health economy rather than on any single element in the pathway. Any financial stresses caused by the existence of the SOTC had to be weighed against the centre's contribution to local elective orthopaedic capacity, and against the local health economy's ability to deliver against the national 18 week waiting time targets (the SOTC is able to process cases more quickly than most general hospital based services). Ms Fadero noted that, although the 18 week targets had now been formally discontinued by the new Government, NHS Brighton & Hove was still committed to commissioning services to an 18 week timetable.

9.4 In answer to a question from Cllr Rufus on how the SOTC was reimbursed for activity, members were told that the SOTC contract, in common with all Independent Sector Treatment Centre (ISTC) contracts, was nationally determined on a principle of 'take and pay' – i.e. that the SOTC was paid a set volume of procedures each year, whether or not it actually undertook all of this activity. Providing Care UK was able to undertake all the activity contractually required of it, the onus was therefore on NHS Brighton & Hove, as lead commissioner for the SOTC, to ensure that there were sufficient referrals into the Centre to achieve value for money from the contract. Amanda Fadero, Interim Chief Executive of NHS Brighton & Hove, added that Care UK had been very flexible in terms of interpreting its contract.

9.5 In response to a query from Cllr Kitcat regarding the difference between the SOTC's contracted activity (paid in full via the SOTC contract) and its actual activity, Ms Mackie agreed that there was a difference here across the year, and that this did translate into additional profit for Care UK. Ms Carberry stressed that this was typically not because the SOTC was unable to operate at full capacity, but because the number of patients seeking orthopaedic surgery varied from month to month, meaning that there were sometimes fewer patients requiring treatment than the contract assumed. Care UK and NHS Brighton & Hove have been working to better control patient referral into the SOTC, and the Quarter 1 performance data for 2010-11 does indicate much better utilisation of theatre capacity at the SOTC.

9.6 Members also had more detailed questions they wished to ask about the SOTC. However, it was agreed that there was little point in asking these questions in the meeting as it was unlikely that there would be answers to hand, and that instead, a list of written questions should be submitted to Care UK and NHS Brighton & Hove at a later date.

9.7 RESOLVED – (1) That the report be noted; (2) That a further monitoring report be requested at a later date; (3) That a list of written questions be submitted to Care UK and NHS Brighton & Hove.

10. BRIGHTON & SUSSEX UNIVERSITY HOSPITALS TRUST: POTENTIAL MERGER WITH QUEEN VICTORIA HOSPITAL NHS FOUNDATION TRUST, EAST GRINSTEAD

10.1 This item was introduced by Alex Sienkiewicz, Director of Corporate Affairs, Brighton & Sussex University Hospitals Trust (BSUHT).

10.2 Mr Sienkiewicz explained that Queen Victoria Hospital Foundation Trust (QV) had approached BSUHT and asked them to consider a merger. BSUHT had thought about this and was generally in favour of merging, as this would bring benefits to both hospitals and to the people that they serve.

10.3 In answer to a question from Cllr Marsh regarding the process via which a non-Foundation Trust (FT) could merge with an FT, Mr Sienkiewicz told members that BSUHT's FT application had been placed on hold whilst the merger with QV was discussed. If the merger went ahead, then the merged trusts would jointly apply for FT status. The trusts have sounded out Monitor, the Foundation Trust regulator, which has agreed to expedite any such FT request.

10.4 Members were informed that there was a longstanding clinical partnership between BSUHT and QV, and many clinical adjacencies, particularly involving the key '3T' project to develop the Royal Sussex County Hospital as a regional trauma centre (QV's expertise in work such as burns and reconstructive surgery make it an important player in this development). QV also provides general acute services for residents of East Grinstead, and BSUHT is already involved in supporting this work.

10.5 Members thanked Mr Sienkiewicz for his presentation and asked to be kept informed of the progress of the merger plans.

11. BRIGHTON & SUSSEX UNIVERSITY HOSPITALS TRUST EMERGENCY PLANNING

11.1 This item was introduced by Mr Jonathon Andrews, Brighton & Sussex University Hospitals Trust (BSUHT).

11.2 Mr Andrews explained that the trust was extensively engaged in planning for emergencies, as part of its broader business continuity management programme. The trust's resilience in the face of emergency events is assessed by both the Strategic Health Authority and the Care Quality Commission.

11.3 Members thanked Mr Andrews for attending and noted the contents of his update.

12. SOUTH DOWNS HEALTH NHS TRUST: INTEGRATION WITH WEST SUSSEX COMMUNITY SERVICES - UPDATE

12.1 This item was introduced by Andy Painton, Chief Executive, and Andrew Harrington, Director of Operations, South Downs Health NHS Trust (SDH).

12.2 Members were informed that the South East Coast Strategic Health Authority (SHA) was due to consider the final business case for the integration of SDH with West Sussex community services in autumn 2010. However, the two organisations have effectively been integrated for over a year now.

12.3 Integration with East Sussex community services has also been agreed in principle with the East Sussex Primary Care Trusts and with the SHA, although this is subject to a detailed evaluation of the proposals.

12.4 The integrated trust faces major challenges in the coming months, including the need to make very significant savings and the requirement to develop the trust's senior management to best reflect clinical input and to ensure it is capable of the challenges of running a much expanded organisation.

12.5 In response to a question from Cllr Kitcat concerning how a small trust could realistically expect to take on the work of two much larger organisations, Mr Painton told members that it was very important to think of the integration process as the creation of an entirely new organisation rather the take-over of any one organisation by another. The new entity would not be over-centralised, but would maintain the local foci vital to ensure quality community services, whilst centralising those services which benefited from being run centrally (e.g. infection control). Mr Harrington added that it made sense for SDH to be the organisation into which the others were integrated as it already existed as a free-standing legal entity, whilst the community services in both East and West Sussex had formally been part of their respective PCTs, and were therefore not in a position to take on any other organisation.

12.6 In answer to a question from Cllr Allen concerning economies of scale to be achieved by integrating community services across Sussex, Mr Painton told members that there were considerable economies to be realised by integrating SDH with its West Sussex counterpart (approximately £2 million), but relatively minor additional savings from including East Sussex services.

12.7 In response to a question from Mr Robert Brown concern the upgrading of trust estates to make them compatible with the requirements of the Disability Discrimination Act, Mr Painton told members that responsibility lay with the owners of the estates in question: this is principally SDH in Brighton & Hove, but is NHS West Sussex in terms of West Sussex community healthcare buildings.

12.8 In answer to a question from Cllr Allen concerning how the expanded trust would guarantee it maintained a local focus, members were told that this would be guaranteed by the recently unveiled GP commissioning arrangements, which would mean that services for local people were commissioned by GP consortia at a very local level. In addition, Mr Painton pointed out that the nature of community services tended to militate against large scale solutions: whilst it might be sensible to run some services on a county-wide basis, there would simply be no advantage in scaling up the majority of the trust's work.

12.9 Members thanked Mr Painton and Mr Harrington for their input and invited them to return to a future meeting to provide an update on the progress towards integration.

13. BETTER BY DESIGN - UPDATE

13.1 Members considered a letter sent to the HOSC Chairman by Sussex Partnership NHS Foundation Trust and NHS Brighton & Hove. The letter set out progress in terms of the ongoing initiative to re-design local mental health services. It was agreed that this subject should be considered as a substantive item at a later committee meeting.

14. 2009/2010 HOSC WORK PROGRAMME

14.1 Members discussed the committee work programme.

14.2 It was agreed that two additional items should be considered for the work programme:

(i) implications of the Health White Paper. Members decided that this should be offered to all Councillors rather than just HOSC members, and it was therefore determined that officers should seek to set up a members' seminar with support from NHS Brighton & Hove.

(ii) Annual Report of the Director of Public Health. Members agreed to invite Dr Scanlon to the next (29 September 2010) committee meeting to talk to his recently published annual report.

15. ALCOHOL-RELATED HOSPITAL ADMISSIONS - REFERRAL TO OSC (UPDATE)

15.1 Members received a verbal update on progress in establishing this Select Committee.

16. ITEMS TO GO FORWARD TO CABINET OR THE RELEVANT CABINET MEMBER MEETING

16.1 There were none.

17. ITEMS TO GO FORWARD TO COUNCIL

17.1 There were none.

The meeting concluded at Time Not Specified

Signed Chair

Dated this day of

Report from Brighton and Hove LINk and West Sussex LINk on Nutrition in the Royal Sussex County Hospital (Brighton) and Princess Royal Hospital, Haywards Heath (Brighton Sussex University Hospitals NHS Trust)

June 2010

Brighton & Hove LINk MAKE IT HAPPEN!

West Sussex LINk
Your voice on local health and social care

Brighton and Hove LINk Report

June 2010

Contents

1. Acknowledgements

Brighton LINk wishes to extend their gratitude to the staff of Brighton Sussex University Hospitals Trust for their help and co-operation. The LINk also thanks East Sussex Health Overview and Scrutiny Committee for their financial contributions to help make this research possible. The LINk would like to say a special thank you to all the patients, their families and carers who took part in this survey.

This project was guided by LINk members and LINk support staff including:

Brighton and Hove LINk:
Enter and View authorised representatives
- Mick Lister
- Diana Ward-Davis
- Dawn Webb
- Merle Blakeley

B&H LINk Staff attending some visits:
- Val Young, LINk Development Worker
- Claire Stevens, LINk Manager

B&H LINk Nutrition Report – drafted by Claire Stevens (B&H LINk Manager)

2. Summary

- Overall the satisfaction with the food and drink in the Royal Sussex County (RSC) was positive.
- Regarding choices for the three main meals served each day, most patients agreed that the range available was sufficient (67%)
- Most of the patients surveyed did not have special dietary requirements (84%) but some vegetarians felt the meal options were limited.
- The LINk did not observe any interruptions to meals by clinicians although it was noted that relatives often did not adhere to the protected meal times and were not seen to be assisting with eating.
- The majority of patients said they were not aware that they could have something to eat outside of the normal meal times. This could be because they were admitted via Accident and Emergency and therefore did not receive the hospital booklet explaining facilities etc. It is important that these patients are given this information so they are aware of what is available. Due to illness/fatigue it is often more convenient for patients to access snacks etc outside of meal times and may help satiate appetite and encourage eating.
- Most patients (61%) did not have the opportunity to clean their hands before their meal.
- There was no evidence of any indentifying equipment/signage being used for people who may be at risk from malnutrition or require assistance/encouragement to eat.
- It is difficult to assess from this research whether the hospital adequately provides for special diets including religious requirements as most of the patients said they did not have specific needs.
- 61% (22 of 36) of patients reported that they had seen other patients who needed help to eat but did not receive it. It should be acknowledged that this is a perception and may not be entirely accurate. However, this question was deliberately included in the survey as interviewer's presence on the ward could bias the results and so this question tested what happens when interviewers are not present.

3. Introduction

East Sussex Health Overview and Scrutiny Committee (HOSC) commissioned East Sussex, Brighton and Hove (B&H) and later West Sussex LINks to feed into their nutrition, hydration and assistance with eating in Sussex Hospitals. The rationale was to compare and contrast data throughout Sussex, highlighting good practice and identifying areas of improvement.

LINks are statutory bodies established in 2008 under the Local Government and Public Involvement in Health Act 2007. They are independent networks of people and groups who help make social and health care better in their local area. The LINks help people have their say and make sure that what they say is listened to. B&H LINk has powers to monitor and investigate issues relating to publicly funded health and social care.

The LINks were asked to provide data direct from patients via enter and view as this is a legal power which Overview and Scrutiny Committees do not have. Enter and View enables LINks to:

- observe the delivery of health and social care services
- collect the views of people whilst they are directly using those services.

The LINk enter and view team of authorised representatives are fully trained and all have completed an enhanced Criminal Records Bureau check.

4. Background of Nutrition in Hospitals

£500 million is spent on NHS food each year. It is estimated that poor nutrition in hospital costs the NHS almost £300m a year.

Good nutrition is paramount to recovery and must be recognised as part of treatment/clinical care. It is vital that patients' nutritional needs are met and risks of malnutrition in hospital are reduced. Patients who receive good nutrition may have shorter hospital stays, fewer post-operative complications and less need for drugs and other interventions.

Older people are more likely to be malnourished when admitted to hospital and remain so during their hospital stay. They also have longer periods of hospital stay. 1 in 4 hospital patients are admitted into British hospitals malnourished (**BAPEN 2007**).

In a briefing to Parliament by Age Concern (7 February 2006), the charity stated that:
"Around 40% of hospital inpatients are also malnourished on admission and sadly the likelihood is that malnourishment will get worse for these (mainly older) people during their hospital stay. Patients over the age of 80 admitted to hospital have a five times higher prevalence of malnutrition than those under the age of 50."

Patients who are malnourished at admission have been shown to be up to have 8 times higher mortality rates at discharge **(Sullivan 1999).**

According to the Alzheimer's Society two thirds of medical beds, in general hospitals are occupied by people over the age of 65 and around 30% of them will have dementia.

The National Patient Safety Agency (NPSA) has identified poor nutrition as a patient safety issue and believes protected mealtimes have the potential to improve patient safety by "ensuring patients receive the right meal at the right time with the right amount of help".

Most patients depend on ordinary hospital food to improve or maintain their nutrition in order to optimise their recovery from illness. It is likely that by:

- providing appropriate food and drink
- a wide range of choice of food and drink
- providing and promoting snacks and outside of meal times food and drink

it could help cut down the length of hospital stays and cost from in-patient admissions.

The Royal College of Nursing (RCN) carried out a survey of nursing staff to explore attitudes towards nutritional care. 81% of nurses thought nutrition was 'extremely important' but 42% felt there was not enough time to devote to patients' nutrition (RCN, 2007).

As people age their taste buds decline, so food becomes less appealing. Therefore, it is even more important that hospital food is tasty and appetising to encourage older patients to eat. Pioneering research from the University of Reading is being used to enhance the taste of hospital food to help prevent or treat malnutrition in older people (Science Daily 2010).

Recent Initiatives/Research on Hospital Food

August 2008: The Department of Health launches online nutrition training
In support of the Nutrition Action Plan, an online e-learning programme is launched to help nursing and other staff learn more about nutrition for hospital patients.

July 2008: Cabinet Office Food Matters report promises action
The Cabinet Office publishes Food Matters: Towards a Strategy for the 21st Century. It states that: “The public sector in England should be leading by example. More nutritious, environmentally sustainable food will be delivered through a new ‘Healthier Food Mark’ linked to standards for food served in the public sector.

2008: Which?
Investigates the unhealthy state of hospital food Which? (Formerly the Consumers Association) conducts an investigation and finds that in 18 of the 21 hospitals checked, 86% of meals contain too much salt; 67% too much saturated fat and more than half (52%) contain too much fat, tested against government health guidelines.

April 2009:
Public health minister commissions sustainable food guidelines for hospitals following a visit to a pioneering hospital in Cornwall where healthy and sustainable food is paramount, guidelines (Sustainable Development Commission report) for hospitals to improve their food are introduced.

April 2009:
Royal College of Nursing Nutrition Now! campaign is terminated due to lack of take-up.

February 2009:
Government drafts Healthier Food Mark guidelines which means food should be both health and from sustainable sources.

April 2009:
Malnutrition in hospitals and care homes continues to rise and in answer to a parliamentary question, the Department of Health reveals that over 2,600 people have died from malnutrition in hospitals and care homes in England during the past decade.

August 2009:
University researchers say hospital food is worse than prison food Bournemouth University undertakes research into hospital food and announces that hospital food is worse than prison food ‘Hungry in hospital, healthy in prison?’

5. Methodology

The LINks met regularly to develop the research tools to enable them to conduct the research. A questionnaire was formulated to gather data on patients' views regarding their satisfaction with the food and drink they were being served in hospital, as well as access to information on food and help with eating. Careful consideration was given to the wording of questions to minimise bias and leading questions. It was agreed to use a combination of open and closed questions and for the interviewers to use the same introduction text at the start of each survey.

The LINks also decided to us non-participant observation which meant data was collected by observing behaviour without interacting with patients or staff. The LINks developed an observation checklist to enable them to do this. The survey and observation checklist are included in the appendices.

In total 36 interviews were conducted with patients with a questionnaire completed by the interviewer for each patient. It was felt that leaving questionnaires with patients to complete themselves would be inconvenient and time consuming for both patient and interviewer. Also, this method provided strong qualitative data in the form of comments from patients, which they may otherwise be reluctant to make.

When were visits undertaken?

The LINks agreed to undertake the visits during protected meal times. This is a period of time over lunch and supper, when all activities, on the wards stop. This helps prevent unnecessary interruptions to mealtimes and enables staff to be available to help serve the food and give assistance to patients who may need help. The LINks acknowledged that undertaking the enter and view visits during protected meal times would be somewhat disruptive but it was considered necessary to obtain the data.

It was also agreed to survey during different meal times to assess whether there were any key differences between meals and to obtain a fuller picture.

Why were the enter and view visits announced?

The LINk is able to make unannounced visits meaning that health and social care providers do not know in advance when visits will take place. The LINks considered that it was unnecessary to make unannounced visits as there would be no real benefit in turning up on wards unexpectedly. The Department of Health recommends that unannounced visits are used very occasionally and that there must be tangible evidence from the community that this is an issue.

Why were stroke, medical and surgical ward patients chosen to undertake this survey?

To enable accurate comparisons between hospitals and wards it was agreed to select similar ward types. Unfortunately, it was not possible to survey children's wards as they are not sited in all of the hospitals in the research. Stroke patients were identified as being as being at higher risk of needing assistance with eating due to the nature and complexity of the condition.

Details of Visits to the Royal Sussex County Hospital

Ward Type	Ward Name	Meal	Meal & Time
Stroke	Donald Hall & Solomon male and female	Breakfast: 8.00-8.30 19th April	Lunch: 12.00-12.10 pm 28th April
Surgical (orthopaedic)	Level 8a West Thomas Millennium Block	Lunch: 12.30 pm 21st April	Dinner: 18.30 26th April
General medical (older people)	Jowers (Barry building)	Breakfast: 7.45-8.00am 26th April	Dinner: 18.00-18.15 29th April

Limitations of the LINk Research

Representativeness of Sample

The number of patients the Enter and View Team were able to survey on some wards was quite limited, particularly on some wards. It was difficult to find sufficient numbers in some wards and this meant that some people were excluded:

- patients being too unwell/asleep to participate
- a small minority (2) not wanting to participate
- patients with visitors and too busy to participate
- patients engaged in other activities e.g. using mobile phones
- patients with dementia etc. who were unable to participate

Bias

Using non-participant observation can mean that patients and staff modify their behaviour accordingly, as people often do not act as they would if not being observed if they know they are being watched (the Hawthorne Effect).

Perceptions

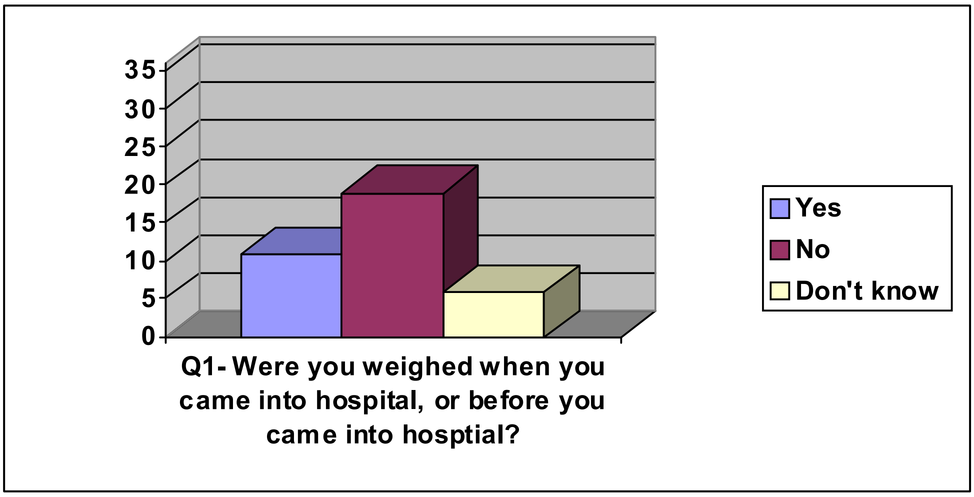
Although the Enter and View Team did witness a significant amount of plate wastage, it is recognised that the food quality, choice or lack of assistance may not be the main factor in this. Many patients may be feeling nauseous after anaesthetic, procedures etc, some patients may be overly particular about their food likes and dislikes, too tired/unwell to eat at meal times etc. It should also be acknowledged that some patients had low expectations of hospital food and were just grateful to be treated well clinically:

"it is better than the food in the war"
"It's hospital food, so what can I expect?"
"It's not too bad, I can put up with it."
"I'm not here for the food"

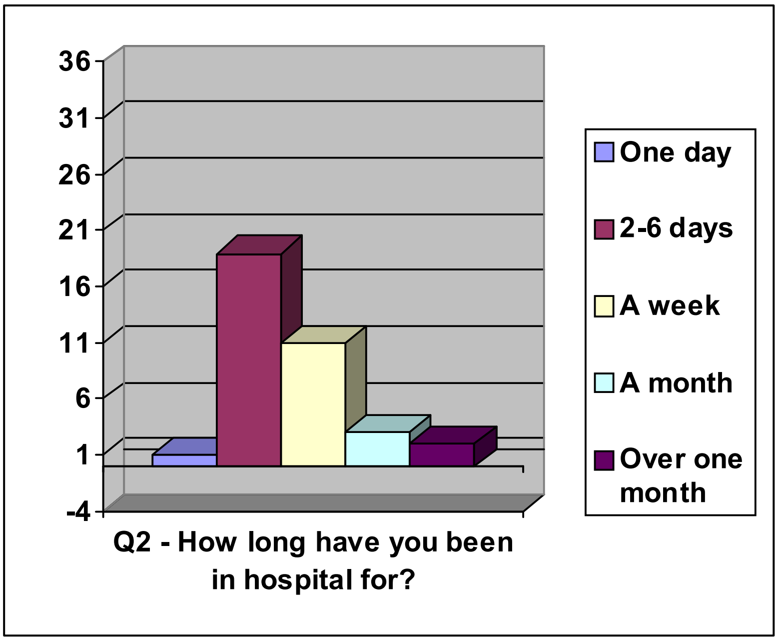
6. Results

Statistical Data

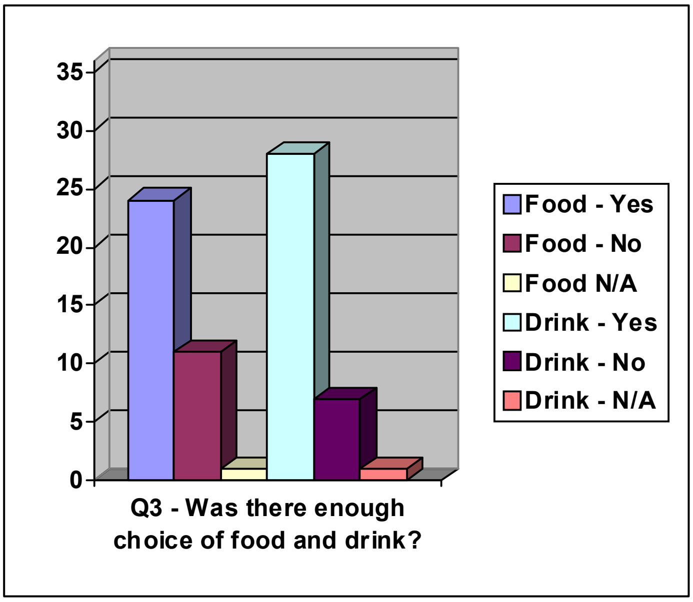
Q1: Were you weighed when you came into hospital or before you came into hospital?					
Overall score: 36					
Yes	31% (11)	No	53% (19)	Don't Know	17% (6)



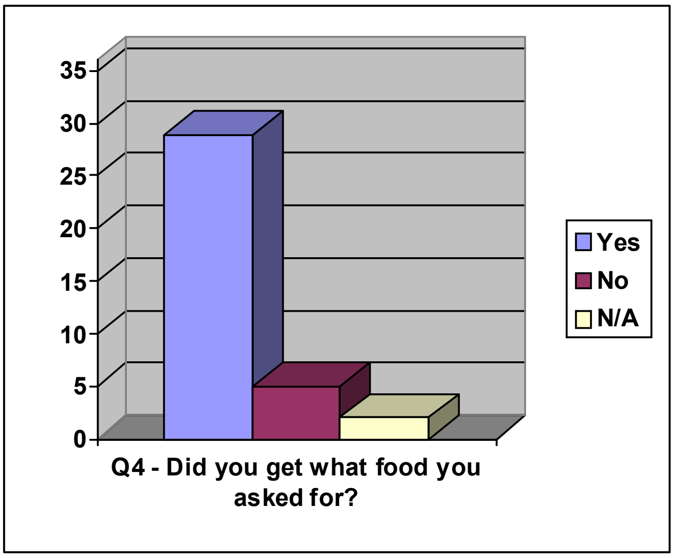
Q2: How long have you been in hospital for?				
Overall score: 36				
One day	2-6 days	A week	A month	More than a month
3% (1)	53% (19)	31% (11)	8% (3)	6% (2)



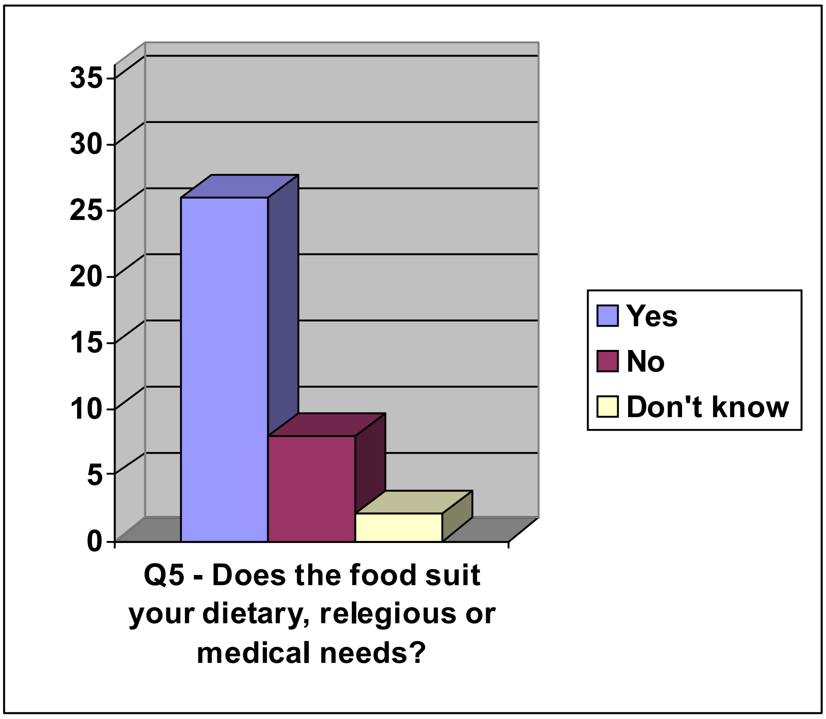
Q3: Was there enough choice of food and drink?		
Overall score: food: 36 Drink: 36		
Food: 67% YES (24)	31% No (11)	Don't Know: 3% (1)
Drink: 78% YES (28)	42% No (7)	Don't Know: 3% (1)



Q4: Did you get what food you asked for?		
Overall score: 36		
Yes 81% (29)	No 14% (5)	Don't Know 6% (2)

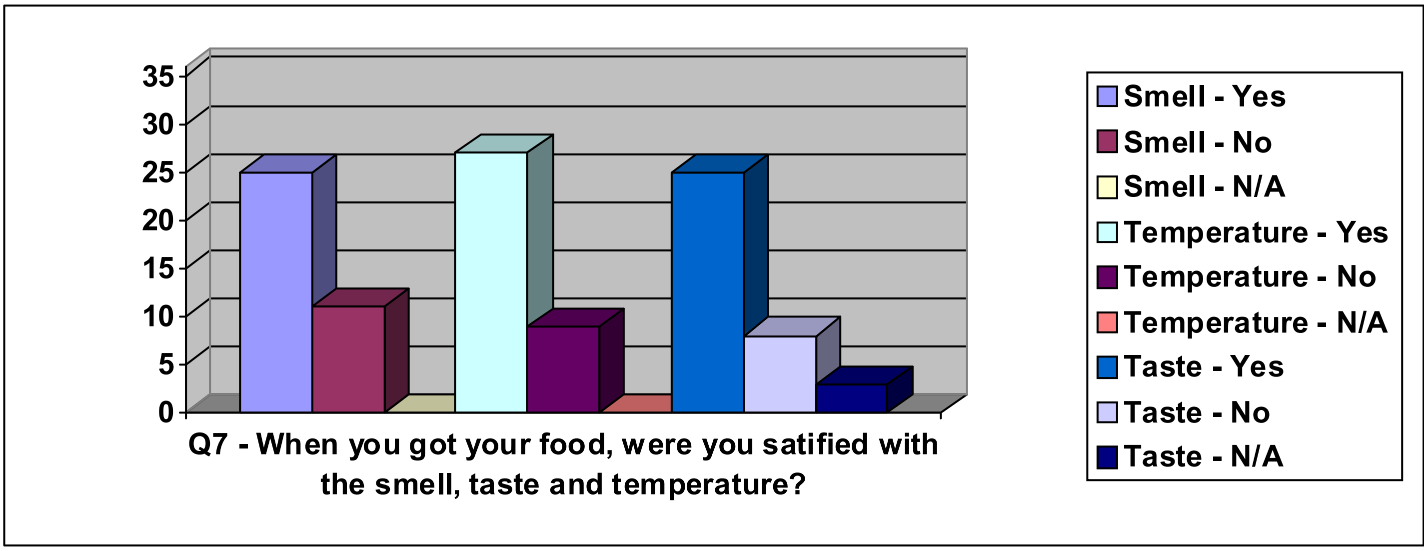


Q5: Does the food and drink suit your dietary, religious or medical needs?		
Overall score: 36		
Yes 72% (26)	**No 22% (8)**	**Don't Know 6% (2)**

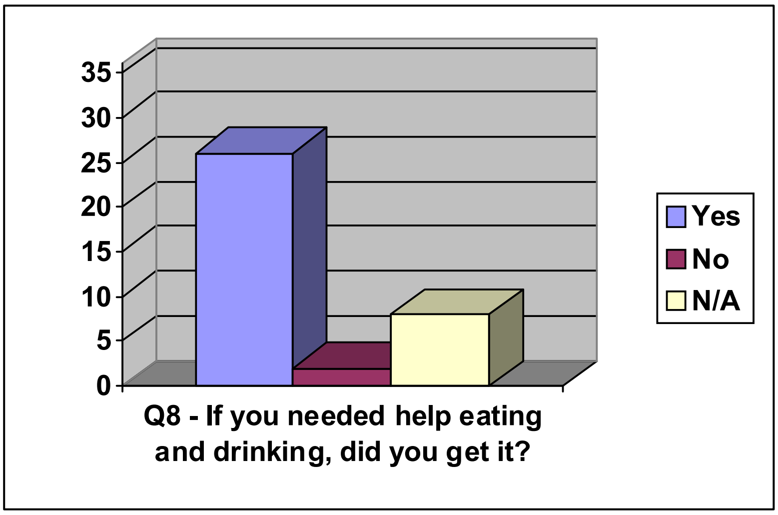


Q6: Were you given a chance to clean your hands before the meal?		
Overall score: 36		
Yes 38 % (14)	**No 61% (22)**	**Don't Know 0% (0)**

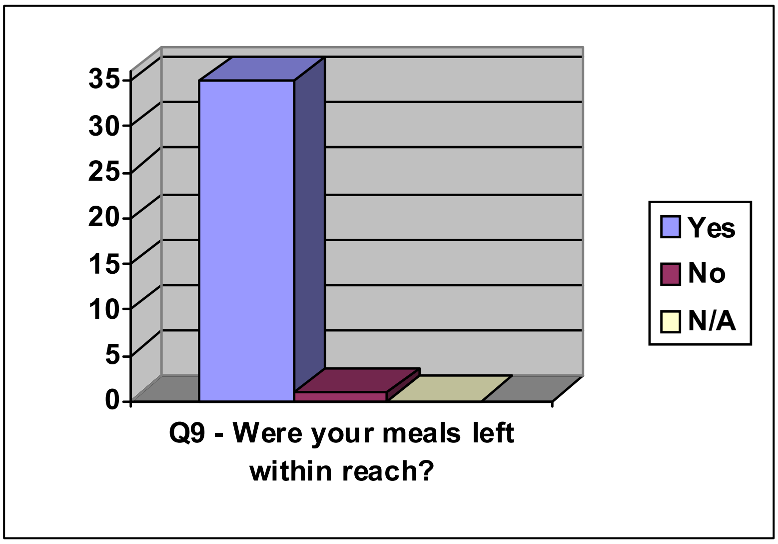
Q7: When you got your food, were you satisfied with:		
Overall score: 36		
Smell: 69% Yes (25)	No: 31% (11)	Don’t Know: 0% (0)
Temperature: 75% Yes (27)	No: 25% (9)	Don’t Know: 0% (0)
Taste: 69% Yes (25)	No: 22% (8)	Don’t Know: 8 % (3)



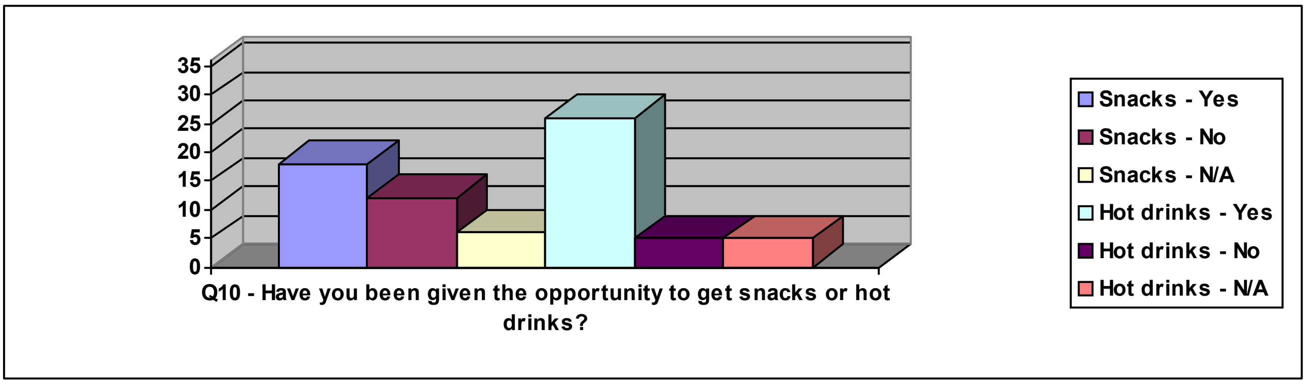
Q8: If you needed help eating and drinking, did you get it?		
Overall score: 36		
Yes: 72% (26)	No: 6 % (2)	Don’t Know: 22% (8)



Q9: Were your meals left within reach?		
Overall score: 36		
Yes 72.22% (35)	No 2.77% (1)	Don’t Know 0% (0)



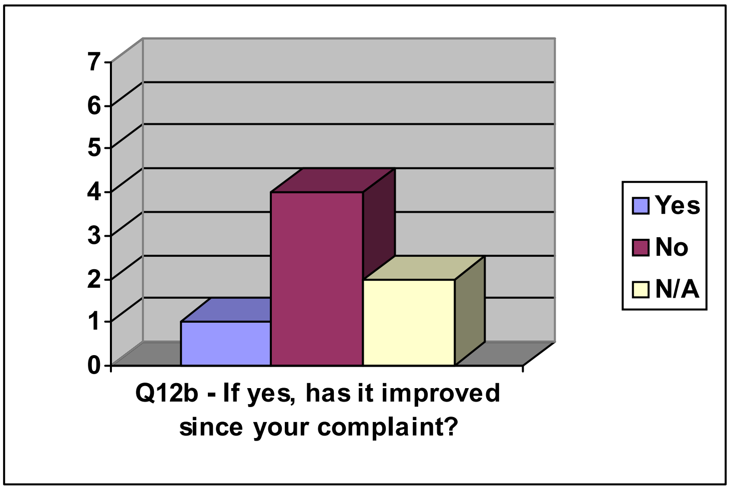
Q10: Have you been given the opportunity to get:		
Overall score: 36		
Snacks: 50% Yes (18)	Snacks: 33% No (12)	Snacks: 17%N/A (6)
Hot drinks: 72% Yes (26)	Hot drinks: 14% No (5)	Hot drinks: 14% N/A (5)



Q11: Have you been given enough information about when and where food is available to buy elsewhere?		
Overall score: 36		
Yes 31% (11)	No 61% (22)	Don't Know 8% (3)

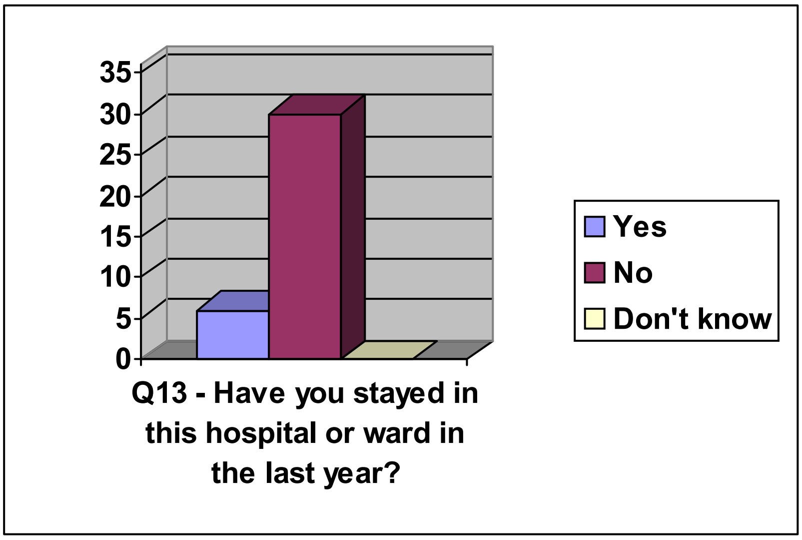
Q12: Have you complained about the food or drink?		
Overall score: 36		
Yes: 19% (7)	No: 81% (29)	Don't Know: 0% (0)

Q12b: If yes, has it improved since your complaint?		
Overall score: 7		
Yes: 14% (1)	No: 57% (4)	Don't Know: 29% (2)



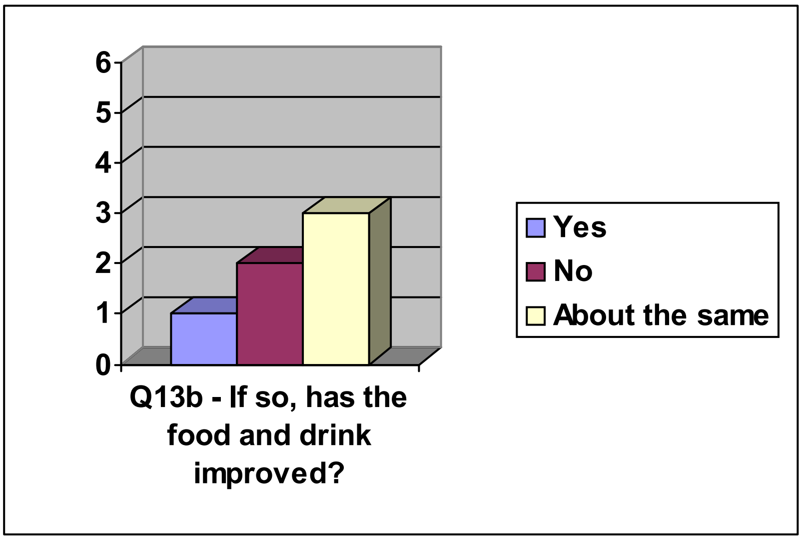
Q12b - If yes, has it improved since your complaint?

Q13: Have you stayed in this hospital or ward in the last year?		
Overall score: 36		
Yes 17% (6)	No 83 % (30)	Don't Know: 0% (0)

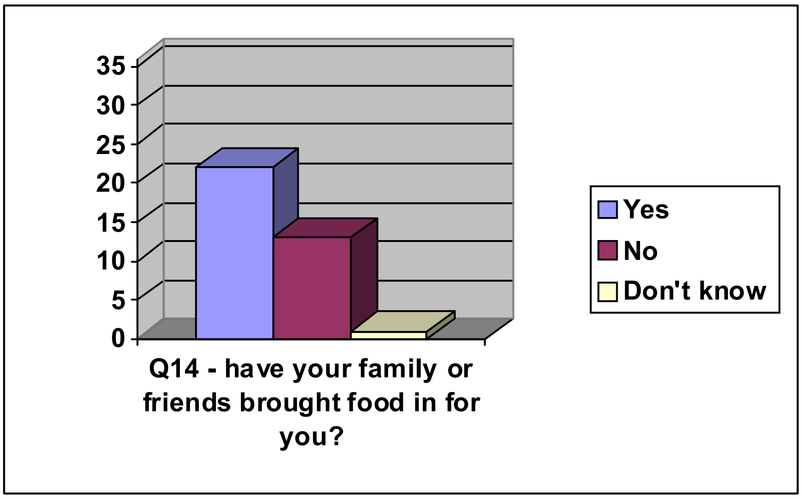


Q13 - Have you stayed in this hospital or ward in the last year?

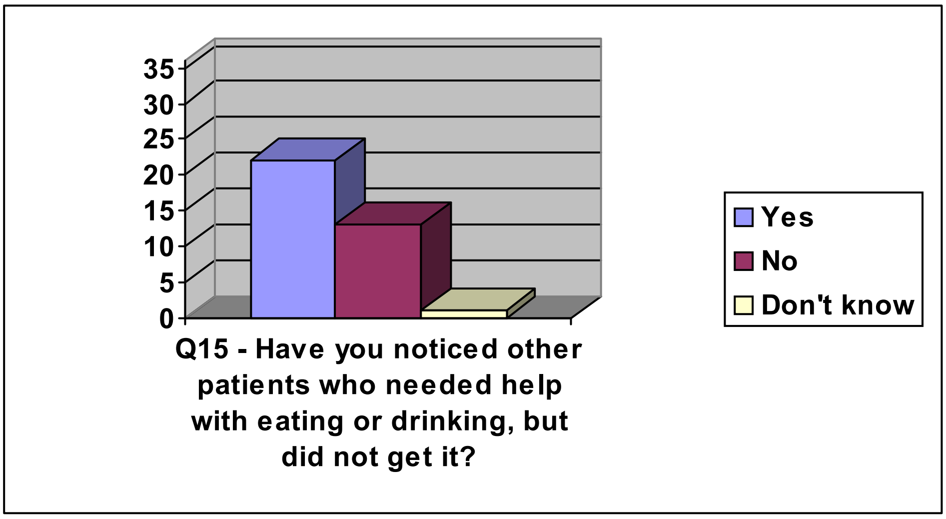
Q13b: If so, has the food and drink improved?		
Overall score: 6		
Yes 17% (1)	**No 33% (2)**	**About the same: 50% (3)**



Q14: Have your family and friends brought food in for you?		
Overall score: 36		
Yes 61% (22)	**No 36 % (13)**	**Don't Know: 3% (1)**



Q15: Have you noticed other noticed patients who need help with eat and drink but didn't get it?		
Overall score: 36		
Yes: 61% (22)	No: 36% (13)	Don't Know: 3% (1)



Observations

Royal Sussex County Hospital, Brighton

- Although most people said they were not weighed before coming into hospital, the main reason for this is likely to be due to being admitting via Accident and Emergency.
- 7 patients said they had complained about the food but had their complaints satisfactorily dealt with.
- Water jugs all seem to be filled and available but did not have lids. This may be because it is easier for patients to access their water jug.
- Most patients were unaware that snacks are available between meals and seemed surprised to hear that they were.
- Interviewers witnessed staff giving assistance to those that needed it
- Some staff seem to be over stretched during meal times. It is difficult to get round to all the patients who need help eating as meals get cold.
- Vegetables looked over-cooked and unappetising
- Some respondents said they felt the vegetarian options were limited and opted for sandwiches.
- Most patients received the meal options they had chosen although some patients said they could not remember what they had ordered anyway.
- Some patients felt the food could be healthier with more fresh fruit and vegetables available
- Most patients seem satisfied with the temperature of the food
- No visitors or volunteers were observed helping with patients' eating but this may be because it can be unsafe to use volunteers to assist with eating when the patient has complex care needs.
- There seemed to be a lot of food left on plates but it is acknowledged that this is not necessarily an indication of poor quality but could be attributed to illness etc. (as discussed in Chapter 5).
- Staff were seen assisting quite a few patients with eating with a sensitive, caring approach and most patients seemed to respond well to this.
- One older patient who appeared to be quite fragile and possibly had dementia was seen with a pasty type dish. This was left half eaten and did not have any gravy. This looked quite difficult to swallow as it was so dry.
- The LINk did not observe any patients using specially adapted eating aids.
- Although most patients' friends and family did bring in food and drink this was not due to poor quality of the food, it appeared to be mainly as an act of kindness.

Positive Patients Comments on RSC
The breakfast is nice, just the sort of thing I eat at home.
Staff seem willing to help with feeding if people need it
I always get lots of water and tea
Lunch and breakfast is good
Always get what I ordered
Staff are friendly and helpful

Negative Patients Comments on RSC
Haven't had jelly since I was 8, not what I want
Dinner is the worst meal, boring and over-cooked
I would prefer more fruit and low fat food
Not much choice for vegetarians, so chose sandwiches
The food is pretty bad, not tasty at all
Very unhealthy, can't wait to get home to eat properly
Food is often very dry and tasteless, but not in long enough to worry really

7. Recommendations

1. **Photographs of every meal.**

Picture menus are obviously particularly useful for people with communication difficulties and those whose first language is not English. However, they may also be useful for others who are not familiar with the dishes and perhaps to stimulate interest in food.

2. **Menus in large print available for those that need this**

3. **Clear coding for special diets and healthy eating indicating low fat options, suitable for those with diabetes, gluten free etc.**

4. **Menus recorded on to cassette tape for people with visual impairments.**

5. **Use a red tray system (or similar) to easily identify patients who need additional feeding support from staff and volunteers. And can also identify patients who are experiencing loss of appetite and weight.**
   Evidence suggests using this system can improve nutritional care (Age Concern 2006). It can also act as an aide memoir for staff to complete food/fluid charts and/or to provide supplement/fortified drink.

6. **Using a red jug and cup to identify those patients at risk nutritionally and of dehydration.**

7. **Patients are provided with at least 7 beverages a day as well as fresh water.**
   Sufficient fluid intake is vital to patient recovery and may help prevent problems such as constipation and urinary tract infection.

8. **Protected meal times poster at the entrance of every ward.**
   To encourage visitors to adhere to this. However, we recognise that visitors can be useful in assisting patients to eat.

9. **Staff to enforce protected meal times with visitors who are not there to help encourage patients to eat.**
   Patients who are not interrupted and receive appropriate service and support during mealtimes are happier, more relaxed and eat more.

10. **Add to the Hospital Welcome booklet and Visitor Code and to Trust website: encourage visitors to bring in soft drinks such as high juice squashes, blackcurrant drinks and fruit juice. Try to avoid fizzy (carbonated) drinks as these often of no nutritional value and can cause wind (gas) particularly for patients who are lying in bed for most/all of the day.**
    Often people find it difficult to drink plain water and therefore may not drink enough to keep them properly hydrated.

11. **Menus have a text reminder (or symbol) to encourage patients to choose healthier dishes/options e.g. that they have their five portions of fruit and vegetables a day (if appropriate to their clinical needs).** Hospitals should highlight good practice and lead by example in providing and encouraging healthier food choices to enable the population to reduce the risks of developing preventable diseases.

12. **Increased/widespread use of modified eating aids.** According to NICE “healthcare professionals should ensure adequate quantity and quality of food and fluid is available in an environment conducive to eating and there is appropriate support, e.g. modified eating aids”

13. **To offer snacks three times per day for those patients with increased energy and nutrient requirements.** The LINk Enter and View were not aware of the specific dietary needs of most of the patients unless they disclosed this so it was difficult to determine whether these patients were offered snacks 3 times a day.

14. **Provide a selection of extra bread (including brown and wholemeal) and should be available as an accompaniment to all meals.** This may help patients meet their nutrient and energy requirements and may help prevent constipation.

15. **Water jugs have lids to minimise foreign debris and bacteria contaminating the water.**

16. **All patients are made aware that snacks and snack boxes are available.** This helps increase flexibility, interest and variety and is particularly important for those with poor appetites etc.

17. **Jelly has minimal nutritional value although it is recognised it is easy to swallow.** Fruit (fresh or tinned in light syrup or natural juice), yoghurt, rice/custard/semolina, muesli/cereal bar etc. would perhaps be a better option.

18. **Use red cups for patients with dementia.** Research (Alzheimer’s Society) has shown that people with dementia patients respond better to red and are more likely to drink from a red cup than a clear one.

19. **Vegetarian menu options are interesting and varied.** Research from the Vegetarian Society shows that generally many vegetarians do not receive suitable or satisfactory food in hospital. With a larger than average vegetarian population in Brighton and Hove this is an important consideration at the Royal Sussex County Hospital.

20. **It might help patients if they were observed after the serving is completed and to be asked straight away if there was a problem and whether some assistance was needed.**

21. **All patients receive the patient booklet which explains that snacks are available and what facilities such as vending machines and snack shops are on site.** This is important since some patients are admitted via accident and emergency so would not have been sent literature.

22. **That volunteers are used to help with eating to help staff ensure patients are given as much assistance and encouragement to eat.**

8. Glossary

Dietician
A person who is specially trained in the nutritional needs/care of patients. A dietician will assess a person in order that the food/fluid given to the person is nutritionally balanced and meets their therapeutic needs.

Malnutrition
A state of nutrition in which a deficiency, excess or imbalance of energy, protein or other nutrients, including minerals and vitamins, causes measurable adverse effects on body function and clinical outcome.

Protected Meal Times
Periods of time on a hospital ward when all non-urgent activity stops, allowing the patient to eat without being interrupted and staff are available to provide assistance.

Screening Tool
Aid to assess a patient's status. A nutritional screening tool is an aid to assess a patient's nutritional status or their risk of poor nutritional status.

Therapeutic Diet
Food/fluid which has had its nutrients modified to meet the nutritional needs of a person, and which forms part of their medical treatment to prevent symptoms or improve nutritional status.

9. References

Council of Europe Resolution on Food and Nutritional Care in Hospitals
November 2003

Hungry to be Heard (2006) Age Concern England

Improving Nutritional Care A joint Action Plan from the Department of Health and Nutrition Summit stakeholders (2007) Department of Health. England

Organisation of Food and Nutritional Support in Hospital. (2007) BAPEN

RCN (2007) Nutrition Now. London: RCN.

Sullivan DH, Sun S, Walls RC. Protein-energy under nutrition among elderly hospitalized patients: a prospective study. Jama 1999;281(21):2013-9.
TV Chef Backs Hospital Food Project for Older People Science Daily (May 6, 2010)

The National Institute for Clinical Excellence published Nutrition Support for Adults – Oral Nutrition Support, Enteral Tube Feeding and Parental Nutrition

LINk Nutrition Survey

What to say to patients:

- I'm <<your name>> from <<LINk name>> which is an independent body that gives people the chance to say what they think and to suggest ideas to help improve services. We're completely independent of the NHS.
- We're asking people the same questions across 4 hospitals in Sussex to find out what patients think about hospital food.
- We would like to hear your opinions and be grateful if you could some answer questions.
- You will not be asked to give your name and any information you give will be used to help improve hospital services.

LINk name:	
Name of Enter & View representative:	
Date of visit:	
Hospital name:	
Ward name:	
Ward type:	
Meal time:	
Type of respondent:	patient ☐ relative ☐ carer ☐

1. **Were you weighed when you came into hospital or before you came into hospital?**
   ☐ Yes ☐ No ☐ don't know/don't remember

2. **How long have you been in hospital?**
   ☐ one day ☐ 2-6 days ☐ a week
   ☐ a month ☐ more than a month

3. **Is there enough choice of food and drink?**
   Food ☐ Yes ☐ No
   Drink ☐ Yes ☐ No

4. **Did you get what you asked for?**
   ☐ Yes ☐ No

5. **Does the food and drink suit your dietary, religious or medical needs?**
   ☐ Yes ☐ No ☐ N/A

If no, why not:

____

6. Are you given the chance to clean your hands before a meal?
☐ Yes ☐ No

7. When you got your food, were you satisfied with its:

Smell	Yes ☐	No ☐
Temperature	Yes ☐	No ☐
Taste	Yes ☐	No ☐

8. If you need help eating or drinking, did you get it?
☐ Yes ☐ No ☐ N/A

9. Was your meal/drink left within reach?
☐ Yes ☐ No

10. Have you been given the opportunity to get snacks?

Snacks	☐ Yes	☐ No	Don’t know/never asked ☐
Hot Drinks	☐ Yes	☐ No	Don’t know/never asked ☐

11. Have you been given enough information about when and where food is available to buy elsewhere? e.g. hospital shop, cafe
☐ Yes ☐ No

12. Have you complained about the food and/or drink?
☐ Yes ☐ No

If yes, has it improved since your complaint?
☐ Yes ☐ No

13. Have you stayed in this hospital or ward in the last year?
☐ Yes ☐ No

If so, has the food and drink improved?

Food	☐ Yes	☐ About the same	☐ No
Drink	☐ Yes	☐ About the same	☐ No

14. Have your family or friends brought food in for you?
☐ Yes ☐ No

If so, why?

____

15. Have you noticed <u>other</u> patients who need help to eat or drink, but didn't get it?

☐ Yes ☐ No

Do you have anything else to say about food and drink in the hospital or anything else you would like to tell the LINk about?

Thank you for answering these questions. We will use this information to improve services to patients.

If you would like further information on the LINk please take a leaflet.

LINk Nutrition Observation Checklist

LINk name:	
Name of Enter & View representative:	
Date of visit:	
Hospital name:	
Ward name:	
Ward type:	
Meal time:	

1. Have you seen any interruptions to meal times?

☐ Yes ☐ No

If yes, describe below:

2. Are people who need it, being helped to eat their meals and drink?

☐ Yes ☐ No

3. Are there menus readily available for people to make choices?

☐ Yes ☐ No ☐ N/A

4. If people are not eating their food, or drinking, what are staff or volunteers doing about it?

5. Is there evidence of any of the patients' food and/or drink being recorded? (do staff appear to recording information when patients leave a lot of food, any visible charts)

☐ Yes ☐ No

6. Is there evidence of snacks/drinks being available between meals?
(check if there is a nearby vending machine, water jugs topped up etc)
☐ Yes ☐ No ☐ Don't know

7. How are patients identified who are at risk/in need of help e.g. coloured tray, marker by bed etc.
☐ No evidence of identification
☐ Coloured Tray
☐ marker on bed
☐ other (please state)

____

8. How much food is being wasted and why?

Anything else?

45

West Sussex LINk
Your voice on local health and social care

West Sussex LINk Report

Review of Nutrition, Hydration and Feeding in 3 Wards of the Princess Royal Hospital by members of the West Sussex LINk Enter and View Team, April 2010

1. Introduction

East Sussex Overview and Scrutiny Committee commissioned a review of aspects of the level of nutrition, hydration and feeding that patients from that county were receiving in the various hospitals where they underwent treatment. As the Princess Royal Hospital is sited in Haywards Heath in West Sussex the West Sussex LINk agreed to carry out 'the enter and view visits' for this investigation.

A joint questionnaire was developed and it was agreed with the Hospital Management that three different wards should be visited; twice each so that visits would take place at the 3 daily meal times and on different days of the week. 4 members of the 'Enter and View Team' made the visits.

Details of Visits

Date & Meal	Team Members	Ward & Type
Wed 14 April evening	Tony Reynolds, Theo Verner	Hurstpierpoint (surgical/medical)
Sun 18 April lunch	Tony Reynolds, Lilian Bold	Ardingly (stroke/ medical)
Mon 19 April breakfast	Tony Reynolds, Theo Verner	Ardingly
Thur 22 April evening	Tony Reynolds, Chris McCrory	Balcombe (medical)
Fri 23 April breakfast	Tony Reynolds, Theo Verner	Balcombe
Sat 24 April lunch	Tony Reynolds, Chris McCrory	Hurstpierpoint

2. Analysis of Enter and View Visits

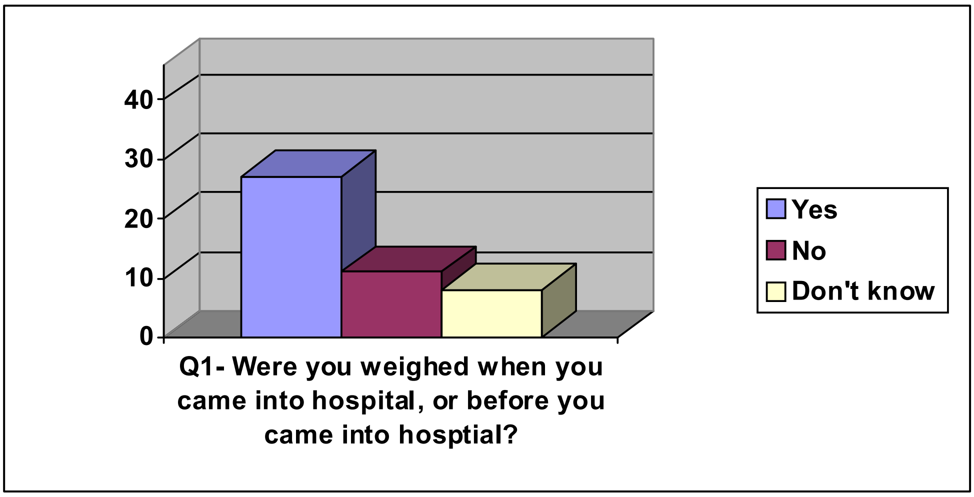
Administratively there were no problems. The West Sussex LINk staff and the Hospital Patient Experience Manager liaised about the visit and the visiting team found they were expected on the wards. Questions were readily answered and ward staff were happy to show visitors the procedures for dishing up meals and assisting patients to feed, and the methodology of record-keeping.

46 interviews were completed, 11 more than the target. In each of the wards there were patients too poorly to speak to or fast asleep. There were refusals from each ward, about 8 altogether. Nearly as many men as women were interviewed.

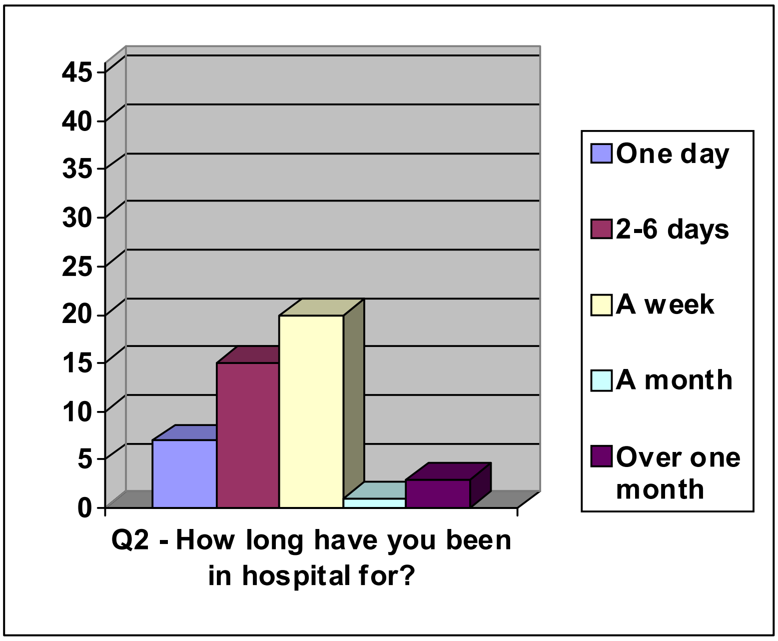
Meal times were 'protected' and screens unfolded across the entrances to wards stating that patients were to be allowed their meal without interruption. This worked and only once did an emergency cause a disruption to this ruling in one bay of one ward during our observations

Results:

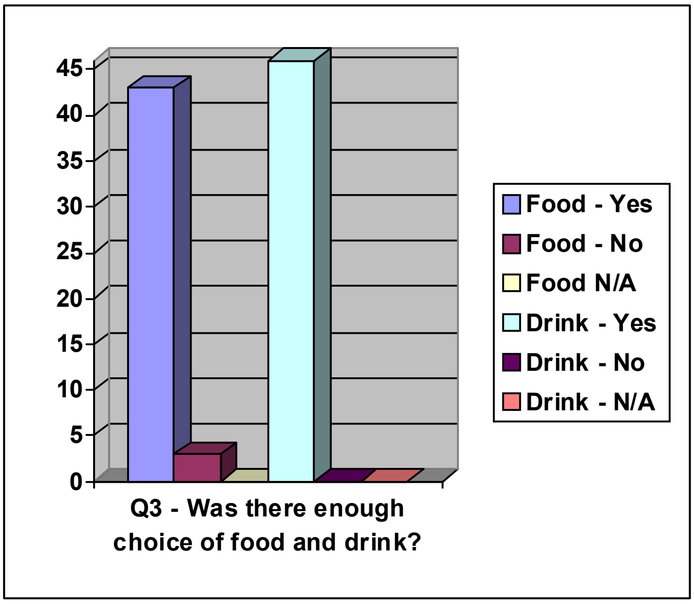
Q1: Were you weighed when you came into hospital or before you came into hospital?					
Overall score: 46					
Yes	59% (27)	No	24% (11)	Don't Know	17% (8)



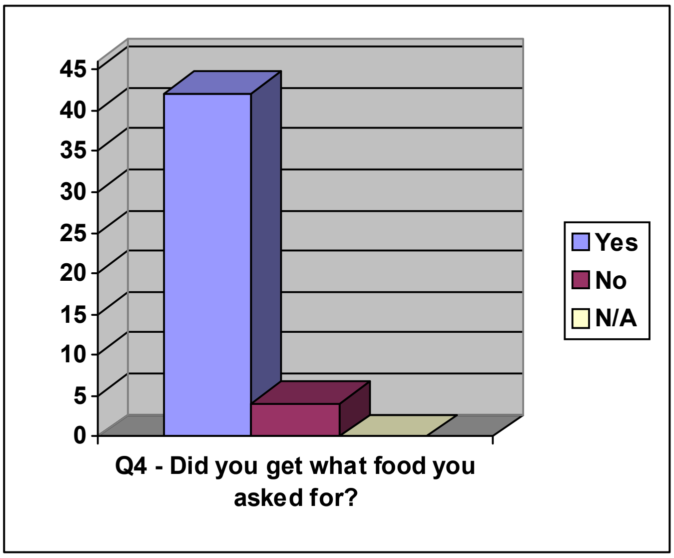
Q2: How long have you been in hospital for?				
Overall score: 46				
One day	2-6 days	A week	A month	More than a month
15% (7)	33% (15)	43% (20)	2% (1)	7% (3)



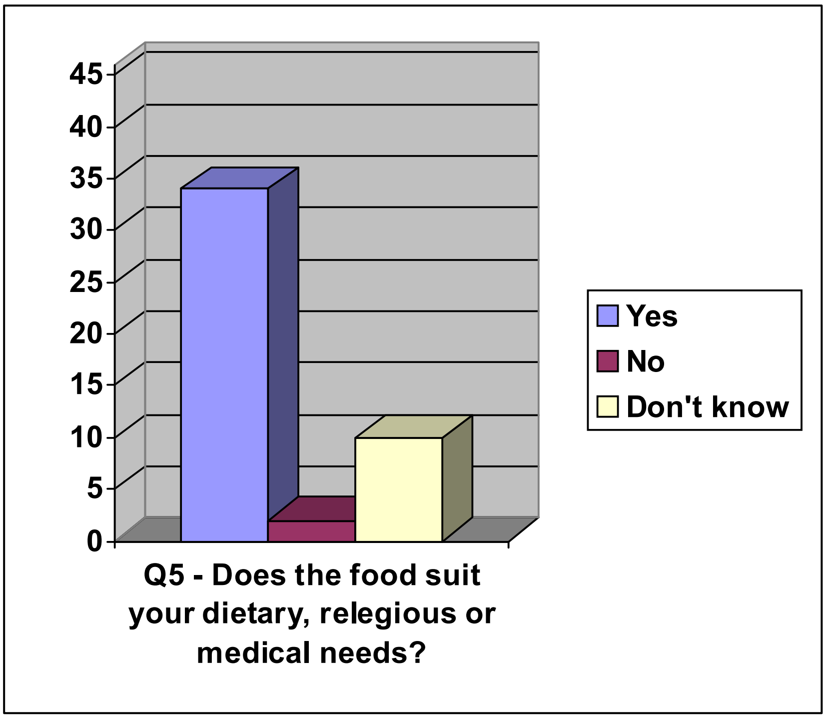
<table>
<tr><th colspan="3">Q3: Was there enough choice of food and drink?</th></tr>
<tr><td colspan="3">Overall score - Food: 46, Drink: 46</td></tr>
<tr><td>Food: 93% YES (43)</td><td>7% No (3)</td><td>Don’t Know: 0% (0)</td></tr>
<tr><td>Drink: 100% YES (46)</td><td>0% No (7)</td><td>Don’t Know: 0% (0)</td></tr>
</table>



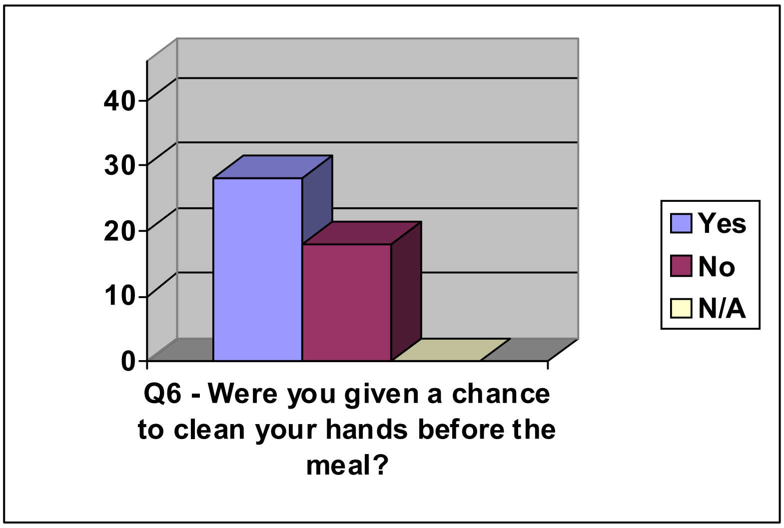
<table>
<tr><th colspan="3">Q4: Did you get what food you asked for?</th></tr>
<tr><td colspan="3">Overall score: 46</td></tr>
<tr><td>Yes 91% (42)</td><td>No 9% (4)</td><td>Don’t Know 0% (0)</td></tr>
</table>



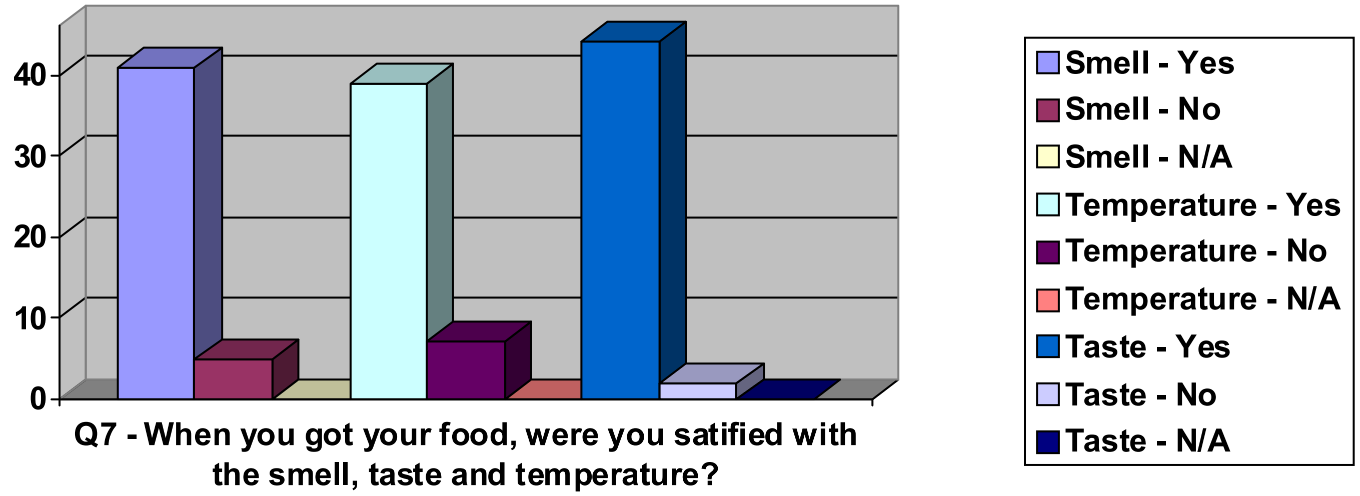
Q5: Does the food and drink suit your dietary, religious or medical needs?		
Overall score: 46		
Yes 74% (34)	No 4% (2)	Don't Know 22% (10)



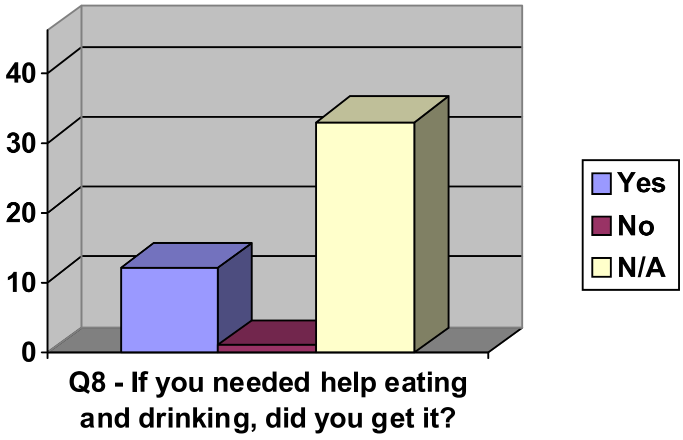
Q6: Were you given a chance to clean your hands before the meal?		
Overall score: 46		
Yes 61% (28)	No 39 % (18)	Don't Know 0% (0)



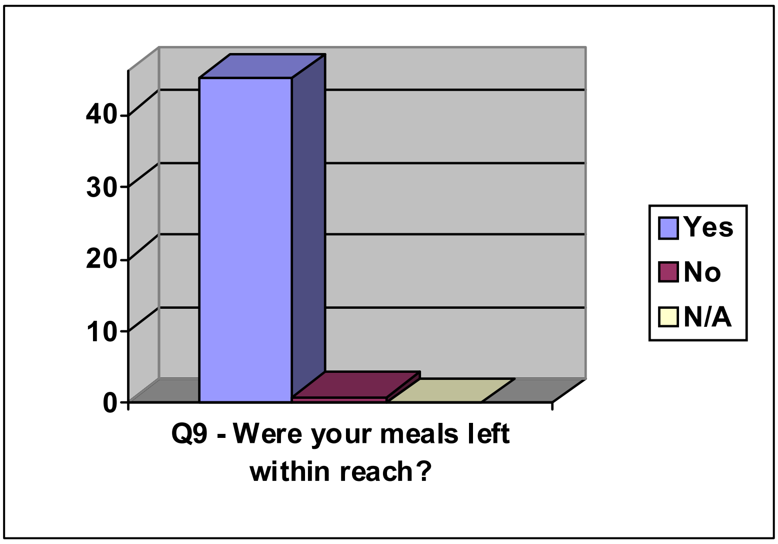
Q7: When you got your food, were you satisfied with:		
Overall score: 46		
Smell: 89% Yes (41)	No: 11% (5)	Don't Know: 0% (0)
Temperature: 85% Yes (39)	No: 15% (7)	Don't Know: 0% (0)
Taste: 96% Yes (44)	No: 4% (2)	Don't Know: 0 % (0)



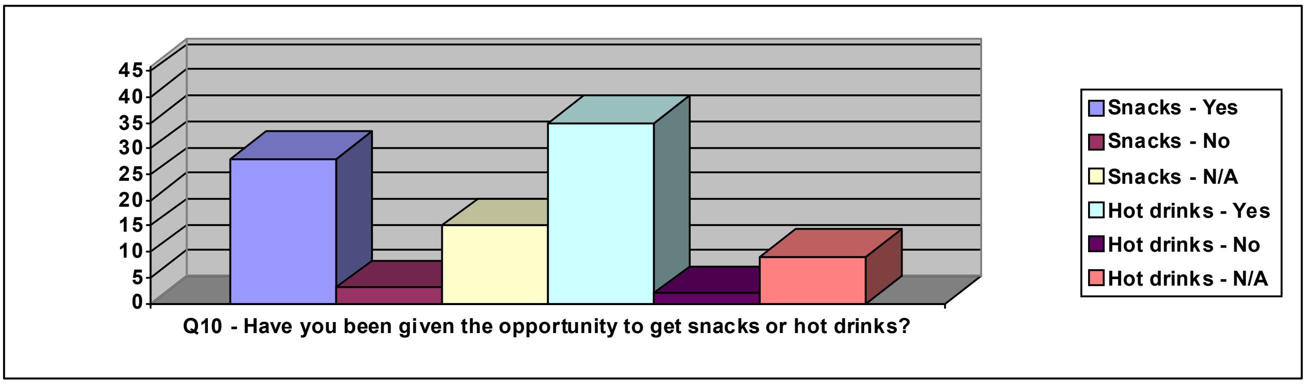
Q8: If you needed help eating and drinking, did you get it?		
Overall score: 46		
Yes: 26% (12)	No: 2 % (1)	N/A: 72% (33)



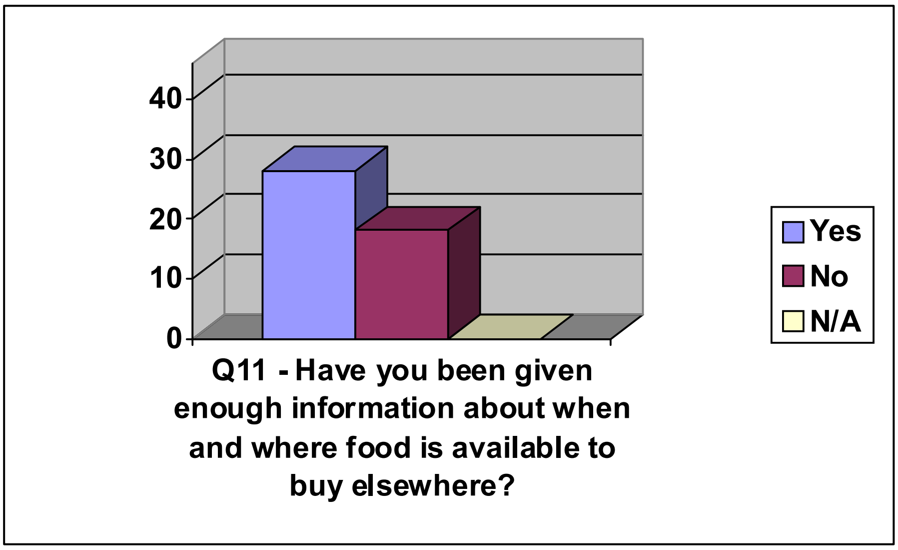
Q9: Were your meals left within reach?		
Overall score: 46		
Yes 98% (45)	No 2% (1)	Don't Know 0% (0)



Q10: Have you been given the opportunity to get:		
Overall score: 46		
Snacks: 61% Yes (28)	Snacks: 7% No (3)	Snacks: 32% N/A (15)
Hot drinks: 76% Yes (35)	Hot drinks: 4% No (2)	Hot drinks: 20% N/A (9)

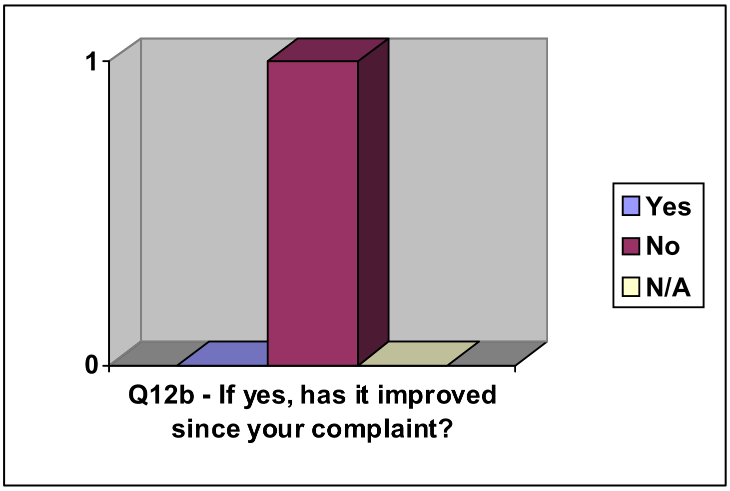


Q11: Have you been given enough information about when and where food is available to buy elsewhere?		
Overall score: 46		
Yes 61% (28)	No 39% (18)	Don't Know 0% (0)

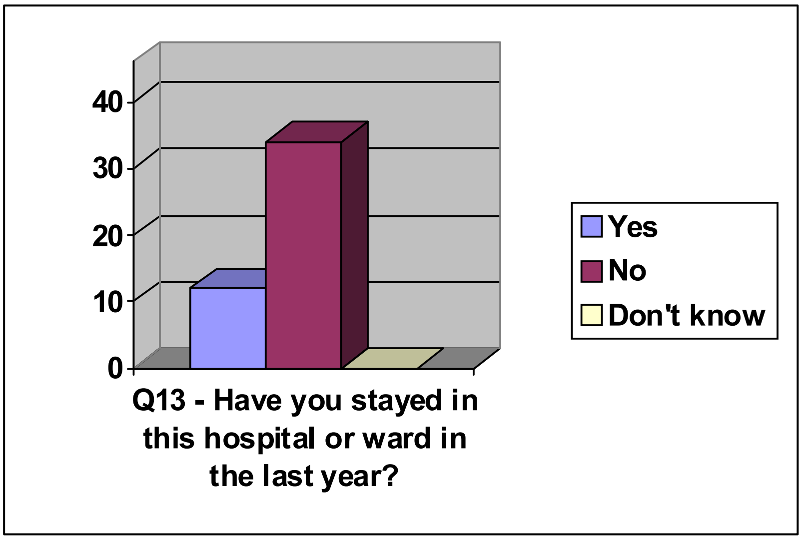


Q12: Have you complained about the food or drink?		
Overall score: 46		
Yes: 2% (1)	No: 98% (45)	Don't Know: 0% (0)

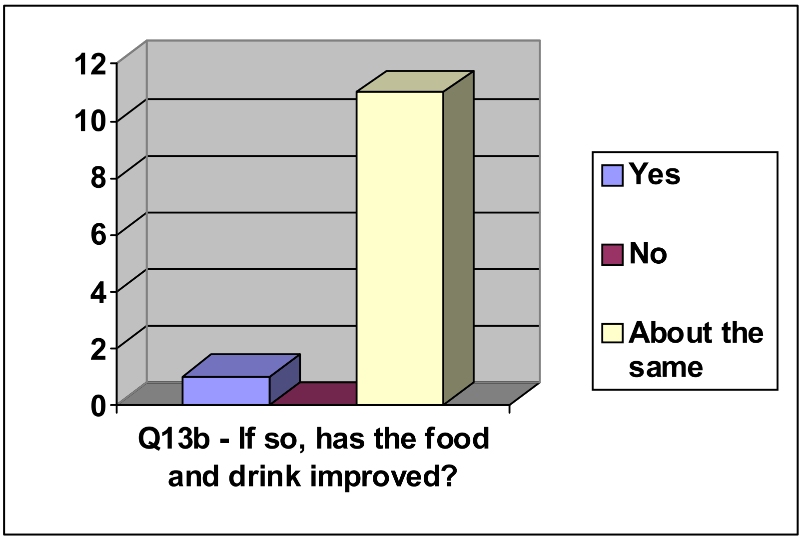
Q12b: If yes, has it improved since your complaint?		
Overall score: 1		
Yes: 0% (0)	**No: 100% (1)**	**Don’t Know: 0% (0)**



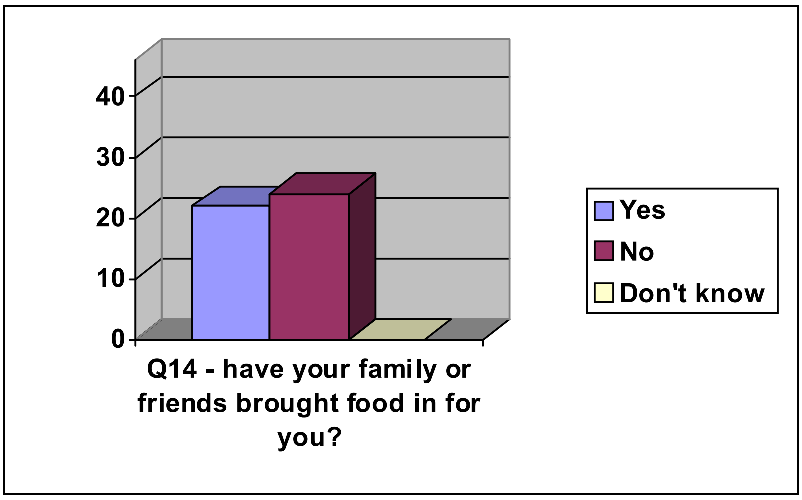
Q13: Have you stayed in this hospital or ward in the last year?		
Overall score: 46		
Yes 26% (12)	**No 74% (34)**	**Don’t Know: 0% (0)**



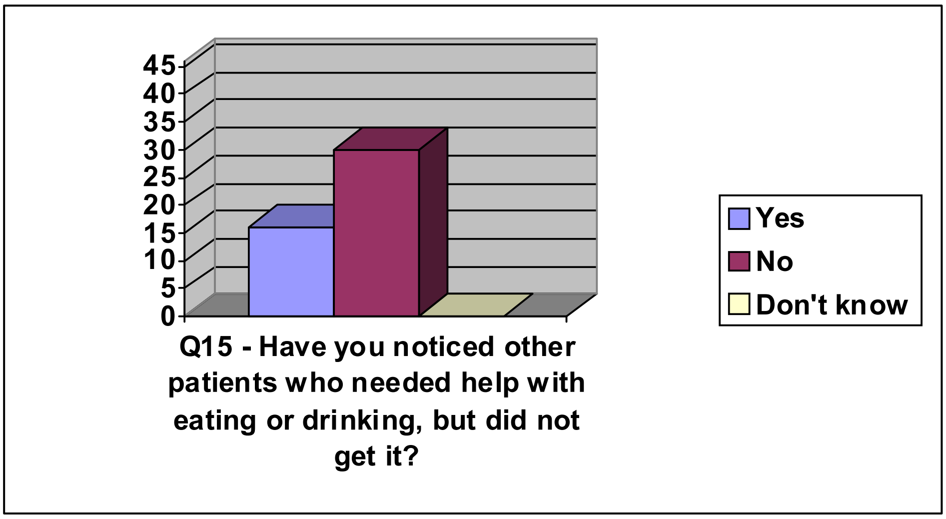
Q13b: If so, has the food and drink improved?		
Overall score: 12		
Yes 8% (1)	**No 0% (0)**	**About the same: 92% (11)**



Q14: Have your family and friends brought food in for you?		
Overall score: 46		
Yes 48% (22)	**No 52% (24)**	**Don't Know: 0% (0)**



<table>
<tr><td colspan="3">Q15: Have you noticed other noticed patients who need help with eat and drink but didn’t get it?</td></tr>
<tr><td colspan="3">Overall score: 46</td></tr>
<tr><td>Yes: 35% (16)</td><td>No: 65% (30)</td><td>Don’t Know: 0% (0)</td></tr>
</table>



4. Observations and Recommendations

The 6 visits enabled the 'Enter and View Team' to see the staff in action at mealtimes and the impression gained was of care taken in the preparation and heating of the food by the Patient Catering Assistant, responsible for dishing up at lunch and the evening meal. Temperature control is adhered to, using the special heated food trolleys. There is a good choice of menus usually chosen the day before and portion size can be regulated. The dishing-up process is carried out efficiently with all ward staff engaged in carrying food to the patients and making sure patients were sitting upright and had access to it. It was pleasing to see a ward sister carefully vetting each patient's dish and keeping track of the whole serving process.

Coloured trays for different needs are in use but on the visits there were few patients being given them. There was evidence of patients being assisted with food and drink but it seemed to be after all the meals had been dished out and there was an instance of one patient having to wait 10 minutes for assistance, so that the food would have been cold.

No friends or relations were observed helping feed patients, Care seemed to be taken in presenting the food on the plate and the smell and appearance were appetising. It was noted that after the meal was served patients had their food in front of them on their bed tables within easy reach.

There is no cooked breakfast, although toast, cereal and porridge are available with orange juice to drink. Preparation is done by ward staff assistants on demand. The reason is a budget/cost matter, and did rankle with some, mainly male patients who missed a full cooked breakfast.

Water jugs seemed well replenished and on one ward we saw staff refilling all the jugs as a routine procedure. Fruit could be obtained through the lunch-box system or asked for separately but was usually supplied by patients' visitors.

There were many instances in all wards where patients had not been encouraged to clean their hands before the meal, either by washing or using the convenient hand gels.

Nutrition charts are completed after meals for those patients where there is cause for concern about lack of eating, malnutrition etc and kept with their medical notes. On one ward the visiting team was told it was policy to try to coax patients to eat rather than not have enough food.

Menus are chosen the day before but sometimes patients can change their minds at the meal time and if there is enough left over have an alternative. This was noted once. Several patients found portions too large. There is an opportunity to order a small portion from the menu when patients complete their forms the day before and the servers could adjust the portion size if asked at the meal time.

At one weekend meal there were concerns by a member of staff that with less staff on duty it was difficult to serve the meals as efficiently as normal. There was one instance where some of a patient's meal had a cling-film wrapping which the patient found hard to undo and should have received some help.

Food wasted is measured on a ward basis but nurses note cases of individual patients leaving much of their food and the doctors can be informed. The Patient

Catering Assistant is responsible for logging the total amount of wasted food per ward. Sodexo Healthcare who is responsible for providing cooked meals carries out a comprehensive monthly survey covering a wide range of their activities from patient satisfaction to food waste.

Recommendations

In all three wards meals are served efficiently and there is a high patient satisfaction of choice quality and temperature and taste. Sometimes it might help patients if they were observed not eating after the serving is completed to be asked straight away if there was a problem and whether some assistance was needed. Every patient should have the meal system explained to them as soon as possible after arrival on the ward. Advice on obtaining snack-boxes, fruit and food and drink and how to get dietary advice, outlets for visitors to obtain food and drink should be included.

The biggest concern is with hand cleanliness. It is recommended that patients should be actively encouraged to clean their hands before meals and eating snacks and fruit. Although a patient may not move from bed between meals it does not mean the hands cannot become contaminated! If and when hand wipes are provided patients must be encouraged to use them.

A patient's weight doesn't seem to be factored into a patient's diet or at least none of the patients interviewed seem to have discussed this with staff during their hospital stay and an enforced stay in hospital would seem an appropriate time and place to do this.

Thanks

The Enter and View Team thank all the Staff for their willing co-operation and helpfulness and time spent explaining procedures to the Enter and View Team

Post-script

Tony Reynolds has taken up the matter of cleaning hands before eating with the Medical Director of the Trust who recognises it as an important factor of infection control and will raise the problem as an urgent item in the Infection Control Committee.

Tony Reynolds, West Sussex LINk, 23rd May 2010

# HEALTH OVERVIEW AND SCRUTINY COMMITTEE	**Agenda Item 26** Brighton & Hove City Council

Subject:		**Increasing Democratic Legitimacy in Health: Department of Health Consultation on Elements of the Health White Paper**	
Date of Meeting:		**29 September 2010**	
Report of:		**The Director of Strategy and Governance**	
Contact Officer:	Name:	Giles Rossington	Tel: 29-1038
	E-mail:	Giles.rossington@brighton-hove.gov.uk	
Wards Affected:	All		

FOR GENERAL RELEASE

1. SUMMARY AND POLICY CONTEXT:

1.1 In July 2010 the Department of Health (DH) published a white paper: “Equity and Excellence: Liberating the NHS”.

1.2 Allied to the white paper are several DH consultation exercises. The one which has direct relevance to HOSCs is the “Increasing Democratic Legitimacy in Health” consultation. This focuses on the white paper plans for changing the ways in which the NHS is to be governed and held to account, including proposals to significantly alter health scrutiny.

1.3 The closing date for submissions to this consultation is 11 October 2010. Should members wish to submit comments from HOSC, they may therefore wish to take the opportunity to agree a submission at the 29 September 2010 committee meeting.

1.4 The DH consultation paper ‘Increasing Democratic Legitimacy in Health’ is reprinted as **Appendix 1** to this report.

2. RECOMMENDATIONS:

2.1 That members:

(1) Note the contents of this report and its appendix;

(2) Decide whether to submit comments to the ‘Increasing Democratic Legitimacy in Health’ Department of Health consultation;

And if members do decide to submit comments:

(3) Agree on the contents of their submission.

3. BACKGROUND INFORMATION

3.1 The DH consultation paper ‘Increasing Democratic Legitimacy in Health’ asks respondents to comment on a series of questions relating to the governance and democratic oversight of NHS health services.

3.2 Whilst the DH welcomes comments on any of its proposals, there are two questions which are likely to be of particular interest to HOSC members. These are:

Q14: Do you agree that the scrutiny and referral function of the current health OSC should be subsumed within the health and wellbeing board (if boards are created)?

Q15: How best can we ensure that arrangements for scrutiny and referral maximise local resolution of disputes and minimise escalation to the national level?

3.3 **Q14** refers specifically to the statutory powers that HOSCs were granted by the Health and Social Care Act (2001). In short, these powers enable HOSCs to require senior NHS trust officers to attend committee meetings and also make it possible for HOSCs to refer NHS plans to make ‘substantial variations’ in local health services to the Secretary of State for Health on the grounds that the plans have either been introduced without properly consulting local people/stakeholders, or are detrimental to the health interests of local people. The health white paper proposes that these statutory powers be transferred to health and well-being boards.

3.4 Perhaps the most obvious effect of this proposal would be to transfer scrutiny and referral powers from a cross-party scrutiny committee to an executive committee (assuming that health and well-being boards will be executive bodies – the exact nature of these boards is also up for consultation). It would also presumably transfer scrutiny from a *disinterested* body to one which, insofar as it is also charged with overseeing local commissioning strategies and will presumably include service commissioners and providers, has a potential *interest* in developments in the local health economy.

3.5 **Q15** is essentially concerned with the powers of referral currently enjoyed by HOSCs. In recent years, these powers have quite frequently been used in the context of major NHS reconfiguration plans – for instance, East Sussex PCT plans to reconfigure East Sussex consultant-led maternity units were referred to the Secretary of State by East Sussex HOSC; NHS West Sussex plans to reconfigure West Sussex acute health services were referred to the Secretary of State by the Joint HOSC examining this initiative. Referrals can be very time-consuming and awkward for the NHS (not least because any reconfiguration is suspended whilst the referral is being heard), and it is unsurprising that the Government should wish to minimise them, particularly ones which are of questionable merit. (However, several recent HOSC referrals, such as the East Sussex maternity issue, have been upheld by the Secretary of State. It is therefore by no means the case that HOSC referrals are invariably unmerited.)

3.6 The main question here may be whether questionable referrals would be more or less likely should the power to refer be vested with health and well-being boards rather than HOSCs? It may also be relevant to note that many major NHS reconfiguration plans cut across local authority boundaries (for example) the ‘Fit For the Future’ proposals which potentially impacted upon West Sussex, East Sussex, Surrey, Portsmouth, Hampshire and Brighton & Hove) and are typically scrutinised by Joint HOSCs which are required to make decisions in the joint best interest of their residents rather than the interests of their specific populations. There may therefore be a question as to whether it is thought that local authority executives would be more or less likely to work together constructively for the common good than local authority scrutiny committees.

4. CONSULTATION

4.1 No formal consultation has been undertaken in preparing this report.

5. FINANCIAL & OTHER IMPLICATIONS:

Financial Implications:

5.1 None directly in terms of a HOSC response. Brighton & Hove City Council will submit its own response to this consultation, and this response may be made with reference to financial implications for the council.

Legal Implications:

5.2

Equalities Implications:

5.3 None to this report.

Sustainability Implications:

5.4 None to this report.

Crime & Disorder Implications:

5.5 None to this report.

Risk and Opportunity Management Implications:

5.6 None to this report.

Corporate / Citywide Implications:

5.7 None to this report.

SUPPORTING DOCUMENTATION

Appendices:

1. Increasing Democratic Legitimacy in Health: Department of Health consultation document

Documents in Members' Rooms:

None

Background Documents:

1. "Equity and Excellence: Liberating the NHS" – Department of Health white paper

NHS

Liberating the NHS:

Local democratic legitimacy in health

A consultation on proposals

Communities and Local Government

DH Department of Health

DH INFORMATION READER BOX

Policy
HR / Workforce
Management
Planning /
Clinical
Estates
Commissioning
IM & T
Finance
Social Care / Partnership Working

Document Purpose	Consultation/Discussion
Gateway Reference	14531
Title	Local Democratic Legitimacy in Health
Author	Department of Health & Communities and Local Government
Publication Date	22 Jul 2010
Target Audience	PCT CEs, Care Trust CEs, Directors of PH, Local Authority CEs, Directors of Adult SSs, PCT Chairs, GPs, Directors of Children's SSs
Circulation List	PCT CEs, Care Trust CEs, Directors of PH, Local Authority CEs, Directors of Adult SSs, PCT Chairs, GPs, Directors of Children's SSs, Voluntary Organisations/NDPBs
Description	The document sets out proposals to strengthen the role of local government in health by: i) local authorities taking on local public health improvement functions; ii) local authorities having a new role in promoting integration; and iii) Local HealthWatch organisations acting as independent consumer champions, accountable to local authorities.
Cross Ref	Equity and Excellence: Liberating the NHS (July 2010)
Superseded Docs	
Action Required	Interested parties should respond to the consultation
Timing	**Respond by 11 October 2010**
Contact Details	The White Paper Team - Consultation responses 6th Floor Richmond House 79 Whitehall London SW1A 2NS nhswhitepaper@dh.gsi.gov.uk www.dh.gov.uk/liberatingtheNHS
For Recipient's Use	

Foreword

A decade of centralising, controlling government has left our public services strangled with red tape, focused on processes not outcomes, and weakened by the need to account to bureaucrats instead of the public. Too many decisions have been made nationally, rather than locally, without enough public involvement. The NHS, like other public services, has suffered as a result. The creativity and innovation of health professionals has been stifled while the public are frustrated at the lack of opportunities to speak up and make a difference to their local health services.

Localism is one of the defining principles of this Government: pushing power away from Whitehall out to those who know best what will work in their communities. Our plans to make this happen in health are set out in the recent white paper: *Equity and Excellence: Liberating the NHS*. It will restore real decision-making powers to patients and GPs.

The NHS is one of Britain's greatest achievements, and a service of which we can all be proud. It will continue to be a national service, held to account by Parliament. But for the first time in forty years, there will be real local democratic accountability and legitimacy in the NHS. Elected councillors and councils will have a new role in ensuring the NHS is responsible and answerable to local communities. By commissioning HealthWatch - the new way for patients and the public to shape health services - councils will be responsible for ensuring local voices are heard and patients are able to exercise genuine choice. Councils will also take the lead in improving local public health.

In this new role, councils will be assessing local needs, promoting more joined up services, and supporting joint commissioning. This builds on the excellent work that is already being done by some councils in joining up services to improve local health and social care and will help ensure a closer working relationship between health and other council responsibilities, such as housing and environmental health. This means that patients who need the help of both health and social care services can expect to get much more coherent, effective support in future.

This short paper seeks your views on these important changes to establish local democratic accountability in the NHS. We look forward to hearing from you.

Rt. Hon. Andrew Lansley CBE MP
Secretary of State for Health

Eric Pickles

Rt. Hon. Eric Pickles MP
Secretary of State for Communities
and Local Government

Contents

Introduction

1. The White Paper *Equity and Excellence: Liberating the NHS* set out the Government's strategy for the NHS. Our intention is to create an NHS which is much more responsive to patients, and achieves better outcomes, with increased autonomy and clear accountability at every level.

2. *Liberating the NHS* makes clear the Government's policy intentions, and provides a coherent framework. Further work lies ahead to develop and implement detailed proposals. In progressing this work the Department will be engaging with external organisations, seeking their help and wishing to benefit from their expertise.

3. This short document, *Local democratic legitimacy in health,* provides further information on proposals for increasing local democratic legitimacy in health, through a clear and enhanced role for local government. Through elected members, local authorities will bring greater local democratic legitimacy to health. They will bring the perspective of local place - of neighbourhoods and communities - into commissioning plans. Local authorities can take a broader, more effective view of health improvement. They are uniquely placed to promote integration of local services across the boundaries between the NHS, social care and public health.

4. This consultation has been produced jointly by the Department of Health and the Department for Communities and Local Government.

5. It is part of a public consultation on specific aspects of the White Paper. The initial suite of supporting papers also includes:

   - *Commissioning for patients*
   - *Regulating healthcare providers*
   - *The review of arm's-length bodies*
   - *Transparency in outcomes: a framework for the NHS*

   The Government will publish a response prior to the introduction of a Health Bill later this year.

6. National accountability for the health service is critical. It currently receives about £100 billion of taxpayers' funding, and it is right that it is held to account for the stewardship of these finances and outcomes through Parliament. The reforms the Government set out in *Liberating the NHS* will remove ongoing political interference from the health service, through the creation of an independent NHS

Commissioning Board, but national accountability will remain. In the future, there will be a more transparent relationship between national government and the NHS, with less scope for day-to-day political interference.

7. One of the central features of the proposals in the White Paper is to devolve commissioning responsibilities and budgets as far as possible to those who are best placed to act as patients' advocates and support them in their healthcare choices. Through our world-renowned system of general practice, GPs and other primary care professionals are already supporting patients in managing their health, promoting continuity and coordination of care, and making referrals to more specialist services. In empowering GP practices to come together in wider groupings, or 'consortia', to commission care on their patients' behalf and manage NHS resources, we are building on these foundations. We are also empowering them to work more effectively alongside the full range of other health and care professionals.

8. Most commissioning decisions will now be made by consortia of GP practices, free from top-down managerial control and supported and held to account for the outcomes they achieve by the NHS Commissioning Board. This will push decision-making much closer to patients and local communities and ensure that commissioners are accountable to them. It will ensure that commissioning decisions are underpinned by clinical insight and knowledge of local healthcare needs. It will enable consortia to work closely with secondary care, other health and care professionals and with community partners to design joined-up services that make sense to patients and the public. It will not be appropriate for all commissioning decisions to be made at a local level and some specialist services, such as paediatrics, will need to be commissioned at a higher geographical unit, by the NHS Commissioning Board. *Commissioning for patients* - published alongside this document - gives further detail of how GP commissioning consortia and the NHS Commissioning Board will work.

9. Within this strong national system, the Government wants to strengthen local democracy. Giving people the opportunity to exercise their voices as individuals is an important part of this. The proposals build on the existing mechanisms, such as patients using information about a provider to exercise choice, or participating as an active member of a local foundation trust. We will strengthen the collective voice of patients and the public through arrangements led by local authorities, and at national level, through a powerful new consumer champion, HealthWatch England, located in the Care Quality Commission.

10. Within this new system, local authorities will have an enhanced role in health. The Government intends that they will have greater responsibility in four areas:

- leading joint strategic needs assessments (JSNA)[1] to ensure coherent and co-ordinated commissioning strategies;
- supporting local voice, and the exercise of patient choice;
- promoting joined up commissioning of local NHS services, social care and health improvement; and
- leading on local health improvement and prevention activity.

11. With the local authority taking a convening role, it will provide the opportunity for local areas to further integrate health with adult social care, children's services (including education) and wider services, including disability services, housing, and tackling crime and disorder. This has the potential to meet people's needs more effectively and promote the best use of public resources. The local authority will lead the process of undertaking joint strategic needs assessments across health and local government services and promote joint commissioning between GP consortia and local authorities. GP consortia and the NHS Commissioning Board will be responsible for making health care commissioning decisions, informed by the JSNA. We would encourage local authorities to take the NHS Constitution into account when influencing local commissioning decisions about NHS services.

12. The Government will work with the Local Government Association to understand the potential benefits of place-based budgets through the Spending Review period. We will look at the potential application of these approaches to cross-cutting areas of health spending that require effective partnerships with local authorities and other frontline organisations, for example older people's services, and substance misuse.

13. The Government is committed to ensuring that there is a strong local voice for patients through democratic representation in healthcare. The Coalition Programme proposed directly elected individuals on the primary care trusts (PCT) board as a mechanism for doing this. However, because of the proposed transfer of commissioning functions to the NHS Commissioning Board and GP consortia, the Government has concluded that PCTs should be abolished. Instead, we propose an enhanced role for elected local councillors and local authorities, as a more effective way to boost local democratic engagement. In this document, the Government is bringing forward practical plans that give stronger effect to its intentions for local democratisation in health.

---

[1] A joint strategic needs assessment is an assessment of the health and wellbeing needs of the population in a local area and since 2007 it has been a statutory duty for primary care trusts and local authorities to undertake one. They aim to establish a shared, evidence based consensus on key local priorities to support commissioning to improve health and wellbeing outcomes and reduce inequalities. In practice the JSNA falls to the Directors of Public Health, Directors of Adult Social Services and Directors of Children's Services to carry out, as set out in the JSNA guidance.

Strengthening public and patient involvement

14. *Liberating the NHS* set out plans to create a much more responsive NHS that is genuinely centred on the needs and wishes of patients, through increased choice, an information revolution, stronger voice, and commissioning by GP consortia. These changes will radically shift the power of the health service away from Whitehall and closer to the individual and the professionals that serve them.

15. Choice, control and better information are at the heart of these plans, but these need to be backed up by support for individuals and local voice. We want local people to have a greater say in decisions that affect their health and care and have a clear route to influence the services they receive. Since the *NHS Plan*, structures for leading local involvement have been subject to numerous changes. The Government intends to build on the current statutory arrangements, to develop a more powerful and stable local infrastructure in the form of local HealthWatch, which will act as local consumer champions across health and care. Local Involvement Networks (LINks) will become the local HealthWatch.

16. We propose that local HealthWatch be given additional functions and funding. Like LINks, they will continue to promote patient and public involvement, and seek views on local health and social care services which can be fed back into local commissioning. Also like LINks, they are likely to continue to take an interest in the NHS Constitution.

Q1 Should local HealthWatch have a formal role in seeking patients' views on whether local providers and commissioners of NHS services are taking account of the NHS Constitution?

17. We also propose that HealthWatch perform a wider role, so that they become more like a "citizen's advice bureau" for health and social care - the local consumer champion - providing a signposting function to the range of organisations that exist. We therefore propose that they are granted additional specific responsibilities, matched by additional funding, for:

- NHS complaints advocacy services. Currently, this is a national function for the NHS, exercised through a Department of Health contract for the Independent Complaints Advocacy Service. We propose that this responsibility is devolved to local authorities to commission through local or national HealthWatch, so that they can support people who want to make a complaint.

- Supporting individuals to exercise choice, for example helping them choose a GP practice. Giving patients and users the right to choice, and greater information, is essential, but it is not always sufficient to enable everyone to exercise it. Local HealthWatch will have a key role in offering support to those that need it.

Q2 Should local HealthWatch take on the wider role outlined in paragraph 17 with responsibility for complaints advocacy and supporting individuals to exercise choice and control?

18. Local authorities have a vital role in commissioning HealthWatch arrangements that serve their local populations well. They will continue to fund HealthWatch, and contract for their services. Local authorities have an important responsibility, set out in statute, for discharging these duties, and holding local HealthWatch to account for delivering services that are effective and value for money. They will also ensure that the focus of local HealthWatch activities is representative of the local community. In the event of under-performance, a local authority should intervene; and ultimately re-tender the contract where that is in the best interests of its local population.

Q3 What needs to be done to enable local authorities to be the most effective commissioners of local HealthWatch?

19. Local HealthWatch would still be able to report concerns about the quality of the provision of local NHS or social care services to HealthWatch England, in order to inform the need for potential regulatory action, independently of its host local authority. HealthWatch England will form a statutory part of the Care Quality Commission (CQC), the quality regulator for health and social care. This key role for local HealthWatch will be underpinned by continued rights to visit provider services.

Improving integrated working

20. People want services that feel joined up, and it can be a source of great frustration when that does not happen. Integration means different things to different people but at its heart is building services around individuals, not institutions. The Government is clear that joint, integrated working is vital to developing a personalised health and care system that reflects people's health and care needs. Services also need to be developed in ways that fit around the people who use them, and their families, and that they can understand and shape. We have an opportunity to strengthen integrated working across the health and social care agenda, from the point of providing services, to people understanding how services need to be commissioned to best meet the health and wellbeing needs of local populations. We can also improve integrated working right along the care pathway - from prevention, treatment and care, to recovery, rehabilitation and re-ablement.

21. *Liberating the NHS* has been designed to strengthen integration in many ways, for example:

    - by giving people using services more choice and control about what matters most to them. Critically this includes choice of treatment and care not just choice of provider. People will have more power in the system to decide what matters most to them;
    - by extending the availability of personal budgets in the NHS and social care, with joint assessment and care planning;
    - quality standards will be developed systematically across patient pathways, for example the recently published NICE dementia standard;
    - through the CQC as an effective inspectorate of essential quality standards, that span health and social care;
    - through payment systems being used to support joint working, for example the proposals around payment by results and hospital readmissions, which should create opportunities for the full engagement of the wider health and care economy before discharging people from hospital; and
    - through freeing up providers to innovate and focus on the needs of people using services rather than the needs of a top-down central bureaucracy. For example, the Government is proposing to remove the

constraints that currently exist for foundation trusts to enable them to augment their NHS role, by, for example, expanding into social care.

22. The existing framework provided in legislation[2] sets out optional partnership arrangements for service-level collaboration between local authorities and health-related bodies. The arrangements include:

- lead commissioning (with PCTs or local authorities leading commissioning services for a client group on behalf of both organisations);
- integrated provision (for example care trusts); and
- pooled budgets.

23. Take up of the current flexibilities to enable joint commissioning and pooled budgets has been relatively limited. It has tended to focus on specific service areas, such as mental health and learning disabilities. The full potential of joint commissioning, for example to secure services that are joined up around the needs of older people or children and families, remains untapped. The new commissioning arrangements will support this. GP commissioning consortia will have a duty to work with colleagues in the wider NHS and in social care to deliver higher quality care, a better patient experience and more efficient use of NHS resources.

Q4 What more, if anything, could and should the Department do to free up the use of flexibilities to support integrated working?

Q5 What further freedoms and flexibilities would support and incentivise integrated working?

24. The Government believes that there is scope for stronger institutional arrangements, within local authorities, led by elected members, to support partnership working across health and social care, and public health. Local authorities' skills, experience and existing relationships present them with an opportunity to bring together the new players in the health system, as well as to provide greater local democratic legitimacy in health.

25. One option is to leave it up to NHS commissioners and local authorities as to whether they want to work together, and should they so wish, to devise their own local arrangements. An alternative approach, which the Government prefers, is to specify the establishment of a statutory role, within each upper tier local authority, to support joint working on health and wellbeing.

---

[2] Section 75 of the NHS Act 2006

26. The advantages of having a statutory arrangement are that it would provide duties on relevant NHS commissioners to take part, and provide a high-level framework of functions. In this way it would offer clarity of expectation about partnership working.

> ***Q6 Should the responsibility for local authorities to support joint working on health and wellbeing be underpinned by statutory powers?***

27. One way in which respective roles and responsibilities could be enhanced further, is through a statutory partnership board - a health and wellbeing board - within the local authority. This would provide a vehicle and focal point through which joint working could happen. Alternatively, local partners may prefer to design their own arrangements. We would like your views on how best to achieve partnership working and integrated commissioning.

28. If health and wellbeing boards were created, requirements for such a board would be minimal, with Local Authorities enjoying freedom and flexibility as to how it would work in practice.

> ***Q7 Do you agree with the proposal to create a statutory health and wellbeing board or should it be left to local authorities to decide how to take forward joint working arrangements?***

Functions of health and wellbeing boards

29. The primary aim of the health and wellbeing boards would be to promote integration and partnership working between the NHS, social care, public health and other local services and improve democratic accountability. The local authority would bring partners together to agree priorities for the benefit of patients and taxpayers, informed by local people and neighbourhood needs.

30. The Government proposes that statutory health and wellbeing boards would have four main functions:

    - to assess the needs of the local population and lead the statutory joint strategic needs assessment;
    - to promote integration and partnership across areas, including through promoting joined up commissioning plans across the NHS, social care and public health;
    - to support joint commissioning and pooled budget arrangements, where all parties agree this makes sense; and

- to undertake a scrutiny role in relation to major service redesign (as set out in paragraph 42 - 50).

Q8 ***Do you agree that the proposed health and wellbeing boards should have the main functions described in paragraph 30?***

Q9 ***Is there a need for further support to the proposed health and wellbeing boards in carrying out aspects of these functions, for example information on best practice in undertaking JSNAs?***

31. The health and wellbeing board would allow more effective engagement between local government and NHS commissioners. There would be a statutory obligation for the local authority and commissioners to participate as members of the board and act in partnership on these functions. Whilst responsibility and accountability for NHS commissioning would rest with the NHS Commissioning Board and GP consortia, the health and wellbeing board would give local authorities influence over NHS commissioning, and corresponding influence for NHS commissioners in relation to health improvement, reducing health inequalities, and social care.

32. The aim is to ensure coherent and coordinated local commissioning plans across the NHS, social care and public health, for example in relation to mental health, older people's or children's care, with intelligence and insight about people's wants and needs systematically shaping and commissioning decisions. These arrangements would also enable local authorities to engage more effectively via GP consortia, who would be making health care commissioning decisions. A significant benefit of the health reforms will be the removal of political interference in the day-to-day running of the health service. The local authority and its partners will only be able to ensure that the needs of their population are adequately assessed if they work together to ensure that national politics are not replaced by unconstructive local politics.

33. The health and wellbeing board could also be a vehicle for taking forward joint commissioning and pooled budgets, where parties agree this makes most sense and it is in line with the financial controls set by the NHS Commissioning Board.

Q10 ***If a health and wellbeing board was created, how do you see the proposals fitting with the current duty to cooperate through children's trusts?***

Operation of health and wellbeing boards

34. We anticipate that the statutory health and wellbeing boards would sit at the upper tier local authority level. However, the boards would want to put in place

arrangements to discharge their functions at the right level to ensure that the needs of diverse areas and neighbourhoods are at the core of their work, and that democratic representatives of areas below the upper tier can contribute. This would be particularly important in two-tier areas, where boards may want to delegate the lead for some functions to districts or neighbourhoods. Neighbouring boroughs may also choose to establish a single board covering their combined area, should that make most sense locally.

35. We anticipate that the health and wellbeing boards would have a lead role in determining the strategy and allocation of any local application of place-based budgets for health. The health and wellbeing boards would have an important role in relation to other local partnerships, including those relating to vulnerable adults and children's safeguarding. If the Local Children's Safeguarding Board became concerned that the local safeguarding arrangements were not working as they should, and in particular if there were concerns about the NHS partners, they could raise this with the health and wellbeing board, who would escalate it to the NHS Commissioning Board if they were unable to achieve local resolution.

36. To reduce bureaucracy, we anticipate that local authorities may want to use the proposed health and wellbeing boards to replace current health partnerships where they exist, and work with the local strategic partnership (at the upper tier) to promote links and connections between the wider needs and aspirations of local neighbourhoods and health and wellbeing.

37. If these proposals are taken forward, we will need to ensure that appropriate arrangements are made to support the full package of reforms in London with links between the borough boards and the Mayor. The Government would particularly welcome views on this point.

Q11 How should local health and wellbeing boards operate where there are arrangements in place to work across local authority areas, for example building on the work done in Greater Manchester or in London with the link to the Mayor?

Membership of health and wellbeing boards

38. If taken forward, the boards would bring together local elected representatives including the Leader or the Directly Elected Mayor, social care, NHS commissioners, local government and patient champions around one table. The Directors of Public Health, within the local authority, would also play a critical role. The elected members of the local authority would decide who chaired the board.

39. The board would include both the relevant GP consortia and representation from the NHS Commissioning Board (where relevant issues are being discussed). It may be relevant for the NHS Commissioning Board to attend when issues relating to the services that they commission are being discussed, for example family health services, specialised services and maternity services. We would specify both parties' duty to take part in the partnership in legislation.

40. In addition to the strategic role, at a practical level, health and wellbeing boards could agree joint NHS and social care commissioning of specific services, for example mental health services, including prevention, or agree the allocation and strategy for place-based budgets on cross-cutting health issues. The precise role of place-based budgets should be a decision for the health and wellbeing board in light of local priorities. For the board to function well, it will undoubtedly require input from the relevant local authority directors, on social care, public health and children's services. We also propose a local representative from HealthWatch will have a seat on the board, so that it has influence and responsibility in the local decision-making process. We recognise the novelty of arrangements bringing together elected members and officials in this way and would welcome views as to how local authorities can make this work most effectively.

41. To ensure that the board is able to engage effectively with local people and neighbourhoods, local authorities may also choose to invite local representatives of the voluntary sector and other relevant public service officials to participate in the board. They may also want to invite providers into discussions, taking care to adhere to the principles of fairness, engaging providers in an equal and transparent manner.

Q12 Do you agree with our proposals for membership requirements set out in paragraph 38 - 41?

Overview and scrutiny function

42. In the current system, overview and scrutiny committees (OSCs) have the power to scrutinise major health service changes and the ongoing planning, development and operation of services. They are set up in local authorities and set their own priorities for scrutiny, reflecting the interests and concerns of the communities they serve. They are able to hold the NHS to account by:

    - calling NHS managers to give information, answer questions and provide explanation about services and decisions and making recommendations locally;

- requiring consultation by the NHS where major changes to health services are proposed; and

- referring contested service changes to the Secretary of State for Health.

43. If a health and wellbeing board was created within a local authority, it would have a key new role in promoting joint working, with the aim of making commissioning plans across the NHS, public health and social care coherent, responsive and integrated. It would be able to exercise strategic oversight of health and care services. It would be better equipped to scrutinise these services locally. To avoid duplication, we propose that the statutory functions of the OSC would transfer to the health and wellbeing board.

44. This transfer would strengthen the overview that local authorities have on health decisions and bring in the voice of the local HealthWatch. Having a seat on the health and wellbeing board gives HealthWatch a stronger formal role in commissioning discussions than currently exists for LINks. This would provide additional opportunity for patients and the public to hold decision makers to account and offer scrutiny and patient voice.

45. Members of the health and wellbeing board, including elected councillors, would have the opportunity to identify shared goals and priorities and to identify early on in their respective commissioning processes how best to address these. This emphasis on proactive local partnership would minimise the potential for disputes. We will work with local authorities and the NHS to develop guidance on how best to resolve these issues locally, so that they are only referred on in the most exceptional circumstances.

Q13 What support might commissioners and local authorities need to empower them to resolve disputes locally, when they arise?

46. Within the scope of NHS services, as defined by the Secretary of State, GP consortia will be free to decide commissioning priorities to reflect local needs, consistent with the public sector equality duties and supported by the national framework of quality standards, tariffs and national model contracts established by the NHS Commissioning Board. GP consortia will also have a duty to engage and involve the public in planning services and considering any proposed changes in how those services are provided. In addition, the health and wellbeing board would have an important role in enabling the NHS Commissioning Board to assure itself that GP consortia are fulfilling their duties in ways that are responsive to patients and the public.

47. If health and wellbeing boards had significant concerns about substantial service changes, an attempt should first be made to resolve this locally, for example with local commissioners, through the health and wellbeing board itself. The boards

would be expected to take account of the need to deliver services more efficiently, and of the wider quality, innovation, productivity and prevention (QIPP) agenda. The board may choose to engage external expertise to help resolve the issue, for example a clinical expert, the Centre for Public Scrutiny or the Independent Reconfiguration Panel.

48. For a minority of cases, there will still need to be a system of dispute resolution beyond the local level. This should happen only in exceptional cases as local resolution should be the preferred course of action. Where the dispute is unable to be resolved, the health and wellbeing board would have a power to refer the commissioning decision to the NHS Commissioning Board. If the issue relates to a decision made by the NHS Commissioning Board (e.g. in relation to maternity services) the health and wellbeing board may choose to refer it directly to the Secretary of State.

49. If the NHS Commissioning Board is satisfied that the correct procedure has been followed and that the decisions are based on clinical evidence, but the health and wellbeing board still has significant concerns about the issue, the health and wellbeing board would have a statutory power to refer cases to the Secretary of State. The Secretary of State would then consider the NHS Commissioning Board's report alongside the reasons for referral, seeking advice from the Independent Reconfiguration Panel. In the context of the new regulatory framework, the Secretary of State for Health's involvement will be subject to independent decisions made by regulators - the economic regulator, and the Care Quality Commission - for example on the basis of patient safety.

Q14 Do you agree that the scrutiny and referral function of the current health OSC should be subsumed within the health and wellbeing board (if boards are created)?

Q15 How best can we ensure that arrangements for scrutiny and referral maximise local resolution of disputes and minimise escalation to the national level?

50. Public scrutiny is an essential part of ensuring that Government and public services remain effective and accountable. It helps to achieve a genuine accountability for the use of public resources. A formal health scrutiny function will continue to be important within the local authority, and the local authority will need to assure itself that it has a process in place to adequately scrutinise the functioning of the health and wellbeing board and health improvement policy decisions.

Q16 What arrangements should the local authority put in place to ensure that there is effective scrutiny of the health and wellbeing board's functions? To what extent should this be prescribed?

Local authority leadership for health improvement

51. In future, local authorities will have a stronger influence on the health outcomes of their local area. When PCTs cease to exist we intend to transfer responsibility and funding for local health improvement activity to local authorities. Embedding leadership for local health improvement activity within local authorities builds upon the existing success of the many joint Director of Public Health appointments between local authorities and PCTs. It is intended to unlock synergies with the wider role of local authorities in tackling the determinants of ill health and health inequalities.

52. Funding for health improvement includes that spent on the prevention of ill-health by addressing lifestyle factors such as smoking, alcohol, diet and physical exercise. So, for example, we envisage that smoking cessation services would be funded from the resources transferred to the local authority, but treatment for individuals with impaired lung function through smoking would be funded from resources allocated to GP consortia by the NHS Commissioning Board.

53. Local authority leadership for local health improvement will be complemented by the creation of a National Public Health Service (PHS). The PHS will integrate and streamline health improvement and protection bodies and functions, and will include an increased emphasis on research, analysis and evaluation. It will secure the delivery of public health services that need to be undertaken at a national level.

54. In order to manage public health emergencies, the PHS will have powers in relation to the NHS, matched by corresponding duties for NHS resilience. The NHS Commissioning Board will have a role in supporting the Secretary of State for Health and the PHS to ensure that the NHS in England is resilient and able to be mobilised during any emergency it faces, or as part of a national response to threats external to the NHS.

55. The local authority will also play an important role in PHS campaigns of national importance, which aim to protect public health or provide population screening; and it will have a role in national health improvement campaigns, tailoring programmes to meet the needs of its local population.

56. Local Directors of Public Health will be jointly appointed by local authorities and the PHS. They will have a ring-fenced health improvement budget, allocated by the PHS; and they will be able to deploy these resources to deliver national and local priorities. There will be direct accountability to both the local authority, and, through the PHS, to the Secretary of State. Through being employees of the local authority, local Directors of Public Health will have direct influence over the

wider determinants of health, advising elected members and as part of the senior management team of the local authority.

57. The Secretary of State, through the PHS, will agree with local authorities the local application of national health improvement outcomes. It will be for local authorities to determine how best to secure the outcomes and this may include commissioning services, for example, from providers of NHS care. Local neighbourhoods will have freedom and flexibility to set local priorities, working within a national framework.

58. In the Government's work to develop a public health White Paper, we will engage stakeholders on arrangements for the abolition of PCTs and the establishment of the public health ring-fenced health improvement budget. Arrangements for health improvement will also be aligned with future arrangements for outcomes in local government, and in particular with the approach to social care outcomes.

Conclusion and summary of consultation questions

59. This document has set out the Government's plans for increasing local democratic legitimacy in health, by giving local authorities a stronger role in supporting patient choice and ensuring effective local voice; promoting more effective NHS, social care and public health commissioning arrangements, through the proposed new health and wellbeing boards; and local leadership for health improvement. We will need to ensure, through this consultation exercise and broader policy work, that the health system is financially sustainable through the transition to the new structures that we lay out here, as well as in the longer term.

60. Implementation will be consistent with the new burdens doctrine. Subject to legislation, health improvement functions will transfer to local authorities from 2012. We propose that statutory partnership functions would also be established formally from 2012. However, if the idea receives positive support, the Departments of Health and Communities and Local Government will support local authorities to establish shadow arrangements with the PCT, emerging GP consortia and LINks in 2011. The Government proposes to make the changes through its forthcoming Health Bill, planned for introduction this autumn, subject to the responses received to this consultation.

61. The Government would welcome views on the following questions:

Q1 ***Should local HealthWatch have a formal role in seeking patients' views on whether local providers and commissioners of NHS services are taking account of the NHS Constitution?***

Q2 ***Should local HealthWatch take on the wider role outlined in paragraph 17, with responsibility for complaints advocacy and supporting individuals to exercise choice and control?***

Q3 ***What needs to be done to enable local authorities to be the most effective commissioners of local HealthWatch?***

Q4 ***What more, if anything, could and should the Department do to free up the use of flexibilities to support integrated working?***

Q5 ***What further freedoms and flexibilities would support and incentivise integrated working?***

Q6 ***Should the responsibility for local authorities to support joint working on health and wellbeing be underpinned by statutory powers?***

Q7 ***Do you agree with the proposal to create a statutory health and wellbeing board or should it be left to local authorities to decide how to take forward joint working arrangements?***

Q8 ***Do you agree that the proposed health and wellbeing board should have the main functions described in paragraph 30?***

Q9 ***Is there a need for further support to the proposed health and wellbeing boards in carrying out aspects of these functions, for example information on best practice in undertaking joint strategic needs assessments?***

Q10 ***If a health and wellbeing board was created, how do you see the proposals fitting with the current duty to cooperate through children's trusts?***

Q11 ***How should local health and wellbeing boards operate where there are arrangements in place to work across local authority areas, for example building on the work done in Greater Manchester or in London with the link to the Mayor?***

Q12 ***Do you agree with our proposals for membership requirements set out in paragraph 38 - 41?***

Q13 ***What support might commissioners and local authorities need to empower them to resolve disputes locally, when they arise?***

Q14 ***Do you agree that the scrutiny and referral function of the current health OSC should be subsumed within the health and wellbeing board (if boards are created)?***

Q15 ***How best can we ensure that arrangements for scrutiny and referral maximise local resolution of disputes and minimise escalation to the national level?***

Q16 ***What arrangements should the local authority put in place to ensure that there is effective scrutiny of the health and wellbeing board's functions? To what extent should this be prescribed?***

Q17 ***What action needs to be taken to ensure that no-one is disadvantaged by the proposals, and how do you think they can promote equality of opportunity and outcome for all patients, the public and, where appropriate, staff?***

Q18 ***Do you have any other comments on this document?***

62. Responses to the questions in this consultation document should be sent to nhswhitepaper@dh.gsi.gov.uk or to the White Paper Team, Room 601, Department of Health, 79 Whitehall, London SW1A 2NS by 11 October 2010.

Annex 1: The consultation process

Criteria for consultation

This consultation follows the ‘Government Code of Practice’, in particular we aim to:

- formally consult at a stage where there is scope to influence the policy outcome;
- consult for at least 12 weeks - the policies in this document were included in the NHS White Paper, *Liberating the NHS*, which was launched on 12 July for a 12 week consultation period closing on 5 October;
- be clear about the consultations process in the consultation documents: what is being proposed, the scope to influence and the expected costs and benefits of the proposals;
- ensure the consultation exercise is designed to be accessible to, and clearly targeted at, those people it is intended to reach;
- keep the burden of consultation to a minimum to ensure consultations are effective and to obtain consultees’ ‘buy-in’ to the process;
- analyse responses carefully and give clear feedback to participants following the consultation;
- ensure officials running consultations are guided in how to run an effective consultation exercise and share what they learn from the experience.

The full text of the Code of Practice and related guidance is on the Better Regulation

website at www.bis.gov.uk/policies/better-regulation/consultation-guidance

Comments on the consultation process itself

If you have concerns or comments which you would like to make relating specifically to the consultation process itself please contact:

Consultations Coordinator
Department of Health
3E48, Quarry House

Leeds
LS2 7UE
e-mail: consultations.co-ordinator@dh.gsi.gov.uk
Please do not send consultation responses to this address.

Confidentiality of information

We manage the information you provide in response to this consultation in accordance with the Department of Health's Information Charter (available at www.dh.gov.uk).

Information we receive, including personal information, may be published or disclosed in accordance with the access to information regimes (primarily the Freedom of Information Act 2000 (FOIA), the Data Protection Act 1998 (DPA) and the Environmental Information Regulations 2004).

If you want the information that you provide to be treated as confidential, please be aware that, under the FOIA, there is a statutory Code of Practice with which public authorities must comply and which deals, amongst other things, with obligations of confidence. In view of this, it would be helpful if you could explain to us why you regard the information you have provided as confidential. If we receive a request for disclosure of the information we will take full account of your explanation, but we cannot give an assurance that confidentiality can be maintained in all circumstances. An automatic confidentiality disclaimer generated by your IT system will not, of itself, be regarded as binding on the Department.

The Department will process your personal data in accordance with the DPA and in most circumstances this will mean that your personal data will not be disclosed to third parties.

Summary of the consultation

A response to this consultation will be made available at www.dh.gov.uk by the end of this year.

NHS
Brighton and Hove

Date: 29th September 2010

=

To: Cllr Garry Peltzer Dunn

Joint Letter from NHS Brighton and Hove and Sussex Partnership Foundation Trust

As you will be aware, there has been a significant amount of work undertaken across Sussex reviewing the demand for acute inpatient mental health beds. Based on this work it is estimated that if there were developments in the community services including early interventions in crisis, enhanced community case management and improved discharge planning, we in Brighton and Hove could reduce the total number of beds by up to 16 for people with a functional mental health problem and 3 for people with an organic illness.

The NHS in Brighton and Hove is committed to local solutions and ensuring that services remain in the city. The proposals for Brighton and Hove therefore include a range of high impact changes in community services in order to support an appropriate reduction in bed numbers. This would be realised by moving beds from the Nevill Hospital to Mill View Hospital and moving dementia beds from the first floor to the ground floor at the Nevill Hospital. It remains the case that no beds will be lost without evidence of the positive impact of the community changes.

Sussex Partnership has released an internal document which outlines their high impact changes to enhance and increase community services. These are supported in principle by Commissioners in Brighton and Hove and the detail is being worked on in partnership with operational managers. The key changes include:

a. A refresh of the Crisis Resolution Home Treatment service (CRHT) to ensure these services are working in accordance with the national guidelines. The Trust is also developing plans to enable the CRHT service to support all adults over 18 (including those over 65) by March 2011.

b. A 7 days a week community services and extended hours within the working week.

c. The redevelopment and implementation of 4 priority clinical pathways to manage people’s needs in the community. The priority areas are: Psychosis, Personality Disorder, Dementia and Depression.

d. The refreshed Care Programme approach.

e. The roll out of NICE related training programmes across community staff.

f. More closely managed performance in respect of observing eligibility thresholds into community services, throughput and discharge planning targets, waiting times from referral to assessment/treatment, carer assessment levels, 7 day follow up post discharge.

In parallel to these high impact changes there are the following major redesigns being proposed that will impact on all services and will be redesigned in collaboration between clinicians, and commissioners:

- A new primary care mental health services in Brighton and Hove
- New specialist assessment and therapy centre/s
- An integrated and extended community case management service
- Improvements to the current rapid response for urgent care referrals and out of hours service

East and West Sussex proposals for bed changes have been agreed at Board level and do not have direct impact on any of the services in Brighton and Hove. The one option that could have led to a number of beds for Ouse Valley residents in East Sussex in either Mill View or Nevill Hospitals will not be taken forward. It does, however remains the case that operationally East and West Sussex and Brighton and Hove do occasionally utilise capacity across the County as demand fluctuates, however this is generally seen as an advantage to a pan Sussex arrangement to responding to the need for inpatient services.

CONSULTATION IN BRIGHTON AND HOVE

The proposals for changes to services will continue to be commented on and influenced by users, carers and clinicians. These community development and restructuring plans have been influenced by a series of events with users and carers that have been managed by Commissioners and Brighton and Hove MIND. There are a number of sub groups being asked to make comments on specific redesigns as appropriate to their experience of current services. Primary Care clinicians are highly involved in the redesign proposals and the Clinical Commissioning Executive is overseeing the developments from a clinical perspective.

Both NHS Brighton and Hove and Sussex Partnership together will continue to update the HOSC. The priority over the next six months is embedding the high impact changes in the city. It is clear between all partners that until this is evidenced there will be no implementation of bed reductions. NHS Brighton and Hove is keen to move forward quickly with the high impact changes being proposed as they are fundamental to a more responsiveness and person centred NHS as well as providing more support to primary care clinicians.

Amanda Fadero
Chief Executive
NHS Brighton & Hove

Lisa Rodrigues
Chief Executive

HOSC Work Programme 2009/2011

Issue	Date to be considered	Referred/Requested By?	Reason for Referral	Progress and Date	Notes
Dental Services	02 December 2009	HOSC (March 09)	Update requested re: outstanding performance issues	Report 02 Dec 09	Further update required in 6/12 months
Mental Health – commissioning and provision	02 December 2009	SPFT/NHSBH	Brief HOSC members on major reconfiguration of Sussex MH services – presentation by SPFT; paper from NHSBH	Report 02 Dec 09	SPFT will bring their options for consultation back to a later meeting (Jan 2010)
Health Inequalities	02 December 2009	Audit Committee	Referred from Sep 09 Audit Committee	Report 02 Dec 09	Referred to OSC
NHS Brighton & Hove Strategic Commissioning Plan	02 December 2009	NHS BH	Update of PCT's commissioning intentions	Report 02 Dec 09	

Issue	**Date to be considered**	**Referred By?**	**Reason for Referral**	**Progress and Date**	**Notes**
LINk Update	27 January 2010	HOSC	Regular HOSC item		Postponed from 02 Dec at request of LINk
Annual Health Check Report Back	02 December 2009	HOSC	Report for information on 08/09 Healthcare Commission performance scores for local NHS trusts	Report 02 Dec 09	
3T Progress Report/Transfer of RSCH acute services to community settings	27 January 2010	BSUHT/Cllrs Mitchell and Turton	Update on progress re: the redevelopment of the RSCH site		Item to include the issue of transferring acute services into community settings
Immunisation/Vaccination	10 March 2010	Cllr Kitcat	Report on city vaccination rates compared to national/regional rates	Moved from Jan 2010	
Breast Cancer Screening	10 March 2010	HOSC	Update on screening services (following recent underperformance)	Moved from Jan 2010	
South Downs Health Trust Integration with West (and East) Sussex Community Services	27 January 2010	SDH	Update on plans to integrate SDH with community provider arms of WSPCT and (potentially) ES PCTs		

Issue	Date to be considered	Referred By?	Reason for Referral	Progress and Date	Notes
Better By Design	27 January 2010	SPFT	SPFT presenting reconfiguration options to HOSC		Public consultation delayed until summer
Alcohol Related Hospital Admissions	10 March 2010	HOSC	Examine red LAA indicator with view to setting up an ad hoc panel	Referred to OSC	Agreed by OSC – Select Committee to be formed
Car Park Charges at NHS trusts	10 March 2010	Cllr Peltzer Dunn	Examine local (acute) trust policy for visitor car parking at hospital sites		
BSUHT emergency planning	2010	Cllr McCaffery	Examine BSUH planning for acute care in emergencies	July 14 2010	
Sussex Orthopaedic Treatment Centre Update	2010	HOSC	Update on SOTC performance (as some performance issues remained unresolved following last meeting in Nov 08)	July 14 2010	
Transfers of Care	2010	Cllr McCaffery	Examine delays in transferring patients out of acute care	September 2010	

Issue	Date to be considered	Referred By?	Reason for Referral	Progress and Date	Notes
Swine Flu	2010	HOSC/Cllr McCaffery	Determine lessons to be learnt from swine flu pandemic, including maintaining acute care provision in an outbreak	post May 2010	
Fit For the Future	2010	Joint HOSC	Final results of the Joint HOSC on reconfiguration of West Sussex acute care	post May 2010	
Ad Hoc Panel on GP-Led Health Centre	July 2010	HOSC	12 monthly update on the GP-Led Health Centre (to incorporate report on how the PCT ensures the commercial competitiveness of local health care providers)	July 2010	
Older People in Hospital	Sep 2010	Cllrs McCaffery and Barnett	Report on acute care provision for older people	September 2010	
Older People's Mental Health Care	Sep 2010	Cllr Barnett	Report on nursing (EMI) provision for older people	September 2010	Covered by select Committee on Dementia? (report for information to Sep 10 HOSC)

Issue	**Date to be considered**	**Referred By?**	**Reason for Referral**	**Progress and Date**	**Notes**
Patient Experience/Measuring Outcomes	Dec 2010	BSUHT/NHS BH	Report on how NHS organisations are increasingly focusing on patient experience, and on measuring outcomes rather than processes		
Community Mental Health Services	Dec 2010	Cllr Meadows	Examine how the NHS policy of providing MH services in the community whenever possible impacts upon other services (e.g. police, housing, ASC) and how any costs/risks are shared by partners		
Health Visitors, Midwives and Breast Feeding	Dec 2010	Cllr McCaffery	Examine breast feeding uptake and effectiveness of the integration of pre, peri and post natal services		

# HEALTH OVERVIEW AND SCRUTINY COMMITTEE	**Agenda Item 28** Brighton & Hove City Council

Subject:		**Select Committee on Dementia: Report for Information**		
Date of Meeting:		**29 September 2010**		
Report of:		**The Acting Director of Strategy and Governance**		
Contact Officer:	Name:	Giles Rossington	Tel:	29-1038
	E-mail:	Giles.rossington@brighton-hove.gov.uk		
Wards Affected:	All			

FOR GENERAL RELEASE

1. SUMMARY AND POLICY CONTEXT:

1.1 In 2009 the Overview & Scrutiny Commission (OSC) established a Select Committee to examine local dementia services. The immediate contexts for this were the recent publication of a National Dementia Strategy and the ongoing re-design of the local Dementia Care Pathway.

1.2 Select Committee members were: Cllr Pat Hawkes (Chair), Cllr Dawn Barnett, Cllr Averil Older, Cllr Georgia Wrighton and Mr Robert Brown (representative of the Brighton & Hove Local Involvement Network).

1.3 The dementia report was presented to the Overview & Scrutiny Commission on 07 September 2010. Since the report has a direct bearing on issues relating to both health and social care, it was decided that it should be reported for information to HOSC and ASCHOSC. The Select Committee report on dementia is included as **Appendix 1** to this report.

2. RECOMMENDATIONS:

2.1 That members note the Select Committee report on dementia.

3. BACKGROUND INFORMATION

3.1 Dementia is the term used to describe the effects of a group of conditions which progressively affect people's memory, thinking, orientation, comprehension, calculation, learning capacity, language and judgement. The best known and most common cause of dementia is Alzheimer's disease, but there are several other types of dementia which affect significant numbers of people.

3.2 Dementia is most prevalent amongst older people, and, as the average age of the UK population increases in the next few years, so the morbidity of dementia is expected to grow. This has major implications for people with dementia and for health and social care systems.

3.3 Whilst there is a good deal of ongoing activity aimed at treating/curing dementia, including some very exciting work in Sussex, the main focus of the National Dementia Strategy is on improving assessment, care and support services. In consequence, the Select Committee chose to focus on these areas also.

3.5 More detailed information on dementia and the Select Committee investigation may be found in the Select Committee report (**Appendix 1**).

4. CONSULTATION

4.1 A draft version of the Select Committee report was shared with senior clinicians from Brighton & Sussex University Hospitals Trust and with the city Commissioner for Long Term Conditions and Independence, and their comments were taken into consideration when compiling the final report.

5. FINANCIAL & OTHER IMPLICATIONS:

Financial Implications:

5.1 There are none directly for the HOSC

Legal Implications:

5.2 None to this report for information

Equalities Implications:

5.3 Information on equalities issues is contained in the main report (**Appendix 1**)

Sustainability Implications:

5.4 None directly

Crime & Disorder Implications:

5.5 None directly

Risk and Opportunity Management Implications:

5.6 Detailed information on the risks posed by dementia is included in the main report (**Appendix 1**)

Corporate / Citywide Implications:

5.7 Ensuring that people with dementia, their families and their carers live lives of quality and dignity is a key challenge for city health and social care partners.

SUPPORTING DOCUMENTATION

Appendices:

1. Select Committee report on Dementia

Documents in Members' Rooms:

None

Background Documents:

1. National Dementia Strategy

Report of the Select Committee on Dementia

Chair's Foreword

Dementia is undeniably one of the most frightening of all illnesses: to lose aspects of one's memory and the ability to act rationally is an awful prospect, and many of us who have witnessed the effects that dementia has had on our family and friends can attest to how devastating a condition it can be.

Even in the recent past the impact of dementia was often made worse by the fact that it was a condition that people did not speak about: the stigma that attached to mental illnesses meant that many people with dementia and their carers felt lost and isolated, uncertain what support was available and how to access it.

In the past few years much has changed for the better: health and social care services have begun to work together more effectively; the dementia 'care pathway' – the way in which different aspects of dementia care are integrated with each other – has been re-designed to make it easier to understand and negotiate; the Alzheimer's society and other organisations have been tireless in championing the cause of people with dementia. Most importantly, society has begun to hold a mature conversation about dementia; and, although there is still a long road to travel, there is now hope that we are beginning to break down the secrecy and stigma which still cloaks the illness, moving towards recognising it as an issue for communities as well as for individuals and their families.

How we deal with dementia over the next few years is going to be crucial. Whilst there is a very real chance that medical research will develop effective treatments in the relatively near future, we cannot afford to be sanguine: with the average age of the UK population increasing, dementia is likely to become an even more urgent problem than it is today. We have to get better at dealing with dementia and do so quickly. There is much work going on both nationally and locally to achieve this aim, and we hope that this Select Committee report will contribute in some way to this. Even if dementia cannot be cured in the foreseeable future, we can, as a society, strive to ensure that people with dementia and their families receive the support and understanding that they need and deserve.

I would like to thank all the people who took time to give evidence to the Select Committee, and particularly thank Kathy Caley and Carey Wright, who attended every meeting and offered us invaluable support and advice.

Pat Hawkes

Councillor Pat Hawkes, Chair of the Dementia Select Committee

Executive Summary

Anyone looking at the issue of dementia is bound to be struck by how much is currently going on. Ideas about curing, treating and supporting people with dementia have rapidly evolved in recent years. In part this is because the prevalence of dementia is growing quickly as the average age of our population increases, making finding solutions to the problem even more urgent. In part, it is also because we are becoming better at understanding dementia; and, although there is as yet no cure for the condition, huge advances are being made in the field of disease-modifying treatments for diseases causing dementia, including Alzheimer's disease. These advances offer the possibility that effective prevention of or a cure for dementia may be developed in the relatively near future.[1]

For the moment, however, the focus, in terms of the recently published National Dementia Strategy and local strategies which complement it, is largely on providing practical support for people with dementia. Select Committee members are pleased to say that they have been able to make a number of sensible and practical recommendations intended to help the city commissioners of health and social care improve services for people with dementia. There is much, much more to be said about dementia – too much for any single review to deal with. And there is certainly an argument for scrutiny to re-visit this issue in the future, perhaps with a really strategic examination of local services and their outcomes and how they compare with those of neighbouring areas. A future review might also usefully focus on the ongoing research to prevent or find a cure for dementia, particularly in terms of the innovative local work led by Brighton & Sussex University Hospitals Trust.

However, this review has had a pragmatic focus, looking at how local services can be maintained and improved. Detailed explanations of the recommendations are included in the main report, but in brief they are:

1 **When re-designing the local dementia care pathway, the city commissioners should ensure that all city healthcare workers are appropriately trained in dementia issues, in order to improve early diagnosis of dementia. This should specifically address the issues of GP expertise and that of people working in the acute sector, given the key role that these workers play in the diagnosis of dementia.**

---

[1] Information provided by Dr Dennis Chan, Senior Lecturer in Neurology and Honorary Consultant Neurologist, Brighton and Sussex University Hospitals Trust. More information on recent developments in the treatment and prevention of dementia can be found in the (USA) report: A National Alzheimer's Strategic Plan: the Report of the Alzheimer's Study Group (2010).

2 **That whatever model of memory assessment service model the city adopts, the commissioners should be able to demonstrate that the service: a) provides a homely environment for diagnosis and/or assessment; b) has the capacity to deal with all referrals in a timely manner; c) is able to maintain its core focus if integrated within a team with broader responsibilities.**

3 **That in re-designing the local dementia care pathway, the city commissioners should explicitly address the issue of carer bereavement, ensuring that dementia services support carers as well as people with dementia, and that supports services do not cease suddenly following the death of patients.**

4 **That in re-designing the local dementia care pathway, the city commissioners should explicitly address the issue of how the wishes of people with dementia and their carers can best be reflected in terms of planning appropriate end of life care.**

5 **That the city commissioners should seek to ensure that all their staff and the organisations they commission (e.g. equipment providers as well as health and social care providers) are aware of the need to treat bereaved people with understanding and sympathy.**

6 **When the city commissioners make their decisions on the future of in-patient acute dementia beds, they should bear in mind the position of dementia Select Committee members: that locating this service outside the city should not be agreed unless there are overriding therapeutic benefits to such a move.**

7 **The city commissioners should be able to demonstrate that they have planned for sufficient capacity in terms of in-city nursing and residential home placements to ensure that everyone with dementia who requires such a placement is normally able to access one.**

8 **That NHS Brighton & Hove should arrange the invitation of a representative of the Access Point to forthcoming Locality GP meeting(s) or otherwise facilitate the promotion of the Access Point's work amongst city primary care practitioners.**

9 **That the Access Point should continue to be encouraged to promote its services via all appropriate council/city initiatives (such as Get Involved Day etc.)**

10 **When re-designing the local dementia care pathway, the city commissioners should specifically address the issue of support service capacity in the light of anticipated growth in demand for these services in the near future.**

11 **When re-designing the local dementia care pathway, the city commissioners should explicitly address the issue of ensuring that all aspects of the pathway are as easy to negotiate as possible, so as to reduce the pressure on advocacy and advice services.**

12 **The city commissioners should investigate the potential benefits of engaging with local communities in order to encourage them to better support people with dementia and their carers.**

13 **When re-designing the local dementia care pathway and commissioning city dementia services, the city commissioners should specifically address the needs of people with early onset dementia, ensuring that appropriate support services are in place to deal with current and likely future demand.**

14 **The issue of dementia and the ongoing changes to local dementia services should inform Overview & Scrutiny work planning, particularly with reference to the work programmes of the Adult Social Care & Housing Overview & Scrutiny Committee (ASCHOSC) and to the Health Overview & Scrutiny Committee (HOSC).**

Most of the above recommendations are intended to inform the ongoing partnership project to re-design the local dementia care pathway. This project is expected to be completed in Autumn 2010, and to be ratified by the Joint Commissioning Board shortly thereafter. It should therefore be possible to report back on the implementation of the Select Committee recommendations in early 2011.

This type of scrutiny report – i.e. making a series of recommendations to inform the design of a commissioning strategy, care pathway etc. – is likely to become much more common when the council moves to its ‘Intelligent Commissioning model’. For Overview & Scrutiny to work effectively with a commissioning system, it is particularly important that scrutiny work is synchronised with commissioning cycles, so that scrutiny reports influence the development of commissioning plans rather than reporting when a strategy has already been finalised.

Introduction

In 2009 the Overview & Scrutiny Commission decided to form a Select Committee to investigate issues relating to dementia services in the city. The immediate context for this decision was the publication of a new national Dementia Strategy[2] and the imminent re-design of the local dementia care pathway[3].

Select Committees can be established either for major pieces of work or for work which cuts across Overview & Scrutiny committee boundaries. Dementia is just such a cross-cutting issue, as dementia services directly involve both health and social care and can impact even more broadly. The Dementia Select Committee therefore sought members from the Adult Social Care and Housing Overview & Scrutiny Committee (ASCHOSC) and the Health Overview & Scrutiny Committee (HOSC), as well as other backbench Councillors with a particular interest in this subject. The Select Committee also included a representative from the Brighton & Hove Local Involvement Network (LINk), the city's main representative body for members of the public wishing to engage with health and social care issues.

Dementia presents perhaps the single biggest single challenge to health and social care services in the foreseeable future, with the number of people suffering from dementia expected to increase rapidly over the next few years. Furthermore, the situation with regard to dementia is extremely fluid, with national and local policies being rapidly developed in very uncertain financial and political circumstances. Given this background, it was never really possible that this Select Committee should provide a definitive review of dementia services[4]. Nor was it intended that this review should be principally strategic in its focus: there might well be considerable value in a strategic review of city dementia services, but the local dementia care pathway is currently being revised, as are all mental health services provided by the Sussex Partnership NHS Foundation Trust (SPFT), the main provider of statutory services for dementia across Sussex. Whilst this certainly provides an opportunity for scrutiny to feed into strategies in development, it also makes it rather difficult to run a strategically-focused review, there being no established medium-term strategy or service model to scrutinise and no 'stable' high-performing service in Sussex to benchmark local services against.

---

[2] Living Well With Dementia: A National Dementia Strategy; Department of Health, 2009.

[3] A 'care pathway' describes a way of looking at, and designing services for particular conditions which aims to make access to each aspect of the care provided, and the transitions between various types of care, as simple and logical as possible, even when a number of different organisations are involved in delivering that care. In recent years, care pathways have become an integral part of UK health and social care planning and commissioning.

[4] This mirrors experiences at neighbouring local authorities. In West Sussex, for example, Overview & Scrutiny members have been involved in three separate reviews of dementia services in the past 3-4 years.

Therefore, given these issues, Select Committee members decided to limit the scope of their investigation and to make mainly practical rather than strategic recommendations. Generally, these recommendations are intended to support the city commissioners in their ongoing task of revising the local dementia care pathway (working together with a range of partners to achieve this). The Select Committee offers its recommendations with the important caveat that there is much more work to be done on this issue, particularly in terms of evaluating the effectiveness of the local dementia strategy, scrutinising funding for Brighton & Hove dementia services and overseeing the SPFT ‘Better By Design’ reconfiguration, which may include significant changes to the provision of some city dementia services, particularly in terms of acute bed capacity and/or location.

The Select Committee was made up of Councillors Dawn Barnett, Pat Hawkes, Averil Older and Georgia Wrighton, and Robert Brown, Chair of the Brighton & Hove LINk Steering Group. Councillor Hawkes was chosen to be the Select Committee Chair.

The Select Committee held four evidence-gathering meetings in public, as well as several private scoping meetings. Amongst the witnesses were Brighton & Hove City Council officers responsible for Adult Social Care services; commissioners from NHS Brighton & Hove; clinicians and managers from the Sussex Partnership NHS Foundation Trust; representatives of the Alzheimer’s Society and witnesses who had direct experience of caring for people with dementia.

The Select Committee did not interview staff from Brighton & Sussex University Hospitals Trust (BSUHT). In part this was because the focus of this review (in line with the focus of the National Dementia Strategy) was on assessment and support services, rather than the research, diagnosis and treatment services typically provided by acute hospital trusts. In part though it was because scrutiny support staff advising the Select Committee were insufficiently aware of the key role that BSUHT plays in the local dementia care pathway, particularly in terms of specialist services providing diagnosis of young onset and atypical dementias, and in terms of a number of clinical research initiatives.[5] In hindsight, we should clearly have involved BSUHT in the work of the Select Committee.

The Select Committee would particularly like to thank Kathy Caley, Commissioner for Long Term Conditions and Independence for Brighton & Hove, and Carey Wright, Community Mental Health Team Manager for the Sussex Partnership NHS Foundation Trust. Kathy and Carey supported the Committee throughout the scrutiny process, and their input was greatly appreciated by committee members.

---

[5] Information provided by Dr Dennis Chan, Senior Lecturer in Neurology, Brighton & Sussex University Hospitals Trust.

The following report begins with a general explanation of what dementia is and the national and local problems it poses, followed by the Select Committee's recommendations and the reasoning behind them.

Information on Dementia

What is dementia?

Dementia is the term used to describe the effects of a group of conditions which progressively affect people's memory, thinking, orientation, comprehension, calculation, learning capacity, language and judgement. The best known and most common cause of dementia is Alzheimer's disease, but there are several other conditions which cause dementia in significant numbers of people.[6] Other types of dementia include: Vascular Dementia (sometimes known as multi-infarct dementia); Dementia with Lewy bodies (DLB); Alcohol Induced Persisting Dementia; Frontotemporal lobar degeneration; Creutzfeldt-Jakob disease; Dementia Pugilistica; and Posterior Cortical Atrophy. It should be noted that dementia is not in itself a disease: it is the state brought about by a number of diseases, such as Alzheimer's, which each have distinctive pathological and cognitive signatures.[7]

The effects of dementia can vary considerably according to the stage that the disease has reached. People with mild or moderate forms of dementia may well be able to live relatively independent lives providing they have appropriate support; people with severe dementia may well require round the clock care. At any one time, most people with dementia exhibit 'mild' rather than 'moderate' or 'severe' manifestations of their condition (although the older a person is, the more likely it is that their dementia will be of the moderate or severe type). It is estimated that around two thirds of people with dementia live in the community, and around one third in residential or care homes.[8]

Causes

Dementia is caused by the conditions listed above. Some of these conditions may have a genetic links, but others (including Alzheimer's) seemingly do not. It is also well established that poor health, particularly in terms of diet and/or

---

[6] Evidence provided by Dr Chris Smith, Specialist Registrar in Psychiatry in Old Age, Sussex Partnership NHS Foundation Trust. See minutes to the Select Committee meeting of 12 June 2009.

[7] Information provided by Dr Dennis Chan, Senior Lecturer in Neurology, Brighton & Sussex University Hospitals Trust.

[8] Dementia UK: the Full Report: Albanese/Banerjee, 2007: p34. The ratio of people living in the community to those in residential care decreases as age increases, and more people over 90 with dementia live in residential care than live in the community. This may be because dementia tends to be more severe amongst older people and/or because older people are less likely to be able to call on carers to help support them at home, and/or are more likely to have co-existing physical problems which restrict their ability to live independently..

cardio-vascular health, can significantly increase the likelihood of developing some dementias.[9] Excessive drinking may also be a significant factor in developing some conditions which lead to early onset dementia, although it is not considered to be a significant factor in developing dementia in general.[10]

Age

Dementia is generally associated with older people, and is most prevalent in the oldest populations. It is estimated that 1 in 14 people over the age of 65 has dementia, with this figure rising to 1 in 6 of over 80s.[11] Given this strong correlation with age, one would expect dementia to be more of a problem at times when the average age of the population increases or in areas with lots of older people.[12]

Some types of dementia affect younger people, although these ‘early onset’ dementias are currently relatively uncommon, with only around 15,000 people currently diagnosed in the UK.[13]

Morbidity

‘Late onset’ dementia is, in contrast to early onset dementias, a relatively common condition, and its incidence is set to rise as the average age of the UK population increases. It is thought that at least 700,000 people currently suffer from dementia across the UK. It is estimated that, by 2038, this will have risen to around 1.4 million people. As well as having a devastating impact upon people’s quality of life, dementia also significantly reduces life expectancy. Dementia is estimated to contribute to almost 60,000 deaths per year.[14]

---

[9] For example, it is estimated that up to 50% of dementia cases have a vascular health component. See Living Well With Dementia: The National Dementia Strategy: p27.

[10] See evidence from Dr Chris Smith, Specialist in Psychiatry in Old Age, Sussex Partnership NHS Foundation Trust, 12.06.09: point 4.7.

[11] Dementia UK: The Full Report: p2.

[12] There is a considerable variation in the prevalence of dementia across England, ranging from 0.51 per 100 people in Newham, to 2.09 per 100 in Torbay. The national average prevalence is 1.1 per 100 people (Dementia UK: the Full Report p25).

[13] Dementia UK: the Full Report p27. Early onset dementia is not predicted to increase as rapidly as late onset dementia, as it is not linked to an ageing population. However, some early onset dementias, such as Korsakoff’s Syndrome, are linked to excessive alcohol consumption, so increased levels of hazardous drinking across society may impact upon early onset dementia morbidity.

[14] Dementia UK: the Full Report, p37.

Sex

Approximately twice as many women as men are living with late onset dementia. However, this imbalance is thought to be mainly due to demographics (there are more elderly women than there are men, and dementia is most prevalent amongst the elderly) rather than any greater susceptibility in women.[15]

Ethnicity

It is currently unclear whether late onset dementia is more prevalent amongst any particular ethnic groups. However, it is anticipated that dementia rates will rise far more quickly amongst some minority ethnic groups than across the population as a whole, as the age profile of some of these groups is significantly higher than for the general population (the bulk of immigrants to the UK in the first wave of mass immigration in the 1950s and 60s were young adults; this cohort is now in its late 60s and 70s - the age groups most likely to develop dementia.)[16]

Treatment

Dementia is incurable and worsens as the condition progresses. However, there are some drug treatments which may work to slow or even temporarily halt the progress of the disease in some patients. The best known of these drugs is marketed in the UK as ‘Aricept’. The use of drugs to treat dementia is a relatively recent development but one which has considerable potential to change radically medical approaches to dementia in the relatively near future. In particular, there are a number of drugs currently undergoing late phase clinical trials which may have true disease-modifying potential.[17]

However, the current NHS position is essentially that medical treatments for dementia are of relatively limited value and should be used only in a minority of cases. This position is based upon an objective analysis of evidence by the National Institute of Clinical Excellence (NICE). NICE collates evidence on the effectiveness of treatments and maps this against cost and the improvement they can make to people’s quality of life in order to determine whether to approve treatments or not. There is therefore likely to be little value in lay people challenging NICE’s analysis of the efficacy of particular treatments.

However, Select Committee members did feel that it was worth stating that they believed it was important that the threshold for dementia treatment was

---

[15] Dementia UK: the Full Report, p31. Considerably more relatively young men (e.g. aged 65-69) have late onset dementia than do women, by around a factor of 1.4/1; but as people get older, this ration is reversed: in the over 90s category for instance, there are more than three times as many women with dementia as there are men.

[16] Dementia UK: the Full Report, p36.

[17] Information provided by Dr Dennis Chan, Senior Lecturer in Neurology, Brighton & Sussex University Hospitals Trust.

set fairly low (i.e. that treatments such as Aricept should be offered even when there was relatively weak evidence of their efficacy), given the impact of the condition on sufferers, their families and their communities. NICE is due to review treatments for dementia in 2012, which is also when the patent period ends for currently licensed dementia drugs (meaning that prices should fall as any manufacturer can produce generic versions of drugs not protected by patent), so it may well be that there is a general move towards providing treatments on the basis of benefits to patients and families rather than on a cost basis.[18]

Financial Impact

Dementia has a major impact upon health and social care budgets. The Government estimates that the cost of dementia services is currently around £17 billion per annum, a figure which is set to rise to over £50 billion by 2038[19]. To put this in context, the total 2009 budget for the NHS was approximately £110 billion. If rates of dementia grow as anticipated and unit costs do not diminish, the NHS will struggle to provide the current level of dementia care in the future, even assuming that healthcare budgets will continue to rise in line with or faster than inflation.

The Future

As the average age of Britain’s population grows, so conditions such as dementia are likely to become much more problematic, in terms both of their impact upon individuals, families and communities and of their financial impact upon health and social care services. It is widely recognised that current services for dementia are expensive and by no means as good as they might be; without a major re-design it is certain that they will not be able to cope with the anticipated increase in demand.

The NHS has identified dementia as a key national health challenge, and the Department of Health has issued a National Dementia Strategy aimed at improving dementia services across England. Local Primary Care Trust (PCT) areas are also expected to develop their own dementia strategies and care pathways. Re-design of the Brighton & Hove dementia care pathway is an ongoing piece of work.

Local Issues

In local terms, Brighton & Hove is bound to experience many of the same problems as other parts of the country. However, as noted above, the incidence of dementia closely maps the age of a population, and Brighton & Hove is unusual in having an age-profile that is not expected to rise very much in the medium term. On the face of things, this should mean that city

---

[18] Information provided by Dr Dennis Chan, Senior Lecturer in Neurology, Brighton & Sussex University Hospitals Trust.

[19] Living Well With Dementia: The National Dementia Strategy: p9.

dementia services will not experience the same pressures as services in many other parts of the country. However, this has to be balanced against other demographic factors such as the relatively high ratio of very elderly people in the local population (the over-80s are the group most likely to contract dementia, the group most likely to manifest severe forms of the disease, the group most likely to experience complicating co-morbidities, and the group least likely to be supported by carers), and other factors such as poor general health across communities (poor cardio-vascular fitness is a factor in developing some forms of dementia). Currently, approximately 2.6% of city residents are aged 85+, in comparison to a national average of 2.1%. By 2031 it is estimated that around 9% of people in Brighton & Hove will be 85+, compared to an average nationally of around 3%.[20] In any case, even if Brighton & Hove faces less of a challenge than many areas in terms of the capacity of its dementia services, the challenge of improving services is still a very considerable one.

Other local issues which will be touched on later in this report include the city provision of nursing home places for people with dementia, the relatively high costs of city Older People's Mental Health (OPMH) services, and the local provision of in-patient acute mental health beds for people with dementia.

Dementia Services

Prevention

Whilst research to find effective treatments for dementia is ongoing, there is little expectation that a 'cure' will be discovered in the very near future. Given this, how are services going to be improved?

One major focus is likely to be on prevention.[21] Although it might not always be possible to prevent the appearance of dementia in an individual, it may be feasible to delay its appearance across populations - for example by encouraging better diet or lifestyles which minimise the risk of having strokes (both poor diet and cardiovascular health are key risk factors for certain types of dementia). If the onset of dementia across the population could be delayed for an average of five years, this would halve its prevalence, improving many thousands of lives and drastically reducing the potential financial burden on health and social care services.

This is clearly an important area, and one in which Overview & Scrutiny should be engaged. However, for the purposes of this report Select Committee members felt that most if not all preventative health work which might have a positive impact upon dementia had a broader remit rather than being specifically dementia-focused - i.e. in terms of campaigns to encourage

---

[20] See the Annual Report of the Brighton & Hove Director of Public Health 2009: Dr Tom Scanlon. P48.

[21] See Living Well With Dementia: The National Dementia Strategy: pp28, 29.

healthier eating, smoking cessation, sensible drinking, cardio-vascular health etc. These issues are probably best dealt with by general scrutiny of city Public Health services rather than via the Dementia Select Committee.

Diagnosis and Support

The other major focus is likely to be on supporting people with dementia to live full lives. This has a number of aspects. Firstly, it assumes that dementia will be diagnosed at a relatively early stage, whilst the effects of the illness are still relatively mild[22]. Early diagnosis significantly increases the opportunity to enable people to cope with more severe manifestations of their condition. For obvious reasons this becomes much harder as cognitive impairment and memory loss get worse. A similar point can be made about supporting carers: if people with dementia are diagnosed at an early stage, their carers can be appropriately trained and supported; if diagnosis occurs further down the line and carer support has not been provided, the carers may be 'burnt out' by the time that support arrives. If dementia is only diagnosed when people suffer a crisis, then it may often be too late to support them or their carers effectively.[23]

However, it seems currently to be the case that there is little effective early diagnosis of dementia, since it is estimated that only around 30% of people with dementia ever have their condition diagnosed[24]. This means that the majority of dementia sufferers and their carers are left to cope without the most appropriate support, and it also means that the cost of dementia care is increased (as late diagnosis is strongly correlated with heavier use of residential care services, which tend to be considerably more expensive than community support).

Why are diagnosis rates so poor? In part this may be because of the stigma which still attaches to dementia – people are reluctant to acknowledge that they have cognitive or memory problems because they don't want to admit to themselves or others that they may have dementia. People therefore often try and develop coping mechanisms to disguise their worsening mental states. Such coping mechanisms may not be much help in making people's lives easier, but they may well be enough to ensure that medical or social care professionals fail to accurately diagnose their condition.

In part it may also be because the principal contact that most people have with the medical profession is with their GPs, and there are problems with GP diagnosis of dementia. These problems include the length of GP appointments (these have actually increased in recent years, but still average

---

[22] It now seems widely accepted that early diagnosis of dementia once symptoms begin to manifest is a good thing. There is however still a debate about whether pre-symptomatic diagnosis (e.g. through people with no symptoms of dementia arranging to have brain scans etc.) is useful or whether it risks 'medicalising' people for no good reason. See evidence from Dr Chris Smith, 12.06.09: point 4.7.

[23] See evidence from Alan Wright, Alzheimer's Society, 17.07.09: point 9.7.

[24] Living Well With Dementia: The National Dementia Strategy: p17.

less than 15 minutes, which is clearly not long enough to do much other than to deal with the ostensible problem with which the patient is presenting); the fact that the great majority of GP appointments take place in GP surgeries rather than patients' homes (it is generally held to be easier to make an accurate assessment of someone's mental health when seeing them in their own home, as many people find the process of visiting a doctor highly stressful and may act in atypical ways, whether or not they have any underlying mental health condition); the fact that patients (and often their partners/carers) will try and conceal cognitive/memory problems from GPs (or will simply eschew GP services in order to hide these problems); and the fact that older people (and especially the 'old old' – i.e. 80 plus) may quite naturally evince some of the symptoms of dementia (e.g. occasional confusion, forgetfulness etc.) whilst generally being in full control of their faculties.

It may also be the case that GPs have been historically reluctant to diagnose dementia because they believe that there is little point in so doing as there are inadequate high quality services to refer people onto, or because they are not always fully aware of the range of services available (particularly in terms of non-NHS support services provided by Social Care or '3rd sector' organisations). Indeed, if proper support is not available, a diagnosis of dementia can itself aggravate problems, as poorly supported patients may well suffer from increased anxiety and/or depression occasioned by their diagnosis rather than by their organic mental health condition.

Finally, it maybe that GPs simply tend not to be as good as they might be at diagnosing dementia - although a high percentage of a GP's caseload is likely to feature mental health problems, many GPs have traditionally not been as well versed in mental health matters as they are in general health.[25] The Select Committee asked NHS Brighton & Hove to contact city GPs and invite them to give evidence. However, no GP came forward, and Committee members were told that this was may have been because no city GP was comfortable with presenting themselves as an 'authority' on dementia.[26] However, it may equally have been because GPs were busy or because some of them did not hear about the invitation in time. It is, nonetheless, a matter of concern that there appears to be no city GP with a specialism or even a particular expertise in the field of dementia, and it does seem as if this is an area where NHS Brighton & Hove could do more to encourage the professional development of the GPs it contracts with, although it must be acknowledged that PCTs have often very limited means of influencing local GP practices to do things not stipulated by their contracts.[27]

---

[25] See evidence from Louise Channon, 15.01.10: point 20.3-20.6.

[26] See evidence provided by Kathy Caley, Commissioner for Long Term Conditions and Independence, in the minutes to the Select Committee meeting 17.07.09, point 9.2.

[27] This was true at the time of gathering evidence for this report. However, NHS Brighton & Hove has subsequently appointed a GP lead for dementia. The Select Committee welcomes this advance.

A similar general point can be made about those working in acute healthcare, and particularly the older people's wards of General Hospitals. Given the prevalence of dementia in the 'old-old' population, it seems likely that a significant percentage of elderly people admitted to hospital for falls, general ill-health etc. may also have dementia, but (at any rate in national terms) it seems relatively uncommon for hospital clinicians to identify dementia or refer people into diagnosis services. This may be because of poor training of hospital staff – i.e. staff simply do not recognise the signs of dementia. It may also be because of the pressures that acute hospital staff are under – i.e. staff do not have the time to do anything other than their core jobs. It may also be because staff are not familiar with the dementia care pathway: they do not know how to refer people into dementia services or are not confident that such services exist. It may also be the case that there are pressures on hospital staff to expedite the discharge of their patients which tend to work counter to the holistic well-being of these patients (i.e. referring a patient for dementia assessment is very unlikely to speed up their discharge and may well delay it). In such instances, the 'fault' may lie, not so much with acute hospital staff, as with the local provision of specialist community beds (e.g. Intermediate Care beds) for people with suspected dementia to be discharged into.

The Select Committee did not have the time to talk with officers of Brighton & Sussex University Hospitals Trust (BSUHT) about their staff training in regard to dementia issues. It may very well be that BSUHT is doing more than many trusts to ensure that its staff are aware of dementia. However, given the national picture, it seems likely that there is more work to be done here.[28]

Neither was the Select Committee able to progress the issue of GP training as far as members would have wished. Nor did the Select Committee have the time to ask similar questions about people employed in community healthcare (e.g. district nurses). Whilst the Select Committee has no hard evidence that training in dementia issues across city healthcare is poor, it does seem reasonable to suggest that the bodies responsible for the development of the city dementia strategy should ensure that training is of a high quality, and that it is given to all those who require it, including independent contractors to the NHS (such as GPs).

It should be stressed that there is no intention here to criticise either clinicians or healthcare managers. Dementia has not been a national health and social care priority until relatively recently, and this has inevitably meant that the focus of attention has been on other issues. There is no culpability in this, but it is clear that the situation must change.

RECOMMENDATION – When re-designing the local dementia care pathway, the city commissioners should ensure that all city healthcare workers are appropriately trained in dementia issues, in order to improve early diagnosis of dementia. This should specifically address the issues of GP expertise and that of people working in the acute

---

[28] See Living Well With Dementia: The National Dementia Strategy: pp51-55.

sector, given the key role that these workers play in the diagnosis of dementia.

Specialist Diagnosis/Assessment[29] Services

Even if the dementia training of primary and acute healthcare workers were to be improved it might not be enough to solve the problem of poor diagnosis/assessment of dementia; it could be argued that effective early assessment and diagnosis will only be achieved via a dedicated service – essentially this is the Department of Health's position as set out in the National Dementia Strategy.

The National Strategy proposes creating local dementia diagnosis/assessment services. However, the model for these services is to be determined locally rather than nationally imposed. There are several possible models for an assessment service, ranging from a dedicated site-based specialist memory assessment and support team (as piloted in Croydon via the Croydon Memory Service); through dedicated teams which works alongside Community Mental Health Teams: CMHTs (as piloted in East Sussex via the East Sussex Memory Assessment and Support Team: MAST); to a community-based service delivered by suitably trained CMHTs.

Memory assessment models differ in several ways, including whether they are discrete units or integrated into larger teams; whether they are community based or situated in a clinic; whether they formally diagnose dementia or refer diagnosis to specialist clinicians; and in terms of the degree to which they offer support services in addition to performing assessment/diagnostic duties.

The Select Committee took evidence from the East Sussex Memory Assessment Team (MAST). Deborah Becker, Team Leader at MAST, explained that the service was set up in 2006 as a pilot project to work with people experiencing relatively mild memory problems.[30] MAST carries out short-term intervention work with these clients, aiming to make an accurate assessment of people's care and support needs and to signpost the relevant services for them. MAST has the capacity to assess people in their own homes, which can be advantageous, as it is generally the case that people will feel less stress in their home environment and therefore act as they normally do, facilitating accurate assessment. When people are assessed in more stressful environments (e.g. hospitals), they frequently act in atypical ways, making it much more difficult to get an accurate picture of their needs.

---

[29] Dementia assessment services do not necessarily make formal diagnoses of dementia, in large part because they do not necessarily have consultant psychiatrists as part of their teams. However, in practical terms, this may be largely irrelevant: dedicated assessment teams should be highly skilled in recognising the symptoms of dementia, and their activity is therefore likely to improve diagnosis rates whether or not they refer to hospital consultants to make actual diagnoses.

[30] See evidence provided by Deborah Becker at the 17.07.09 Select Committee meeting, points 9.4 and 9.5.

Whilst MAST is a dedicated memory assessment and support team, it is co-located with the East Sussex Community Mental Health Teams. The Select Committee also heard from Russell Hackett, Director of Business Development at Sussex Partnership NHS Foundation Trust (SPFT), on the subject of memory assessment services. Mr Hackett confirmed that the MAST model was SPFT's preferred model of memory assessment service across Sussex: the trust would like to run such clinics at six sites across the patch, including a clinic in Brighton & Hove[31]. Clearly, however, the final decision on the model for local memory assessment services will not be made by providers alone, but by the city commissioners after consultation with local providers.

It is quite evident that current memory assessment and support services, both nationally and locally, are inadequate. It is equally evident that some form of improved memory service is needed to serve every local area. However, it is not nearly so clear which model of memory service would be best suited to Brighton & Hove. Any new service has to effectively integrate with the current configuration of local services; as these differ widely from area to area, it is unlikely that any single memory service model is going to prove a successful fit in every local health economy.

Moreover, 'ideal' service models have to fit with actual NHS and local authority finances: with the expectation of very significant real terms cuts to NHS and council budgets in the coming years, and the likelihood that local commissioners will also be looking to reduce expenditure, particularly on services where the local spend is significantly higher than national or regional averages or than the spending of comparable organisations – e.g. Older People's Mental Health services. It may therefore not be practical to roll out very expensive memory services (e.g. based on the 'Croydon' model), even if such services were proven to be most effective.

The Select Committee does not therefore propose to recommend any particular model of memory assessment services, as the local decision on the model to be adopted should properly be the result of a complex piece of work by health and social care professionals, balancing the needs of people with memory problems together with the unique configuration of local services and the budget available for this initiative.

However, members do feel that their research qualifies them to make a couple of suggestions in relation to memory assessment services.

In the first place, members believe that there are considerable advantages to assessment delivered in people's own homes or in a homely environment. As noted above, hospitals and GP surgeries can be very stressful places for people to attend, particularly people who fear that they may be developing dementia. On the other hand, the Select Committee heard that one of the most successful aspects of the Croydon memory clinic was that it was co-

---

[31] See evidence from Russell Hackett, Director of Business Development, Sussex Partnership NHS Foundation Trust, 12.06.09: point 4.5.

located with the local Alzheimer's Society services, meaning that people with memory problems and their carers could access a range of assessment and support services in one place.[32] However, it may not be absolutely necessary to have a dedicated building-based memory service in order to take advantage of close links to the Alzheimer's society etc: really good signposting of 3rd sector services might be just as effective, as might co-location of these support services with CMHTs etc.[33]

Secondly, it is very important that people who are diagnosed with dementia, as well as (at least some) people with memory problems who are diagnosed as not having dementia, and people who are unwilling to be diagnosed (e.g. people who do not want to have brain scans etc), are supported by assessment and support services in a timely fashion. A failure to do so significantly increases the risk of people developing problems with anxiety, depression and social isolation. GPs who encounter lengthy waits when they try and refer their patients into memory assessment services are unlikely to be convinced that they should continue to be pro-active in diagnosing dementia. Therefore, any local assessment service needs to have the capacity to deal with demand promptly.

Thirdly, a memory assessment and support service needs to be well publicised and easy for health and social care professionals to refer into, so as to encourage as many people as possible to use it. At least part of the problem with dementia services as they are currently configured is that the pathway of care and support is not clear, particularly in terms of how people can be referred into the pathway – explaining, to some extent, the apparent reluctance of health professionals to identify dementia. There is potentially an issue here about who should be able to refer into assessment and support services: should it just be GPs, consultants etc? Should it include a much broader range of health and social care professionals? Should it include individuals themselves? (i.e. people could seek memory assessment without having to involve their GP, care workers etc – which might have value for people worried about the stigma of being diagnosed with dementia.)

Fourthly, current practice in the public sector tends not to favour establishing discrete specialist teams, preferring to train generalist workers and teams so that they can themselves deliver much of the specialist input that a dedicated team might provide. There is obviously a good deal to be said for this way of working, and it is central to the development of the Community Mental Health Team model. However, in the context of memory assessment services there do seem to be some real advantages to having a dedicated team available, particularly in terms of the memory service being able to ensure that its staff can concentrate on their core duties.

Therefore, whilst the Select Committee does not seek to recommend any particular model of memory service, it does seem reasonable to recommend

---

[32] Evidence provided by Alan Wright, the Alzheimer's Society, 17.07.09: point 9.10.

[33] This already occurs in Brighton & Hove: see evidence from Alan Wright, 17.07.09: point 9.12.

that the commissioners consider the above points when they do choose their preferred model.

RECOMMENDATION – That whatever model memory service the city adopts, the commissioners should be able to demonstrate that the service: a) provides a homely environment for diagnosis and/or assessment; b) has the capacity to deal with all referrals in a timely manner; c) is able to maintain its core focus if integrated within a team with broader responsibilities.

The Memory Assessment Clinic model described above does not, in any formal sense, provide diagnoses of dementia. Indeed, it could not, since dementia is not itself a disease, but rather the consequence of a range of diseases. Therefore, while memory clinics can detect the presence of objective cognitive impairment which indicates a state of dementia, they are not themselves sufficient to diagnose the diseases causing dementia. This requires specialist investigation, although not necessarily new services: there are already a number of specialist diagnostic services available across Sussex, mainly provided by Brighton & Sussex University Hospitals Trust and Sussex Partnership NHS Foundation Trust. Improving diagnostic services may therefore principally be a matter of ensuring better collaboration between primary care, mental health and acute neurological services. Brighton & Sussex University Hospital Trust has recently proposed a new model of collaborative working across the local health economy to provide a more comprehensive and integrated diagnostic service.[34] This is not an area that the Select Committee examined, but it is one which the hospital trust was very keen to explore. The Select Committee regrets that it did not do more work in this area: should dementia be the subject of further scrutiny (as the Select Committee recommends), the issue of diagnostic services should certainly be treated in depth.

Carers

Carers are central to delivering effective dementia services. It is the nature of dementia that it can render people exceptionally vulnerable and that it can do so at utterly unpredictable times. Whilst it is certainly possible to support people with mild dementia in the community via professional carer-support, it is much easier (and generally much cheaper) to rely upon partners, friends or family members to provide support, and most people living with dementia in the community do rely principally on ‘non-professional’ carers. Without this network of carers it is hard to see how support for people with dementia could effectively be delivered, even in terms of the current scale of the problem.

However, for carers to provide an appropriate level of support over the long term, several things need to be in place.

---

[34] Information provided by Dr Dennis Chan, Senior Lecturer in Neurology, Brighton & Sussex University Hospitals Trust.

Firstly, it is very important that people with dementia are accurately identified in the early stages of their illness. Without this, people are likely to be fulfilling the role of carer, but without any of the financial or practical support and advice available to official carers. This is bound to diminish the effectiveness of carers and may impact on their ability to deliver care over the longer term. For instance, if people are identified as carers, then the authorities can support them by offering respite, augmenting their care with professional carers, ensuring that they receive all benefits to which they are entitled, sign-posting them to groups where they can exchange ideas and experiences with other people in a similar situation etc. This support can enable people to care for longer and to live fuller lives as care-givers.[35]

Secondly, once people are assessed as having dementia, support for them and their carers has to be readily available and easily accessible. There is little point in aspiring to support carers if the necessary resources are not in place, particularly as a diagnosis of dementia can itself be very unsettling and can lead to serious depression and anxiety both for people with dementia and those close to them.

Thirdly, there is a strong argument for providing appropriate financial support for carers. No one becomes a carer for the money, but many may be forced to relinquish their caring responsibilities for lack of money, and it will almost invariably be the case that this will result in a much greater financial burden on social and health care – the option, essentially, is not whether to support carers properly financially, but whether to support them properly or to pay professional carers much, much more to provide the same levels of support. However, whilst the argument for properly supporting carers is very easy to make in theory, it is evident that the current national financial situation is one which makes increased spending in any sector unlikely in the short term, even if there is a very sound case to be made for spending now to achieve greater savings in the future.

Fourthly, although it is important to think of supporting carers in terms of helping them to give support to the people for whom they care, it is also necessary to think holistically, viewing carers as people with their own needs. For example, carers often compromise their own independence in order to provide care, giving up jobs, tenancies etc. to concentrate on their caring role. If the person being cared for passes away, there is a danger that the carer may find themselves dealing with their bereavement at the same time as finding themselves no longer entitled to financial support etc. There is a clear need here for a care system which supports carers while they are carers and for a reasonable time after their caring responsibilities have ceased.[36]

---

[35] See evidence from Alan Wright, 17.07.09: point 9.11.

[36] There may be a specific issue here with day care services. The traditional model of care provision for people with dementia (and others) has typically involved ‘day centres’ where people with a particular condition are brought together to undertake therapeutic and social activities. These types of service can be regarded as rather old-fashioned and institutionally-driven: centred upon the service providers’ convenience rather than the wishes of service users (particularly in the light of the recent moves towards ‘personalisation’ of social care). There may be good reasons to move away from this type of service, particularly if service

In some instances there are already systems in place. For example, Brighton & Hove City Council's Housing Management service has done a good deal of work around bereavement and has produced a policy which all council employed housing staff must adhere to.[37] Similarly, there is a city carers' strategy which spells out the support that carers should receive.

It is however evident that this support is not always as reliably provided as it ought to be, and that carers of people with dementia are not always as involved in making decisions about their loved ones as they should be.

End of Life Care, Death and Bereavement

There is a particular issue around the death of people with dementia, especially given the extremely close and emotionally intense relationship that can develop between people who live in constant proximity for a long period of time, as is often the case with people with dementia and their carers. It is therefore important that carers are supported and treated with sensitivity when they suffer bereavement.

Sadly, this is not always the case. The Committee heard from Louise Channon, who had cared for her mother for 16 years. Ms Channon told members that, following her mother's death she had been offered no emotional support, and there had been little or no recognition from health professionals etc. of the distress she was feeling. For example, when Ms Channon made arrangements to return 'disability' equipment that her mother had used, the equipment providers made no effort to acknowledge or offer sympathy for her bereavement, despite it being obvious that people returning this type of equipment after long term hire would probably be doing so shortly after the death of a loved one.[38]

Ms Channon also noted that, although she was not personally reliant upon carers' benefits, she felt that the abrupt ending of such benefits once the person being cared for had passed away could potentially be extremely distressing for carers.[39]

Committee members also discussed their personal experiences of dealing with, or helping others deal with, bereavement. One member noted that there could be a particular problem in terms of council tenancies, where a carer who lived with a tenant as their live-in carer, but who was not entitled to succeed to the tenancy, found themselves under pressure to vacate the property when

---

users would prefer alternatives – e.g. receiving more services at home. However, day services do provide very important respite for carers, and the carer perspective must be considered when contemplating the re-design of day care.

[37] See 'When a Tenant Dies – Customer Care, Succession and People Left in Occupation', agreed at Brighton & Hove City Council Housing Cabinet Member Meeting, 06 Jan 2010.

[38] See minutes 15.01.10 point 20.13.

[39] See minutes 15.01.10 point 20.13.

the person they were caring for died. Following a history of complaints from tenants, the council's Housing Management service has recently revised its procedures around bereavement and tenancy succession (see footnote 37 above).

There are also issues concerning end of life care, and the degree to which carers and families are involved in planning for the latter stages of their loved ones' lives – i.e. that it may too often be the case that decisions are taken on behalf of people who lack capacity to plan their own end of life journey without sufficient reference to their carers. End of life services are one of the areas currently being focused upon as regional NHS priorities, and the development of regional and local end of life strategies and pathways, particularly in terms of dementia care (i.e. in situations where the person dying lacks the capacity to themselves make their care decisions) should certainly include and involve carers to a high degree.

RECOMMENDATION – That in re-designing the local dementia care pathway, the city commissioners should explicitly address the issue of carer bereavement, ensuring that dementia services support carers as well as people with dementia, and that supports services do not stop suddenly following the death of patients.

RECOMMENDATION – That in re-designing the local dementia care pathway, the city commissioners should explicitly address the issue of how the wishes of people with dementia and their carers can best be reflected in terms of planning appropriate end of life care.

RECOMMENDATION – That the city commissioners should seek to ensure that all their staff and the organisations they commission (e.g. equipment providers as well as health and social care providers) are aware of the need to treat bereaved people with understanding and sympathy.

In-patient Beds

Local health economies need to maintain a relatively small number of specialist mental health in-patient beds for acutely ill patients with dementia (the great bulk of people with dementia who cannot be supported in the community will be placed in nursing homes). In Brighton & Hove these beds are currently provided by Sussex Partnership NHS Foundation Trust (SPFT) at the Nevill hospital in Hove.

It has long been apparent that there are problems with the location of this service: SPFT does not own the Nevill hospital site, and the lease arrangements make it expensive to run. In addition, although the Nevill is not a particularly old hospital, it is a far from ideal environment for people with dementia.

For these reasons, it has for some time been common knowledge that SPFT has been actively investigating other locations for in-patient dementia beds. It is clear that the city's other acute mental health hospital, Mill View, would not be an appropriate location for these beds, since it is generally considered poor practice to co-locate dementia beds with general mental health beds. This essentially leaves four options in the short term: to remain at the Nevill; to purpose-build a new city facility for these beds (surely highly unlikely given the current pressures on NHS capital funding); to co-locate these beds with existing city (general) hospital services; or to re-locate the beds to a site outside the city, presumably an NHS-owned site with lower running costs than the Nevill. (In the longer term it may well be that the local health economy can significantly reduce demand for these beds by more effectively managing community services, enhancing intermediate care provision etc.)

SPFT is currently undertaking a major re-design of its services across Sussex, which will include the reconfiguration of in-patient beds: this initiative is called 'Better By Design'. The Select Committee had hoped to address the issue of the future of dementia beds at the Nevill Hospital as part of its review, as public consultation on changes had originally been scheduled for early 2010. However, the initial timetable for the Brighton & Hove element of in-patient bed reconfiguration has been extended to allow for full canvassing of stakeholder views, and consultation around reconfiguration plans will not now commence until the autumn of 2010.

There are obvious pitfalls involved in taking a view on a possible relocation of services without knowing whether such a relocation is actually being planned, or if it is, what the detailed proposals are. For instance, if plans to relocate dementia beds included a significant enhancement of the therapeutic value of services offered (e.g. to a specially designed environment for dementia rather than to a 'standard' mental health ward), they might appear much more attractive than plans which essentially offered a 'like for like' service in another location.

However, it would surely seem remiss to publish a scrutiny report on dementia services in Brighton & Hove without mentioning this issue at all. In particular, members are very concerned by any plan which would involve the relocation of dementia beds out of the city. Although they may only be used by a relatively small number of people, there is surely a point of principle here: that a city of almost 300,000 people ought to be able to provide all but the most specialised healthcare services within the city, especially for services for the most vulnerable city residents and their families and carers. It seems wholly unacceptable to demand that carers and other family members, many of whom may themselves be elderly and frail, should be required to travel out of the city to visit and support people receiving relatively standard healthcare services. Therefore, whilst the Select Committee would welcome initiatives which sought to reduce reliance upon in-patient dementia beds by improving community services etc, committee members do not believe that there is any justification for relocating dementia beds outside Brighton & Hove, unless perhaps as part of a very significant improvement of service.

RECOMMENDATION – when the city commissioners make their decisions on the future of in-patient acute dementia beds, they should bear in mind the position of dementia Select Committee members: that locating this service outside the city should not be agreed unless there are overriding therapeutic benefits to such a move.

Nursing Homes

It is actually far more likely that people with dementia who are unable to cope with living independently will be placed in a nursing home than that they will require a hospital bed. Therefore issues about the adequacy and location of nursing care places are probably more important to most people than issues concerning in-patient bed provision.

In common with the rest of the country, the Brighton & Hove health economy is largely reliant upon relatively small independent sector firms for the provision of nursing care places. This tends to create two potential problems: in terms of the quality of the provision on offer, and in terms of capacity.

The quality of nursing home care was largely beyond the scope of this review. It is clearly an important issue, and there is a quite reasonable concern that small scale independent sector providers may offer services of much more variable quality than the public or corporate independent sectors. However, this may be an issue that is best dealt with in terms of how the commissioners of *all* nursing care places assure the quality of providers (and how they are assisted by national regulators) rather than focusing on issues relating to nursing homes specialising in dementia care (‘EMI’ homes). It is not clear that there is a particular quality issue with EMI care which might warrant it being examined separately from other types of nursing care. This may be an area that either or both the council’s Health Overview & Scrutiny Committee and its Adult Social Care and Housing Overview & Scrutiny Committee wish to pick up on.

In terms of nursing home capacity, relying upon a number of small independent sector providers can also pose problems. It is well established that the number of nursing home places available within a given area can vary according to fluctuations in housing markets, demand for hotels etc. For example, should residential property prices rise, some nursing home owners may be tempted to ‘cash-in’ by selling their properties for housing. This means that it can be difficult for the local health economy to plan nursing care provision effectively, because this planning may always be undermined by events outside the control of the commissioners of health and social care services.

Should demand exceed capacity, then it may be necessary to commission nursing home places in other areas. Clearly it is not desirable for people to be placed in areas against their wishes, particularly if they have lived in one place for much or all of their lives. (Of course, people and/or their families and carers may actively choose to be placed in an ‘out of area’ nursing home: this issue concerns those who may be placed out of area contrary to their wishes.)

There may be ways around this issue. One possibility is for local authorities and/or NHS trusts to themselves provide nursing home services. This might make it much easier to guarantee local levels of capacity over the medium term, as well as making it easier to ensure quality. In some instances it may also reduce costs, although this may not always be the case (i.e. public sector providers may not seek to make unreasonable profits, but on the other hand they generally have higher wage costs etc. than the private sector). In local terms this is also an area where there has been recent positive experience, with the local authority investing in its own residential provision for some services traditionally commissioned from other sectors (e.g. housing for some people with physical or learning disabilities).

Currently, city capacity for nursing care, including specialist ‘EMI’ care, is generally sufficient to meet demand. Given this, the Select Committee was reluctant to devote too much time to exploring problems which may prove to be of a hypothetical nature. However, Select Committee members do assume that the local health economy is engaged in long term planning on this matter. If not, then there is a clear need for this planning to be undertaken as part of the development of local dementia services – whether this entails the public sector being encouraged to start providing these services or it involves longer term planning and contracting with existing providers. The aim should always be to ensure that there are sufficient in-city nursing home places to cope with the demand, including that for EMI placements.

RECOMMENDATION – the city commissioners should be able to demonstrate that they have planned for sufficient capacity in terms of in-city nursing and residential home placements to ensure that everyone who requires such a placement is normally able to access one.

Housing

The Select Committee did not have time to look in detail at how people with dementia living in the community have their housing needs met. However, members would like to note that this is an area in which social landlords, obviously including the council, could help people to live relatively independent lives in the community for longer by granting them high priority for appropriate types of supported housing: e.g. particularly places on Sheltered and ‘Extra Sheltered’ housing schemes. These schemes offer general needs housing with additional services such as ‘CareLink’, warden support etc. and could have an important role to play in supporting people with relatively mild dementia.

It is currently the case that the local Housing allocations system *does* allow for people with overriding medical needs (including needs allied to a diagnosis of dementia) to gain priority access to vacant properties, so the system does already recognise the needs of people with dementia. However, depending on how highly dementia services are prioritised, there is presumably room to alter the allocations system in order to further encourage people with dementia to use Sheltered and other supported housing. Whilst the Select Committee has no specific recommendation to make in this area, it is certainly something which should be considered when planning dementia services across the city.

Better Cross-Service Working

One of the greatest challenges for health and social care is to work out how best to support people who have multiple needs – e.g. in terms of healthcare, social care, housing support, benefits advice, adaptations for disability etc. Since these services have traditionally been delivered by different organisations or by separate teams within an organisation, it can be very difficult to co-ordinate services effectively. All too often people have to undergo assessment by several different bodies, which can be very frustrating for individuals as well as representing an often unnecessary expense. Perhaps even more seriously, people may never be signposted to a service they could benefit from, because they never hear about it, or because the teams supporting them do not know the entire care system etc. These problems can be aggravated by different services having incompatible IT systems, differing thresholds for taking on clients, different types of team structure etc.

Anyone with multiple needs risks encountering poorly co-ordinated care and support services. However, people with dementia may face particular challenges. This is firstly because they tend to be older people, and are therefore very likely to face multiple challenges, with physical as well as mental health problems (i.e. insofar as older people are more likely to experience general health problems such as poor mobility, breathing difficulties etc). Secondly, the nature of dementia means that it can be very difficult for people, even in the very early stages of the disease, to negotiate labyrinthine health and social care systems. Thirdly, the advanced age of most people with dementia means that they may be socially isolated – unable to draw on the support of friends and family to help them negotiate the care pathway. Even when people do have carers supporting them, the carers themselves may be older people who will struggle to understand opaque care systems.

In order to mitigate the potential atomisation of services delivered across a number of teams and/or organisations, recent years have seen a number of attempts to foster better co-working. Sometimes this may amount to the formal integration of services; in other instances the formation of multi-disciplinary teams or improved ‘whole-system’ training for specific teams. The Select Committee received presentations from three such teams integral to providing support for people with dementia: the Community Mental Health Teams, Intermediate Care Services and the Access Point.

Access Point

The Access Point is a ‘one stop shop’ for people presenting to city social care services. The Access Point team supplies information and advice on social care issues as well as providing a range of services itself. These include: minor adaptations, repairs and equipment, day services, meals on wheels, CareLink, information on self-directed support, and access to the Daily Living Centre (where people can ‘road-test’ disability equipment in a ‘home’ environment).

The Access Point can also assess clients and determine their eligibility for a number of services, saving money and minimising the stress caused by multiple assessments.[40]

Members were impressed by the Access Point and considered it to be an excellent example of a service designed around client needs. Clearly though, for the Access Point to work as effectively as possible, it needs to be very well publicised – people will only use a service like the Access Point if they know that it exists and they understand that it functions as a social care gatekeeper.

To this end the Access Point team has already done a great deal to publicise its service, and these efforts are to be applauded. However, the Select Committee did hear about one specific problem in this context: it seems to be the case that some city GP surgeries do not display information on the Access Point as the practice managers at these surgeries are unwilling to display non-health related information (or information not directly supplied by the NHS). [41]Whilst it seems perfectly sensible for GP surgeries to limit the amount of information they have on display, it is surely perverse that they should decline to display information on the Access Point, as this is likely to be of considerable interest to many people attending surgeries. Furthermore, there would seem to be an obvious benefit for GPs in making their patients as aware as possible about the Access Point, as a large proportion of enquiries to GPs will probably be social care related. Therefore, GPs who actively promote the Access Point service are likely to find that by doing so they can actually reduce their workload by diverting patients to a more appropriate resource.

It may be that there is a danger of placing too much emphasis on what is a fairly minor problem: it is clear that the majority of city GP surgeries are happy to display information on the Access Point. However, the problem should not really exist at all, and to this end, Select Committee members feel that local GPs might be encouraged to better understand the Access Point and to promote it to their patients.

RECOMMENDATION – that NHS Brighton & Hove should arrange the invitation of a representative of the Access Point to forthcoming Locality GP meeting(s) or otherwise facilitate the promotion of the Access Point’s work amongst city primary care practitioners.

---

[40] See evidence from Guy Montague-Smith, Access Point Manager, 04.12.09: point 14.3-14.6.

[41] Evidence from Guy Montague-Smith, 04.12.09: point 14.8.

More generally, members felt that it was important for the council to support the Access Point, particularly in terms of publicising this service; and key that this support was over the long term rather than fading away after a time. To this end members suggested that they should recommend that the Access Point should be routinely included amongst the council services given the opportunity to promote themselves via events such as ‘Get Involved Day’.[42]

RECOMMENDATION – that the Access Point should continue to be encouraged to promote its services via all appropriate council/city initiatives (such as Get Involved Day etc.)

Community Mental Health Teams

Community Mental Health Teams (CMHTs) are integrated, multi-disciplinary teams, bringing together nurses, social workers and occupational therapists, and supported by specialist psychiatric services. CMHTs are designed so that they can either directly provide or arrange for all the support that a patient requires, whether in terms of healthcare, social care, help with financial matters, help with housing, arranging housing adaptations etc.[43]

CMHTs are an example of a formally integrated team providing and signposting a wide range of services for clients with particular types of problem. When CMHTs work well, as they often do in Brighton & Hove, they provide a compelling argument for the formal integration of services.

Intermediate Care Services

Intermediate Care Services (ICS) provide residential beds for people who are temporarily unable to live in the own homes, aiding recovery, avoiding needless acute hospital admission and facilitating quicker discharge from hospital. There are currently 61 ICS beds across the city, either in NHS, local authority or independent sector facilities. ICS is also heavily involved in delivering community services, supporting people to live in their own homes.[44]

ICS is by no means a dedicated service for people with dementia, but an increasing amount of the ICS workload consists of clients with dementia, with perhaps two thirds of patients in ICS having either diagnosed or undiagnosed dementia.[45] However, many of these patients will have other issues too – such as mobility problems: dementia is not necessarily always the main reason why these patients are in ICS.

---

[42] See 04.12.09, point 14.9.

[43] See evidence from Carey Wright, CMHT Manager, Sussex Partnership NHS Foundation Trust, 15.01.10: point 19.4.

[44] See evidence from Eileen Jones, Intermediate Care Team Manager, 04.12.09: points 14.11-14.12.

[45] See 04.12.09: point 14.5.

In order to better deal with the changing nature of its workload ICS has recently employed a Registered Mental Health Nurse. This nurse is responsible for a number of tasks including supporting ICS staff in dealing with patients with mental health problems; assessing patients already in the service; risk-assessing the service taking on particular patients; and liaising with CMHTs, GPs, mental health advocacy services etc.[46]

Select Committee members welcomed ICS's recognition of the increasing importance of dementia, and its attempts to establish effective relationships with key dementia services. Intermediate Care services are likely to increase in importance in the next few years, in the context of dementia and many other conditions, as NHS commissioners try and decrease the use of very expensive acute hospital beds, and it is important that the local system is geared to make the necessary changes.

It seems very likely that the key to improving city dementia services in the current financial climate lies with ensuring that existing support services work together effectively, integrating where necessary, and avoiding unnecessary duplication whilst retaining important specialist knowledge. It is clear that the actual situation in Brighton & Hove, as in many parts of the country, is still some way from this ideal, and that much work needs to be done. However, Select Committee members were heartened by the examples of really good practice from the Access Point, city Community Mental Health Teams and the Intermediate Care Service described above. It is to be hoped that the city can build on these examples to develop and further coalesce services in the future.

Support Services

As there is currently no cure and relatively few effective treatments for dementia, most interventions seek to support people with dementia and their carers via services like day centres, home help, respite care etc. Many of these support services are provided by 'third sector' organisations such as the Alzheimer's Society. These services are key to ensuring that people with dementia and their carers live relatively full lives, and critically, that people are able to live in the community rather than in residential care – not only does this accord with most people's wishes, but it has very significant cost implications as residential care can be very expensive.[47] However, there are several potential problems with dementia support services.

In the first place, the 'map' of support services that people with dementia can access can be rather complicated, particularly since there is no single service provider.[48] There is therefore the real danger that people will not be aware of services which might benefit them. In part the move to more integrated 'gate-

---

[46] See evidence from Dennis Batchelor, ICS Registered Mental Health Nurse, 04.12.09: point 14.4.

[47] See evidence from Alan Wright, 17.07.09: point 9.15.

[48] See minutes to 12.06.09 meeting: point 4.2.

keeping' teams such as the CMHTs and the Access Point should ensure that this problem is minimised: these gate-keepers are aware of the range of services available to people with dementia and should be able to ensure that clients are directed to the most appropriate services. Organisations such as the Alzheimer's Society are also key here: the Alzheimer's Society has an unparalleled knowledge of dementia and is very well placed to help people. The Select Committee was glad to learn that in Brighton & Hove the Alzheimer's Society is already co-located with CMHTs. Innovative close-working arrangements such as this are to be encouraged, and when a local memory assessment service is established it will presumably establish similarly close links with the Alzheimer's Society etc.

Another issue with support services is that of capacity. Even if local capacity is currently not an issue, it may well be in the near future, both because the prevalence of dementia is set to rise (albeit perhaps not as steeply in Brighton & Hove as in other localities), and because improved diagnosis of dementia should mean that many more people present for support services.[49] It is vital that there are sufficient services on the ground to cope with this anticipated spike in demand: diagnosing dementia but then failing to provide appropriate levels of information and support is likely to have a detrimental impact upon service users and their carers. The city commissioners therefore need to be confident that there are sufficient support services in place to cope with both current and likely future demand.

Finally, organisations like the Alzheimer's Society also offer key advocacy and advice services for people with dementia, their families and carers. These services are extremely important, and to a large degree are always going to be needed. However, they are also, at least in part, a reaction to the complexity of dementia services – e.g. if it is necessary to fill in complicated forms in order to access statutory support, then there is an obvious need for advocacy services to help people do this. Therefore, whilst the need for these support services is never going to go away, it might be that making statutory services easier to access will reduce the need for people to rely on third parties to help them negotiate the care system. This is potentially very important in an environment where demand is likely to increase more quickly than resources.

RECOMMENDATION – When re-designing the local dementia care pathway, the city commissioners should specifically address the issue of support service capacity in the light of anticipated growth in demand for these services in the near future.

RECOMMENDATION – When re-designing the local dementia care pathway, the city commissioners should explicitly address the issue of ensuring that all aspects of the pathway are as easy to negotiate as possible, so as to reduce the pressure on advocacy and advice services.

---

[49] See evidence from Alan Wright, 17.07.09: 9.14

Community Support

In addition to support from the statutory services, from third sector organisations, and fundamental support from carers, friends and family, people with dementia can benefit from local community support. At its most obvious, this might take the form of neighbours checking that someone was OK, helping them with shopping or gardening chores, looking out for them in bad weather etc – i.e. the type of support that traditional communities are often said to have provided, but which has dissipated in modern, atomised, urban environments.

This type of community support would certainly not replace professional support, but it might augment it, improving the quality of people's lives (and perhaps particularly the quality of carers' lives, if they could feel that their caring burden was being shared, even to a small degree). It should also be relatively low cost, an important factor given the likely constraints on health and social care spending in the foreseeable future.

There are some successful instances of these types of community support networks having been developed, particularly in terms of providing community support to people with Learning Disabilities (e.g. the 'Circles of Support' model), and is this type of initiative which might potentially be developed for dementia.

Even if the practical level of community support for people living with dementia and their carers was relatively low, encouraging communities to accept some 'responsibility' for people with dementia might pay major dividends in terms of countering the isolation that many people with dementia and their carers experience. In particular, it might prove effective in raising the esteem in which carers are held - this is an issue commonly raised by carers – i.e. that they perform a difficult and vital role for little or no recompense, and get relatively little recognition of what they do. Better community support might help carers to themselves feel better about the sacrifices they are required to make.

RECOMMENDATION – The city commissioners should investigate the potential benefits of engaging with local communities in order to encourage them to better support people with dementia and their carers.

Early Onset Dementia

Most of this report is concerned with late onset dementia, as late onset dementias affect far more people and are set to increase very rapidly. However, a relatively small number of people will contract forms of dementia characterised as 'early onset' – types of dementia which can manifest in people in their 40s, 50s and early 60s.

Although early onset dementia is not a problem on anything like the scale of late onset dementia, it can be a very distressing condition to deal with, and its morbidity is set to rise (albeit not so quickly as late onset dementia with its close demographic tie), both because some of the societal/environmental factors which can lead to early onset dementia, such as very heavy drinking, are increasing; and because better diagnosis of dementia is bound to lead to more under-65s being diagnosed.[50]

Given this likely spike in demand it is important that services for people with early onset dementia have sufficient capacity. Even in terms of current demand this is not necessarily the case. For instance, the Select Committee heard about the Towner Club, a support service for younger people with dementia and their carers. The Towner Club has proved extremely successful and is widely regarded as a model for dementia support services. However, it can only accommodate 10 people, which is not sufficient to cope with current demand. If people with early onset dementia cannot be accommodated by the Towner Club, the only realistic options are to offer them support at a service designed for people with late onset dementia or to not offer them any support at all. The latter is clearly very undesirable, and supporting relatively young people via services intended for much older people can also be problematic.[51]

Therefore, when thinking about city capacity for dementia support services, the commissioners should consider the issue of early onset dementia services, and ensure that city provision is sufficient to meet likely demand without having to divert people into inappropriate services.

RECOMMENDATION – When re-designing the local dementia care pathway and commissioning city dementia services, the city commissioners should specifically address the needs of people with early onset dementia, ensuring that appropriate support services are in place to deal with current and likely future demand.

Future Scrutiny

It is evident that this is a time of considerable flux for mental health services. On the one hand, we are entering into a period when it seems very likely that there will be extreme pressures on health and social care budgets, with most commentators predicting a long period of austerity. Healthcare commissioners will inevitably have to react to real-terms reductions in funding by looking very carefully at the services they commission, and particularly at those areas where their commissioning spend is higher than national averages, the spend of comparable organisations etc. Sussex Primary Care Trusts have already begun this benchmarking process with regard to mental health, as Sussex spending (particularly in relation to services for older people) is considerably higher than that in many other areas.

The Sussex Partnership NHS Foundation Trust (SPFT) is also undertaking a major review of all its activity, and is expected to make significant changes to the way in which it provides services, potentially including services for dementia. These changes are likely to focus on providing value for money, but

---

[50] See evidence from Alan Wright, 17.07.09: point 9.16(b).

[51] See evidence from Alan Wright, 17.07.09: point 9.16(b) and (c).

also on shifting the focus of mental health care from the use of acute hospital beds to a more community-based service.

And, as noted above, demographic change is likely to see an explosion in demand for dementia services across most of the country. Although the effects may not be as severely felt in Brighton & Hove as in East or West Sussex, there is bound to be sharply increasing demand for services in the near future.

For these reasons, it is clear that this review should be considered as the beginning of Overview & Scrutiny's involvement with the issue of dementia rather than any kind of final word. Local dementia services will be evolving very quickly in the coming months and years as ways are found to make less money go further and to help people with dementia and their carers live full and satisfying lives. At this point it is still not clear what reconfigured local services will look like, or indeed whether changes to dementia care will improve things for the people of Brighton & Hove. It is therefore important that Overview & Scrutiny continues to keep a watch on issues relating to dementia – either by constituting further scrutiny panels (perhaps to undertake a more thorough strategic review of local dementia services), or by requesting regular updates to the adult social care and health scrutiny committees.

RECOMMENDATION – that the issue of dementia and the ongoing changes to local dementia services should inform Overview & Scrutiny work planning, particularly with reference to the work programmes of the Adult Social Care & Housing Overview & Scrutiny Committee (ASCHOSC) and to the Health Overview & Scrutiny Committee (HOSC).

As is common practice with Scrutiny reports, the recommendations of this report, assuming that they are endorsed by the Overview & Scrutiny Commission (OSC), will then be submitted to the appropriate executive body/bodies for consideration. If recommendations are accepted, then their implementation will be reviewed by OSC approximately six months after their acceptance. Further monitoring will take place at six monthly intervals until the OSC is satisfied that implementation is complete.

Most of the recommendations in this report are intended to feed in to the re-design of the local dementia care pathway. This re-design is expected to be completed in Autumn 2010, with ratification by the Joint Commissioning Board following shortly after. It should therefore be possible to report back on implementation of the Select Committee recommendations in early 2011.

Cost

It is clear that we are living through a time of very real financial uncertainty, with exceptional pressures on all kinds of services. This will undoubtedly include services for dementia: we already know that local spending on Older People's Mental Health (which includes the bulk of dementia spending) is well above national and regional averages and higher than most comparators. In an era of fiscal restraint, there is therefore bound to be considerable pressure on this and many other budgets.

When drawing up its recommendations, the Select Committee did bear the financial environment in mind: none of the above recommendations are likely to cost very much to implement, and, where there is a cost involved (for example in providing better training on dementia to healthcare staff), there is always a ‘spend to save’ argument to support the recommendation. That is, a relatively small expenditure at the ‘front’ of the system (i.e. at assessment stage) is likely to result in greatly reduced expenditure later on (e.g. by supporting people to live for longer in the community and thereby reducing nursing home costs).

The Select Committee has drawn up its recommendations in this way because members wanted to be realistic about what is practically achievable at the present time, and it is evident that proposals to significantly increase expenditure are unlikely to be welcomed, unless there is a clear argument to show that short term cost increases will lead to longer term value for money improvements.

However, Select Committee members do want to be clear that they would oppose any real terms cuts to the dementia budget or dementia services, even in the context of real terms reductions across health and social care budgets. Dementia is such a major problem that cuts would be bound to be counterproductive in the longer term, as well as impacting upon some of the neediest and most vulnerable people in our society. Moreover, the increasing prevalence of dementia means that it is unlikely that even the present standards of support and treatment could be maintained for very long with falling budgets. Committee members do recognise the very difficult job facing the commissioners of city health and social care services, but urge that maintaining dementia spending should be considered a priority.

Mr Duane Passman
Director of Estates and 3T Project Director
Brighton & Sussex University Hospitals
Trust

Date: 13 September 2010

Dear Mr Passman,

Thank you for providing Brighton & Hove HOSC with the information we had requested concerning car parking at the Royal Sussex County Hospital: specifically, the ratio of staff to public using the hospital multi-storey car-park – with the average staff occupancy of ‘shared’ parking facilities stated as 48%.

We do note with some concern that the number of publicly accessible parking spaces typically occupied by staff is very high, and leaves little free capacity for patients and their visitors.

HOSC members do understand that there is no simple answer to the problem of providing adequate parking for staff and the public on a very cramped site; we appreciate that clinical staff, who may be working shifts when there is limited recourse to public transport, may need to travel to work by car. We also recognise that the trust has been very active in this area, with a comprehensive staff travel plan which seeks to minimise the use of hospital parking by staff.

However, there is clearly a problem here which must be addressed. The HOSC would therefore welcome conversations with Brighton & Sussex University Hospitals Trust about innovative ways to address the parking issue, including exploring ideas for off-site parking to relieve some of the pressure on the County hospital site.

Please don’t hesitate to contact me or the HOSC support officers if you would like to discuss these ideas further.

Yours sincerely

Councillor Garry Peltzer Dunn