





Brighton & Hove  
City Council

# Health & Wellbeing Overview & Scrutiny Committee

Title:	<b>Health &amp; Wellbeing Overview &amp; Scrutiny Committee</b>
Date:	<b>11 September 2012</b>
Time:	<b>4.00pm</b>
Venue	<b>Council Chamber, Hove Town Hall</b>
Members:	<b>Councillors:</b> Rufus (Chair)C Theobald (Deputy Chair), Bowden, Cox, Marsh, Robins, Sykes and Wealls  <b>Co-optees:</b> David Watkins (LINK), Jack Hazelgrove (OPC), Amanda Mortensen (Parent Governor Representative), David Sanders (Catholic Schools Service), Susan Thompson (Diocese of Chichester) and Youth Council (Youth Council)
Contact:	<b>Kath Vlcek</b>  01273 290450 kath.vlcek@brighton-hove.gov.uk

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# AGENDA

- 24.** Procedural Business
- 25.** Minutes of the Previous Meeting **1 - 8**
- 26.** Chair's Communications
- 27.** Public Involvement
- 28.** Issues Raised by Councillors and Co-optees
- 29.** Children with Complex Needs **9 - 50**
- Contact Officer: Kath Vleck, Scrutiny Tel: 01273 290450  
Support Officer*
- Ward Affected: All Wards*
- 30.** GP Performance **51 - 70**
- Contact Officer: Kath Vleck, Scrutiny Tel: 01273 290450  
Support Officer*
- Ward Affected: All Wards*
- 31.** Mental Health Beds (September 2012) **71 - 88**
- Contact Officer: Kath Vleck, Scrutiny Tel: 01273 290450  
Support Officer*
- Ward Affected: All Wards*
- 32.** Local Implementation of the 111 Service **89 - 94**
- Contact Officer: Kath Vleck, Scrutiny Tel: 01273 290450  
Support Officer*
- Ward Affected: All Wards*

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**BRIGHTON & HOVE CITY COUNCIL**  
**HEALTH & WELLBEING OVERVIEW & SCRUTINY COMMITTEE**

**4.00pm 24 JULY 2012**

**COUNCIL CHAMBER, HOVE TOWN HALL**

**MINUTES**

**Present:** Councillor Rufus (Chair)

**Also in attendance:** Councillor C Theobald (Deputy Chair), Bowden, Marsh, Robins, Sykes and Wealls

**Other Members present:** Mr David Watkins (LINK), Mr Jack Hazelgrove (Older People's Council), Mr Ceirney Eddie (Youth Council), Ms Amanda Mortenson (Parent Governor)

**PART ONE**

**12. PROCEDURAL BUSINESS**

**12A Substitutes**

12.1 There were none. Councillor Graham Cox gave his apologies.

**12B Declarations of Interest**

12.2 There were none.

**12C Exclusion of Press and Public**

12.3 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.

**12.4 RESOLVED –that the press and public be not excluded from the meeting.**

**13. MINUTES**

13.1 Members considered the draft minutes from the 12 June 2012 Health and Wellbeing Overview and Scrutiny Committee.

**13.2 RESOLVED that the minutes of the 12 June 2012 Health and Wellbeing Overview and Scrutiny Committee be approved and signed.**

#### **14. CHAIR'S COMMUNICATIONS**

14.1 Cllr Rufus said that he had taken part in the Carer's Challenge, where he had spent the afternoon with a carer. He encouraged everyone to take part in future sessions.

He found it a very positive and inspiring afternoon, and got a deeper understanding of the day to day issues and bureaucratic complexities involved in being a carer, as well as the strength of character needed to be a carer.

#### **15. PUBLIC INVOLVEMENT**

15.1 There were no items to consider.

#### **16. ISSUES RAISED BY COUNCILLORS AND CO-OPTees**

16.1 There were no issues to consider.

#### **17. ANNUAL REPORT OF THE DIRECTOR OF PUBLIC HEALTH**

17.1 Dr Peter Wilkinson presented the report as Dr Tom Scanlon was unable to attend the meeting. Dr Scanlon had compiled 'Vital', the 2011 annual report on public health for Brighton and Hove. Dr Wilkinson summarised the report contents and answered questions from the committee members.

17.2 Councillor Rufus applauded the report and the new layout and style - it provided a new way of looking at a number of important health issues for the city. This was backed up by other committee members.

17.3 In response to a question about the classification system for local GPs, and how this could be used to improve performance, Dr Wilkinson said that it allowed surgeries to compare themselves with practices with a similar patient base rather than with all practices across the city. This allowed more meaningful comparisons to be made.

17.4 In response to a query about the report's intended audience, Dr Wilkinson said that the report was mainly intended for primary care practitioners, practice managers and the Clinical Commissioning Group (CCG). The report was intended to be informative and entertaining and also offered GPs potential CPD points. The report had already been sent to all councillors and to all GP surgeries.

17.5 Geraldine Hoban, Chief Operating Officer for the CCG, said that the classification system was a way of holding peers to account. The CCG was also planning to introduce scorecards for surgeries, again comparing like with like, and providing softer information from patients' experiences. Ms Hoban would be happy to come back and talk to the committee about this at a later date.



- 17.6 Members commented that it might be the case that individual GPs could be the stumbling block for improving care. This might be particularly the case for locums, who did not know the individual patient or their medical history.
- 17.7 There was a discussion around the article on diabetes care. Ms Hoban said that the CCG thought that diabetes should be a clinical priority locally, in order to achieve the results that should be being achieved.
- 17.8 Mr Watkins said that he had not been able to find any reference to Patient Participation Groups (PPG) in the report and would like to see this made more explicit in future reports.
- 17.9 **RESOLVED – that the annual report on public health be noted, and that Ms Hoban be invited back to speak on GP peer reviews and patient feedback.**

## 18. HWOSC WORK PROGRAMME

- 18.1 Councillor Rufus introduced the work programme, explaining that Councillors Rufus, Marsh and Theobald had previously met to discuss and agree the work programme content. Councillor Rufus explained that the work programme was a fluid document and could be amended and updated as needed. The HWOSC co-optees had been contacted for additional work programme ideas that they may have; these would need to be added in.
- 18.2 Councillor Wealls commented on item (d), Autism services for Children and Young People. He was concerned that there may be duplication with the work of the Children and Young People's Committee. In addition, there was quite a narrow focus suggested, by concentrating on the work of CAMHS. Councillor Wealls suggested that this needed broadening out. This was agreed.
- 18.3 Councillor Marsh suggested that items (q) the Clinical Commissioning Group Strategic Commissioning Plan and (r), the Clinical Commissioning Group Annual Operating Plan could be combined. This was agreed.

Councillor Marsh also said that item (m) - Community Meals –was being dealt with by the Adult Social Care Committee and HWOSC should not duplicate their work.

- 18.4 **RESOLVED – the work programme was agreed, with the exception of the amendments made above.**

## 19. MENTAL HEALTH BEDS UPDATE

- 19.1 Anne Foster, Clinical Commissioning Group Lead Commissioner, Mental Health and Sam Allen, Sussex Partnership NHS Foundation Trust (SPFT) Service Director, provided the committee with a verbal update on the decision taken by the Clinical Review Group at its last meeting regarding the temporary acute mental health beds at Mill View Hospital. The HWOSC had asked for a verbal update from the meeting.

- 19.2 Ms Foster said that, since the last HWOSC meeting, the clinical review group had held, as planned, a further meeting. The group, which consists of six clinicians from across SPFT and chaired by the GP Mental Health Lead at the CCG, had carefully considered the current situation with the temporary bed closures and on balance, had decided not to re-open them.

The clinicians felt that, in their experience, if a bed was available, it would be filled; this might artificially alter the threshold for managing patients in the community. Instead, the review group opted to use the resources freed up by the bed closures to invest in community services and other improvements in acute mental health services e.g. discharge team. The review group felt that it was vital to make further improvements to the Crisis Resolution Home Treatment Team (CRHT), and in particular to bolster night-time support as well as looking at enhancements to reduce the length of a patient's stay.

- 19.3 Ms Allen clarified the decision taken by the clinicians regarding the closure of the beds is contingent on further investment (as outlined above) in community services. The preferred model of care is for patients to be managed in the community as much as possible because of the continuity of care with community teams and family and social support networks. There had already been progress in reducing the length of stay since the introduction of the early discharge coordinator at the start of June.
- 19.4 Ms Foster and Ms Allen commented on the fact that although it had not been possible to meet the 95% target for accommodating people within Brighton and Hove, this had only dipped to 93%. They mentioned however that one risk to be aware of was that, if homelessness figures increase, this could put additional pressures on the acute services,
- 19.5 The committee heard that there was further work ongoing to prioritise the investment in community services and that the clinical review group will meet again in August to make a final decision on investment. The impact of the investment would be monitored over a period of two to three months to assess its sustainability before making a permanent decision on the future of the beds.
- 19.6 Councillor Rufus said that he was surprised by the review group's decision and asked how quickly would the extra community support resources have a meaningful effect on the metrics?
- 19.7 Ms Allen said the investment proposals had already been developed; additional services could be in place by September 2012 and should quickly be able to demonstrate their outcomes. The Early Discharge Team was already having a positive impact, and it was hoped to extend their services to make them available for seven days a week.
- 19.8 Committee members said that they were disappointed with the decision not to re-open the beds. They would also have liked to have had a written report available on such an important issue.

Ms Foster and Ms Allen explained that it was not possible to have provided a written report; the tight deadlines with the clinicians' meeting had meant that it was not possible on this occasion. They confirmed that a written report will be provided to the next HWOSC meetings. Councillor Rufus welcomed this confirmation.

- 19.9 Mr Eddie, for the Youth Council, asked about the effect that the bed closures would have on the families of patients, in particular those who might be placed out of the area. Ms Allen said that SPFT would always try and provide someone with their first choice of accommodation location where possible; SPFT has beds across Sussex. It was often the case the patients preferred to be cared for in their own homes; the new investment in community services would support this.
- 19.10 Ms Hoban from the CCG confirmed that clinicians would continually review the situation following the additional investment. Investment was immediately available for some of the services to increase capacity, but in addition to this the CCG were also progressing other plans including the personality disorder day facility and increased capacity in terms of supported accommodation; these changes would come in during 2013. This was part of a long transformational journey for mental health services, following an extensive independent review of services. The new arrangements would be carefully monitored; it was about getting the model of care right and addressing a systemic imbalance.
- 19.11 Clodagh Warde-Robinson, Deputy Chief Executive/Director of Strategy from the Sussex Community Trust, said that they had been through a similar process in West Sussex and stressed the need for a formal evaluation of the programme, and the potential knock on effect for other services. Ms Warde-Robinson, Ms Allen and Ms Foster agreed to continue the discussion following the committee meeting and agreed to keep Councillor Rufus and HWOSC members updated with any outcomes.
- 19.12 Mr Watkins, representing the LINK, said that he was very disappointed with the decision and felt that the community he represented would be unhappy too. He asked that any future reports about the bed closures be sent to the LINK.
- 19.13 Councillor Wealls said that he disagreed with the majority of committee members as he felt that it was a positive move to use resources differently.
- 19.14 Ms Warde-Robinson spoke in support of the proposed changes, commenting that it was necessary to take some of the capacity out of a service in order to transform it and change behaviours. If changes were not made, behaviours would not change.
- 19.15 RESOLVED – that the verbal report be noted and that written reports on the situation regarding the bed closures be brought to all future HWOSC meetings whilst this was a live issue.**

## **20. SCRUTINY PANEL REQUESTS: SCOPING REPORTS**

- 20.1 Item 20 was brought forward in the agenda at the request of Councillor Mitchell.
- 20.2 Councillor Mitchell requested that the HWOSC consider her application for the Youth Justice Plan (YJP) to be scrutinised through a review panel. Councillor Mitchell outlined her reasons for this, explaining that she felt that the YJP was inadequate. It had been severely criticised by Her Majesty's Inspectorate of Probation, and Brighton and Hove

had been placed in the bottom 25 in the country, out of a total of 160 that had been assessed.

- 20.3 Councillor Mitchell understood that an Improvement Plan had been submitted to the Children and Young People's Cabinet Member Meeting in September 2011 but that the HMIP inspection report had not been appended so it was not possible to cross-reference the two documents satisfactorily. The YJP came to Cabinet in March 2012 but Councillor Mitchell and colleagues did not feel that it was up to standard.
- 20.4 Councillor Mitchell felt that it was an appropriate time for the YJP to be scrutinised; the department are due to look at the plan in January 2013 but a panel could look at the restructuring and the proposals that had been suggested within the improvement plan before that time, feeding their comments into the department's proposals.
- 20.5 Councillor Rufus thanked Councillor Mitchell for raising this important issue and invited questions and comments from committee members.
- 20.6 Councillors and co-optees agreed that the YJP was an important topic that needed to be taken up by a review panel as soon as possible and that the issues identified in Cllr Mitchell's letter should be addressed.
- 20.7 Members were anxious that the work of any panel should dovetail with existing work to improve the service. They discussed the best way to take it forward in order to feed into the reporting cycle for the January 2013 committees. It was suggested an initial session with officers involved in developing the service would be beneficial to identify where a panel could add value; it would be necessary for the panel to be completed by mid-autumn 2012.
- 20.8 RESOLVED – that a scrutiny review panel be set up to look at the Youth Justice Plan as soon as possible, to be completed by mid autumn 2012.**
- 20.9 Councillor Wealls then introduced his request for a scrutiny panel, looking at emergency accommodation in Brighton and Hove. This had come to his attention through casework from some of his constituents and he was interested to find out whether emergency accommodation was fit for purpose. In particular, Councillor Wealls had concerns about the availability of drink and drugs which can be a particular problem for recovering addicts living in the accommodation.

Councillor Wealls appreciated the report that officers had supplied in response to his enquiry. He had further questions including those around the level of support that tenants were given, and around the proposed re-tendering process. It might also be opportune to extend the remit of any panel to look at temporary as well as emergency accommodation as this had also been raised as a concern.

- 20.10 Members commented that the situation in terms of the number of people needing emergency and temporary accommodation was not going to improve. They felt that it would be appropriate to look at the issue through a review panel. How could we help people to break out of the cycle of needing emergency accommodation? Members said that they would like to speak to service users (or their representative groups) as well as service providers in order to get as round a view as possible.

- 20.11 Narinder Sundar, Supporting People Manager, from the Housing Commissioning Unit, and Jenny Knight, Housing Commissioning Officer from the Housing Commissioning Unit, addressed some of the queries raised from committee members. They commented that there had been a significant rise in the numbers of people approaching for hep with temporary and emergency accommodation. Residents in hostel accommodation tended to have multiple complex needs, which added to the complexity when looking at accommodation options.
- 20.12 Members discussed how to take this forward. It was felt that a focussed workshop would not allow enough time to fully consider the subject. The committee agreed that this would be an appropriate topic for a scrutiny panel, bearing in mind that the panel looking at the Youth Justice Plan would take priority.
- 20.13 RESOLVED – that a scrutiny review panel be set up to look at emergency and temporary accommodation. The panel should speak to service users (or their representatives) and service providers.**

## **21. SUSSEX COMMUNITY TRUST: FOUNDATION TRUST APPLICATION**

- 21.1 Ms Warde-Robinson, Deputy Chief Executive/Director of Strategy from the Sussex Community Trust, had been due to give an update on the Trust's application for Foundation Trust status. However they had been asked to postpone their application until September 2012 because of the summer break. Ms Warde-Robinson therefore gave a presentation on the work of the Trust and its work in the community.
- 21.2 Ms Warde-Robinson answered questions from committee members, in particular addressing comments about the interface between social services and the Trust. She explained that the Trust did a lot of work to link with homelessness services, in particular, dental services.
- 21.3 RESOLVED – that the contents of the presentation be noted and that Ms Warde-Robinson come back to HWOSC in due course with more information on the application for Foundation Trust status.**

## **22. LETTERS TO THE HWOSC CHAIR**

- 22.1 The Committee considered the letter regarding hearing services.
- 22.2 There were no comments. Ms Hoban agreed to come back to update the Committee at a future date; this was welcomed.
- 22.3 RESOLVED – that Ms Hoban come back to update the Committee at a future date on Hearing Services in the city.**

## **23. FOR INFORMATION: WORK PLAN OF THE CHILDREN & YOUNG PEOPLE POLICY COMMITTEE**

- 23.1 The work plan was noted by the committee.

The meeting concluded at 7.00pm

Signed

Chair

Dated this

day of

# HEALTH AND WELLBEING OVERVIEW AND SCRUTINY COMMITTEE

## Agenda Item 29

Brighton & Hove City Council

<b>Subject:</b>	<b>Children with Complex Needs</b>		
<b>Date of Meeting:</b>	<b>11 September 2012</b>		
<b>Report of:</b>	<b>The Strategic Director, Resources</b>		
<b>Contact Officer:</b>	<b>Name:</b>	<b>Kath Vlcek</b>	<b>Tel: 29-0450</b>
	<b>Email:</b>	<b>Kath.vlcek@brighton-hove.gov.uk</b>	
<b>Ward(s) affected:</b>	<b>All</b>		

### FOR GENERAL RELEASE

#### 1. SUMMARY AND POLICY CONTEXT:

1.1 The Parent Carers' Council and Amaze have produced 'Talk Health' an annual report on health services in the city, and have requested that it be circulated for information and comment to HWOSC members.

1.2 A copy of the report is attached at **Appendix 1**.

#### 2. RECOMMENDATIONS:

2.1 That the HWOSC:

Considers and comments on the 'Talk Health' report

#### 3. RELEVANT BACKGROUND INFORMATION/CHRONOLOGY OF KEY EVENTS

3.1 See **Appendix 1** for more information provided by Amaze/Parent carers' Council.

#### 4. COMMUNITY ENGAGEMENT AND CONSULTATION

4.1 None for this cover report but the annual report focuses on parent participation as a key element of improving health services.

**5. FINANCIAL & OTHER IMPLICATIONS:**

Financial Implications:

5.1 None to this report for information.

Legal Implications:

5.2 None to this report for information.

Equalities Implications:

5.3 None to this report for information.

Sustainability Implications:

5.4 None to this report for information.

Crime & Disorder Implications:

5.5 None to this report for information.

Risk and Opportunity Management Implications:

5.6 None to this report for information.

Public Health Implications:

5.7 None to this report for information.

Corporate / Citywide Implications:

5.8 None to this report for information.

**SUPPORTING DOCUMENTATION**

**Appendices:**

1. 'Talk Health' report

**Documents in Members' Rooms**

None

**Background Documents**

None



# “Talk Health...”

Parent Carers' Views on Health Services  
in Brighton & Hove 2012



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“This year, my child has seen two community paediatricians, a gastroenterologist, a neurologist, an occupational therapist, a physiotherapist, a speech and language therapist, a dietician, a ketogenic diet team, a geneticist, a surgeon, a school nurse, a community nursing team, several different teams of doctors and nurses at the children’s hospital, ten different paramedics and her GP. She has attended medical appointments or hospital visits over 40 times.”

## 1. Executive Summary

Every parent's first wish is for their child(ren) to lead as healthy a life as possible. When you become a parent you may expect to have some involvement with health services. You would expect to visit the GP and have, maybe, the odd visit to A&E. You might expect the occasional broken bone and high temperature.

Yet nothing prepares you for the journey you begin when you have a child with a disability. Due to their complex health, mental health and wellbeing needs this group of children use a wide array of health services.

### a. Who are we?

The Parent Carers Council (PaCC) is a group of 190 parent carers of children with disabilities, complex needs or long term conditions from across the city. The group was set up in 2007 as a work stream of Amaze, a long established parent led organisation supporting parents of children with any special need in Brighton and Hove. Amaze supports approximately 1,600 families of disabled children in this area. PaCC is mostly funded by NHS Brighton & Hove with some funding from the Integrated Disability Services in Brighton & Hove and the DFE (Department for Education).

### b. Why listen to us?

Disabled children's interaction with a wide range of health services can be intensive, extensive and expensive: they are high cost, high incident users of health services. A range of different health services are required including universal services (such as GPs), specialist services (such as specialist neurology services) and condition specific services (such as a service for children with visual impairment). Many of our local children travel up to London to see specialists in a specific field. However, this report is concerned with the services that are provided locally, in Brighton & Hove.

Health professionals from across acute, primary care, specialist services, palliative care and community-based services must actively seek the views of these young patients, and those of their parent carers, if they are to ensure that their experience of health services are as positive as possible. We have sought the views of parent carers who use health services extensively in order to create this report which we hope will help to improve the efficiency and quality of the health services from the perspective of children with disabilities and special needs. For instance, children with disabilities and complex health needs and their families may have used A&E services at all times of the day or night and can provide expert views on what could be improved more than the occasional users. We hope that by addressing the concerns of parent carers, the following outcomes could be achieved:

- More efficient use and targeting of scarce health resources
- Improved quality and 'fit' of service
- Greater user satisfaction with services and fewer complaints

### c. Key Recommendations

See the report below for our full lists of recommendations but the top three key areas that we urge further attention and investment in order to improve the lives of disabled children and young people and to assist them to fulfil their potential are:

- Further improving Parent Participation

The parent carer voice needs to be represented at the highest level in order to ensure that services are as good as they can be for disabled children and their families. The Care Quality Commission's (CQC's) review of services for disabled children [see below] showed that there were few care plans across Sussex with little information about waiting time for therapies but that Brighton and Hove was the only area with "adequate involvement of children and families in assessments, inductions and training". This is very positive and can be built upon. The voice of parent carers needs representation on the new Health and Wellbeing Board, Children's

Committee and Clinical Commissioning Group's Children's Review Board. The PaCC needs increased financial support to ensure that it continues to carry out its vital participation work and reach new, further marginalised groups of parents in the city. We believe that Public Health should match the investment in PaCC that the PCT/CCG makes in order to continue this very valuable work, and that the new CCG should continue this funding at a higher level, if possible, to reach families who face multiple disadvantage and face health inequalities. There needs to be better evaluation of health services. Parent Carer feedback could be standardised across all health service using a standard form. Health services should invite parent carers in to 'evaluate' their services using the Partnership Charter [see appendix 1]. CAMHS has already asked to do this and this should form part of a wider 'parent review' of CAMHS.

- Increased resource for services

The need for increased community support is a strong theme throughout health services. A specialist paediatric epilepsy nurse would be cost effective in the long run, reducing stays in hospital and greatly reducing stress levels in family members looking after children with very complex epilepsy. The community nursing team is under resourced, and there are only two specialist health visitors, who provide vital 'early' support. Also, the disability liaison nurses in adult services are making a huge difference to the experience of adults with learning difficulties in hospital. The same post for paediatrics would greatly improve the experience of young people and their families in hospital. This would reduce complaints and even reduce hospital stays as this valuable professional can give advice over the phone too. Many parents play a 'keyworker' role in their child's health care and this should be recognised and supported with increased access to resilience training (Insiders' Guide offered by Amaze). For those families who do not feel able to play this role, a keyworker is needed and this will become even more vital with the implementation of the new single Education, Health and Care Plan.

- Improved communication and transparency

It is frustrating to see that after 5 years of review, access to therapies is still a huge problem for many children and waiting times are still unacceptably long. There needs to be a citywide code of practice for GPs and young people in transition. Parent journey training (taken up by some professionals) should be made mandatory for all professionals, including consultants. This would greatly improve communication between health professionals and families and reduce complaints. Communication needs to be improved between the multitude of health professionals involved in children and young people's lives. Parent carers should be routinely copied in to any correspondence about their young person and should be routinely given details of eligibility criteria and waiting times.

## 2. Focus on Health: Why Now?

### a. Increasing levels of disability and complex health needs

Nationally, we have seen a marked increase in the number of children with disabilities and complex health needs, due to the increased survival of pre-term babies, children making a better recovery from severe trauma and illness and an increase in children on the autistic spectrum and with mental health issues. This trend is reflected locally.

### b. Child Poverty & Health Inequalities

There is a well-documented link between disability and poverty. It costs 3 times more to bring up a disabled child than a non-disabled one and over half of all families with disabled children are living in (or on the edge of) poverty. [Appendix 2 shows the membership of the City's Disability Register, The Compass, by ward].

In Education, there is a City-wide, strategic drive to 'narrow the gap in attainment' between children in schools with Special Educational Needs (SEN) and we believe there should be a focus on reducing health inequalities (as far as possible) in this population. It is known that inequalities exist for adults with learning disabilities, as underlined by Mencap's report Death By Indifference (which highlighted cases of undiagnosed illness and even avoidable death). A new Children and Families Bill will set in place provisions to allow families with a single Education, Health and Care Plan access to a personal budget by March 2014. If successful, we believe the single planning aspect will provide an opportunity to see a more joined up approach.

PaCC representatives have been significantly involved to date in the SE7 Pathfinder looking into some of these new ways of working. It is still unclear how planning for health outcomes will be incorporated and whether any elements of health budgets will be passed to the family to direct. What is clear is that it is parent carers are provided with sufficient support in any new system to ensure the family get the desired benefits in terms of increased feelings of choice and decision making/buying power.

### c. New Health Bill

The PaCC aims to represent the views of local parent carer in the areas that really matter to them and their children. During 2010-11 we reported on parent carer views on education at a time when SEN (special educational needs) was going through huge change and reform (and this work is ongoing). The same is now happening within health, with the biggest changes in the system for 60 years.

We want to ensure that disabled children's very unique needs are prioritised within this, not only at a national level, but also locally in Brighton & Hove. Amaze and the PaCC have fed into the Children's and Young People's Health Outcomes Forum, co-ordinated by the Council for Disabled Children.

Our focus on health has also been timed to coincide with the establishment of the City's Clinical Commissioning Group (CCG) and the movement of Public Health back into the local authority and we hope to present our findings to these Commissioners and feed into the City's Joint Strategic Needs Assessment (JSNA) and new Health and Well-Being Board

### d. The evolution of parent participation

Parent Partnership working is evolving in a really exciting way in the City, in some areas resulting in true co-production and this must certainly be the way forward. When parents and professionals work together, from the earliest stages of service design, outcomes improve for disabled children. We need to ensure that the voice of parents of disabled children is heard at every level and this is starting to happen in Brighton & Hove because key people operating at a strategic level are working closely with parent carers.

Parent carers are represented on the city's key decision-making boards including the Disabled Children's Strategic Partnership Board, the CAMHS Partnership Board, the SEN Partnership Board and the Learning Disability Partnership Board. They are involved from the outset on the development of information for families about local services for children with disabilities. Parent carers are also now being included on interview panels for key health professionals such as occupational therapists, speech and language therapists and nurse consultants.

In fact, Brighton & Hove is by national standards, well advanced in parent partnership work. Last year saw the launch of the Partnership Charter, a ground-breaking piece of work based on the principals of Aiming High for Disabled Children where teams of trained parent carers 'assess' local services. [see Partnership Charter in Appendix 1].

Although locally, parent partnership has come a long way as with many things, some services and individual professionals are doing this better than others. We hope this report will set out some of the good practice that is occurring in health and highlight where this can improve.

### 3. Methodology and Report Structure

This report has been written to capture a snapshot of parent carers' views of local health services. Given the number of different health services families with disabled children make use of, the PaCC Steering Group decided to prioritise discussion about just four. These are:

- The Royal Alexandra Children's Hospital (RACH)
- Seaside View Child Development Centre (Seaside View)
- Child And Adolescent Mental Health Services (CAMHS)
- General Practitioners (GPs)

At the event we did ask parent carers their views on community health services. However many of the comments that parents made were about community services provided by RACH and Seaside View and therefore we have decided to incorporate these views in to the relevant sections.

We asked parent carers to feed into this report in a number of ways:

- The PaCC held a 'Talk Health' event [in March 2012] providing parent carers with the opportunity to discuss the four areas above, with a senior professional from each service area in attendance to listen to their feedback. [Appendix 3 lists the professionals who attended.]
- The Amaze Health Information Fair took place in November 2011 as a launch event to our focus on health and providing parents and practitioners to come together and share information. A focus group was facilitated to allow parents to discuss 'communication with healthcare providers'.
- The Amaze Parent Carer Survey circulated via the Amaze newsletter to 1200 families. 114 responses returned.
- In addition, we carried out telephone interviews with a further 30 parent carers and asked for feedback on the PaCC Facebook group, which has a current membership of 50 parents.

As such, this report is the result of PaCC talking face to face to over 50 local parent carers about their experiences of local health services as well as email, Facebook and survey results from 164 parents. Our hope is this report will clearly present a picture of the common experiences which families with disabled children face when using healthcare services in Brighton and Hove.

We aim to table this report at the newly established Health & Well-Being Board and the new Health & Wellbeing Overview and Scrutiny Committee, among other key strategic meetings in the City. Our purpose is to facilitate discussion and raise the agenda of improving health services and ultimately the health outcomes for this disadvantaged group of children and their parent carers.

## 4. Parent Carer Findings

This is a snapshot of parent carer experiences in Brighton & Hove. It aims to represent the wider local experiences of health services that families encounter on a daily basis.

### a) The Royal Alex Children's Hospital (RACH)

#### Positive findings

- The hospital

Parent carers acknowledged that the new RACH was a fantastic resource to have on your doorstep, without having to travel out of area. The new children's A&E department was really well received by parent carers and many recalled the 'horror stories' of taking their child to the adult A&E. The triage system worked well and mainly the feedback about communication and understanding of disabled children's needs was good.

- Community services linked to the hospital

Parent carers told us that community support was good, but would like to see the service expanded. Parent carers were very positive about the community nursing team which provided excellent support to parent carers in their homes teaching them to care for nasal gastric tubes or gastrostomies. Parent Carers described them as "well briefed" with a "good understanding" of their child's condition.

- Departments providing an exceptional service

Phlebotomy services came out as particularly strong in the way they interact with disabled children. This was reported by several parents who also noted that the service had "really improved" over recent years. There is also regular paediatric first aid training offered for parents free of charge and this has been offered on a 'bespoke' basis for one family who have a child at risk of choking and having breathing difficulties. This is really exemplary.

#### Areas for improvement

- Parents were left unsupported prior to diagnosis

Often children with disabilities need to be monitored for long periods of time before they get any firm 'diagnosis' or plan of action. Parent carers understand this need to 'wait and observe' approach but felt that some sort of early support while they are waiting would have been ideal.

- Communication between different professionals was often poor

Disabled children have many assessments carried out by a myriad of different professionals. Communication between them could sometimes be improved.

Communication also needed to be strengthened between RACH and Seaside View and parent carers reported a 'disconnect' between specialists at Seaside View and, particularly, reports of A&E visits or unplanned admissions at RACH. Many of the children were treated in specialist units in London and communication could break down between these specialist London hospitals and RACH. One parent reported that having been transferred from Kings College Hospital in London to the RACH, they were approached by a member of staff who asked them "why they were there". The parent became quite agitated before a plan of action was drawn up.

- Parent Carers had to repeat their 'story; over and over (and over) again

Parent carers told us that this can be really irksome. Some noted that taking their child's 'most recent letter' helps but even this didn't totally prevent the repetitive process. The Disabled Children's Acute & Community Liaison Group is looking in to improving this experience by producing an All About Me document that would be carried with the disabled child and their family. This gives basic information about diagnosis, medication and communication methods etc. Hopefully this will help to improve the in-hospital experience of families of disabled children. This is not a 'local' problem but a national one and has been noted in the Kennedy Report.

"My son is on the autistic spectrum and is very anxious. They had really thought through the whole experience. They had an extra member of staff to help and had his favourite DVD poised to play as they took the blood."

"My little girl had a very traumatic birth but despite the fact that her EEG showed abnormalities we were left to 'watch and wait'. We went up to the main hospital and she was 'observed' by junior doctors but nothing seemed to be moving. We found it very difficult to get in to the process, despite the fact that I, as her mother, knew something was wrong."



"I feel that the liaison between consultants at the hospital and professionals at Seaside View is not strong enough. My son has severe seizures and cerebral palsy and when we arrived at hospital, they said that did not know him and could not advise. We had to tell our story again from the beginning. It was if the consultant we were talking to knew nothing about children who attended Seaside View."

"They just don't have time to talk, or to listen"

"The consultant presumed that my son has no understanding of language, because he is wheelchair bound and has a progressive disorder. He started to talk about 'end of life' options in front of him! I was absolutely horrified."

"We were given the first appointment, only for the consultant to be late. He sauntered in 30 minutes late, as my child finished dismantling the over-stimulating waiting room."

"My son hated being on a mixed age ward. No adjustment was made for different ages - in terms of waking times etc... It wasn't an appropriate environment for a teenager."

- Nursing could be inconsistent.

Parent carers reported examples of outstanding practice. They reported that some nurses had extensive experience of working with children with disabilities and special needs. For instance, one child was looked after by a nurse who had worked at a local children's hospice.

However, there were also examples of inconsistent practice. Parent carers told us about nurses who appeared to lack basic disability awareness training, had little understanding of parent carer experiences in hospital and the demands this placed on them. This meant that even to make a simple trip to the toilets had to be planned to ensure that their child was not left unattended, even for a minute. Staff were not always proactive at offering this help and only did so when they were asked. Some staff gave confusing and conflicting advice about specialist equipment and had a 'rushed' approach to parents.

Parents overwhelmingly felt that they were the 'experts' on their child's care and that without them, many nurses would not know how to effectively care for their disabled child. Several parents reported that the lack of a paediatric neurologist on site was difficult when a child with complex epilepsy presented in A&E in 'status epileptics'.

- Consultants can lack sensitivity and make judgements about children with disabilities.

Parent carers reported that some consultants could be patronising or distant. Often there were several students in the room "who were not introduced to me or my child". Some interactions with consultants had lasting and devastating effects. One new mother was told to put her newborn baby down in the cot while she was told 'what was wrong with her'. One family were treated with a lack of empathy and told that "their daughter had half a brain" with no appropriate explanation or a caring delivery of such devastating news.

- Waiting times.

Consultants did not automatically put children, with special needs, first on the list so children who found it difficult to wait had to wait for long periods of time. This was improving, but consultants needed to be mindful that they needed to start their clinics on time, where possible.

- Parking facilities are unacceptably poor

There is one disabled bay at the Children's Hospital. All the parent carers were dismayed by the parking facilities. There were bays in the car park but most of the time, there was such a long queue (often a waiting time of half an hour or more). This was very stressful for families who had a child with special needs. The on road parking nearby was on a hill and parent carers reported "struggling" up and down hills with a wheelchair or a child who was unwilling to walk. One parent carer reported that the experience was so stressful for her child, who is on the autistic spectrum, that her son started to "head bang and hit us" before they had even made it to A&E.

- Mixed Wards and Transition anxiety

Teenagers with a learning disability were placed on a 'mixed age' ward and while difficult for any teenager, this was particularly difficult for a teenager with a disability or special need.

Parents reported a general anxiety about the transfer to adult services, particularly if they had not had a brilliant experience at the children's hospital.

### Parent Carers' Recommendations about RACH

- Parking

Priority should be given in the car park to those with a disabled badge allowing them to queue jump as the bays are there but parents can't get to them and more bays that are currently for 'drop off' freed up for 'disabled badge' holders only. The parking situation frequently puts a visit to hospital off to a really bad start. This could easily be solved.

“I cannot think how my son [now 14] could manage being in a mainstream adult ward in hospital! We need to know he will be catered for and supported in adult services by making available specialist 1:1/2:1 staff to be with him on the wards, appropriate medication/equipment with a single room, giant cot/portable safespace, sedation etc.”

“CAMHS has really taken on board everything that has been said by parents and their stories all correlate with each other. So hopefully we will see some improvements.”

“We had to wait nearly a year to be seen and they also said they would review my son [once seen for the first time] and this hasn't happened. You can only be seen by a specialist in ASC if you have a statement.”

- Parent carer involvement in regular groups

Since the PaCC health event, a PaCC representative is now on the Disabled Children's Acute & Community Liaison Group (a group that aims to improve the experience of disabled children and their families at RACH and also the links with community health services) but parent carers want a wider consultation group and opportunity for senior managers to listen to their concerns.

- Parent journey training for all

Parent journey training should be part of the standard induction for RACH staff and should include consultants, doctors and nurses working at RACH. Amaze offers training workshops, delivered by parent carers, which cover the parent carer journey. We could also develop a protocol on how to treat parent carers differently when they arrive at RACH, in partnership with staff there.

- 'All About Me' Documents

Since holding the health event, it has emerged that this is an area that is being looked at. Although this is a great idea in principal, professionals need to think carefully about who holds this document and how several copies need to be kept updated (in settings such as school, respite home, GP and family). There needs to be a really clear explanation of the difference between these and the 'passports', traditionally used by the main hospital. Many parents will need help filling these in. There needs to be thought about how these documents will change/be modified during transition.

- Disabled children given priority

Disabled children should routinely be put first on the list and where possible consultants should ensure that they arrive on time for clinics especially when the first appointment is for a child with special needs. There needs to be some liaison to ensure that as many appointments as possible are on the same day so that parent carers aren't having to repeat the trauma of a hospital visit unnecessarily.

- Specialist disability liaison nurses

This would be the ideal. There isn't a paediatric 'disability' specialist available and it is 'hit and miss' whether you get a nurse with any real experience. A specialist nurse could train up nurse teams on ethos and approach and ensure consistency. For instance, Kings College Hospital employ a Nurse Patient Liaison Officer that parents can contact at any time. She is able to give direct advice over the phone or contact another professional for advice if required. This has meant that unnecessary trips to London have been avoided because parents can be reassured over the phone.

## **b) CAMHS**

### **Positive findings**

- New Parent Group

The service is listening to parent carer concerns and is keen to develop its partnership working with parents to improve the service.

- Specialist Nurses offer home visits

Several parent carers reported a really positive experience with the specialist CAMHS nurses. One said that she felt "supported and understood" and that really useful, practical help was given with daily challenges, such as going on a simple shopping trip.

### **Areas For Improvement**

Out of all our local health services, parent carers report that CAMHS is the hardest to access and the most difficult to negotiate.

- The waiting time for an assessment is too long (and no support is given in the meantime).

Parent carers reported being "stuck in the system" and "left to it". Guidance for parents as to how to deal with

This story, from a mother who has a son with mental health problems, is typical.

“I have a child with mental health problems. CAMHS? Where can I begin? It takes far too long from point of referral to actually seeing someone, even if your child is really quite poorly. They take stance of it being a family problem as opposed to a medical one or with the child. I have found psychiatrists quite arrogant and often not up to date with the latest developments. I had to make formal complaint and see a third psychiatrist from another county before got anywhere. This psychiatrist said that that my son should have had a proper care plan from the outset. It is the most stressful and exhausting experience I have ever encountered.”

their children at home whilst waiting to be seen by the consultant was not forthcoming and parents felt that time was wasted.

- Parents were not empowered or treated as equals in their child's care and reported that they felt their confidence had been eroded

Many parents reported a feeling of 'disempowerment' when engaging with CAMHS. Several parents described feeling as if professionals felt they were to 'blame' for their child's autistic spectrum disorder. Parents were universal in their criticism. Several parents reported turning to voluntary organisations, such as Amaze and Ayme (Action for Young People with ME) as they were not getting a quality service from CAMHS.

- Transparency was poor

Parent carers reported that there was little transparency on how to access the CAMHS system, and how it works once you are in. Also, this feeling of a lack of transparency was exacerbated by the use of 'psychiatrist's' language and lingo that parent carers did not understand.

### Parent Carer's Recommendations about CAMHS

- Better information (about what CAMHS does and who is and isn't eligible for input and the different sections of CAMHS). Parent carers need to be involved in the creation of this information from the outset.

- User satisfaction survey to be sent out (as agreed by the Children's Overview and Scrutiny Committee last Autumn) and results analysed and presented back to the Disabled Children's Partnership Board and Health and Well-Being Board.

- Transparency about pathways of care and waiting times.

- Training for psychiatrists in the parent journey. There needs to be an ethos change so that parents are seen as the experts in their child's care. This was a very powerfully voiced recommendation from parent carers who said that psychiatrists (some of whom were very newly qualified) made them feel "patronised".

- Autism specialist needed.

- Behaviour network for children with severe behavioural difficulties set up. This would provide much needed support for families who are struggling with behavioural issues, allowing them to support each other as well as get professional input.

#### c) Seaside View Child Development Centre (Seaside View)

The relatively new integrated child development service has been well received by parents and this is a huge strength in Brighton & Hove, compared to other areas which do not have integrated services. Parents reported a feeling of 'joined up' care and really good liaison between different professionals.

### Positive findings

- The coordination and communication between professionals at Seaside View was very good. This was universally reported by parent carers. One talked of the new 'invitation to join', which meant a key Seaside View professional was able to refer you to a new service, without having to get the parent to revisit their story from the beginning again. Seaside View was also working really well with outside agencies (one parent carer reported that the therapists worked really well together at her child's mainstream school). Parent carers also reported the excellent service by the receptionists who always passed messages on efficiently. They were also very welcoming to families and included the children and young people when they visited the unit.

- Personable and approachable staff

One parent carer reported that her child on the autistic spectrum was very anxious about her visit to the

“When giving the diagnosis (of a rare chromosome disorder) we felt they could tell us very little but surely they could have referred us to Unique or even used it themselves to download information?”

occupational therapist but viewed it as a very positive experience. She was very understanding and had a real grasp of her child's difficulties.

- Excellent team of paediatricians

All the parent carers gave positive feedback about paediatricians who they described as 'knowledgeable' and 'empathic'. Many parents described their paediatricians as 'going the extra mile'. Almost all parent carers reported that they were "treated as equals" in their child's care.

- Keyworkers and Specialist Health Visitors

The new team of keyworkers was well received by parent carers. However they were a very small team (of two) so many families (who have multiple professionals involved with their child) were left without a keyworker. This will become even more resonant, with all the changes proposed by the SEN green paper and there will need to be very careful consideration as to how families are supported. Parent carers were universally positive about the small team of specialist health visitors at Seaside View but as it is only a team of two, it is limited.

### Areas For Improvement

- Waiting time transparency

One parent reported their child had been referred two years ago and was still waiting for an appointment. Another parent carer reported that her child was referred every two to three years and was still waiting for an OT appointment. Her child was now due to start secondary school in September. Eligibility for Seaside View services and how children are prioritised needs to be clearer.

- Better signposting

Parent carers reported that, on the whole, professionals at Seaside View were very good at pointing them in the direction of Amaze of further help/advice. However it was felt that this could be improved. Parent carers felt it would be helpful if Seaside View staff could have signposted them to national support services as well and would have preferred a professional steer rather than "scaring myself on the internet."

- Equipment

This was a widespread problem. Parent carers reported huge delays in equipment (a 6 month wait for a sling/slide, for example). They also reported a lack of highly specialised equipment. The waiting time could be so long, that by the time the specialist equipment arrived the child had outgrown it. This is a particular problem at transition, too. There is confusion over who has responsibility to provide/replace/monitor equipment once a young person reaches 19.

- Therapies

Significant problems still existed with the provision of therapies. The PaCC and Amaze produced a report, "More Therapies", four years ago see [http://www.amazebrighton.org.uk/editorial.asp?page\\_id=253](http://www.amazebrighton.org.uk/editorial.asp?page_id=253) and whilst there had been some improvements with improved information about the services provided many of the problems identified in that report had still not been resolved. There was a perceived lack of parity about who was eligible for therapy and how much input they got as well as serious concerns about waiting list times for referrals as well as appointments.

Waiting times from referral to treatment were above the national average in 2011 for occupational therapy and physiotherapy see Care Quality Commission's review of Support for Families of Disabled Children see: [http://www.cqc.org.uk/sites/default/files/media/reports/20092010\\_Support\\_for\\_families\\_with\\_disabled\\_children\\_BrightonandHoveCityPCT.pdf](http://www.cqc.org.uk/sites/default/files/media/reports/20092010_Support_for_families_with_disabled_children_BrightonandHoveCityPCT.pdf)

In particular, parents reported some children were receiving speech and language therapy (SALT) once or twice a year and others got SALT in intensive blocks of weekly provision for a set number of weeks. Parent carers reported finding it very difficult to get sufficient physiotherapy and OT input, even if it was on their child's statement as services were 'overstretched'. One parent reported that it was not clear how occupational

therapy was broken down. One family was told they could not get any 'sensory integration' input for their child and it was only when they complained that this was provided. Some parents reported a high staff turnover within the physiotherapy team had led to inconsistency of provision. Some parent carers were buying in private services to supplement what they get. Parents also report that therapy input appears to be reducing in schools and there is confusion as to whose responsibility this is. Also, there needs to be better planning for therapy provision once young people reach transition. Parent carers report that often families have "no idea" what is going to happen next or who is responsible for next steps. There are problems within Speech and Language therapy services as adult services use a different set of symbols to the Makaton symbols young people are used to and need to embrace the continuing use of VOCAS (Voice Output Communication Aids).

We have been provided with the current (July'12) waiting times for therapy services and some of these still seem unacceptably long:

Speech and Language Therapy	referral to first assessment 6 weeks	referral to first treatment 8 weeks	
Physio	urgent/semi-urgent 4-8 weeks	non-urgent 52 weeks	
Health OT	pre school children with complex needs as part of a multi-disciplinary assessment 10-12 weeks	School age children as part of a multi-disciplinary assessment 22-26 weeks	
	pre school children with complex needs 12-18 weeks	School age children 52 weeks	
Social Care OT	urgent needs 5-10 days	High priority 10-20 days	Chronological order of referral 9-12 months

### Parent Carers' Recommendations about Seaside View

- Therapy Assistants

Following the More Therapies report several years ago, the local authority carried out a review by an external consultant. One of her recommendations was to introduce therapy assistants. Whilst parents would rather have fully qualified therapists working with their children, there is acceptance that this is unlikely to happen given the current lack of additional funding. In this climate, we would welcome a renewed discussion on how therapy assistants could supplement the work of fully trained therapists – providing guidance to TAs and parents about how they can help their children in between appointments.

- Transparency about waiting times and eligibility

There needs to be a coherent system (across therapy services) telling parent carers who is eligible for what and why and what estimated waiting times are. Parent carers need useful advice in the form of advice sheets/parent groups (such as the Hanen Programme which was run at the child development centre in the past) to help them feel 'skilled up' to help their child in the interim period.

- Information at Seaside View is good but could be better.

Professionals need to ensure that they have the very latest information on different conditions and that they can always signpost parents to other areas of support. Whether this is locally (Amaze or local parent groups such as Pebbles or Sweet Peas) or nationally (websites, support groups such as Unique, for children with a rare condition or Swan, for children with an undiagnosed condition). We understand the Council and Amaze are undertaking a joint project to improve web based information for parents which might help to resolve some this

“OT is particularly hard to get. My child has cerebral palsy and severe epilepsy and we still struggle to get any advice about what do at home. The only service we get is that they advise school on a termly basis. We have sourced and paid for all our equipment apart from his commode. We would benefit from advice on exercises that would help with my son's self help skills but this service has been overstretched and understaffed for as long as I can remember. There seems to be a real inequality in this service”

situation but it needs to be recognised that not everyone has access to the internet. Information needs to also be produced in hard format.

#### **d) GPs**

Research carried out by Contact a Family shows that 75 per cent of families with disabled children do not visit their GP about their condition. The relationship between families with a disabled child and their GP is particularly vital on many fronts particularly as children's care is transferred to their GP at 18. GPs knowledge base is understandably wide and their in depth knowledge about specific medical conditions can be limited. For children who have learning difficulties and/or other medical needs but are not eligible for a paediatrician, the GP is absolutely the key medical figure in that child's life.

#### **Positive findings**

- Innovative local solutions

Parent carers reported that some GPs offered services that were making a real difference to families. Such services included an Online booking appointment system for GPs, a drop in clinic for children, a separate room organised for child with challenging behaviour, 'telephone' appointments and home visits.

- GPs see the family as a whole

Parent carers reported that their GP was very holistic, seeing the family as a whole and gave 'carers' support. Families reported being regularly asked how 'their' health was as the main parent carer. GPs also got involved in much needed referrals for respite. Parent carers reported GPs asking if they got enough respite and if they could write letters to support their access to more help.

- Some GPs are taking annual health checks seriously

All adults and young people in transition will have to have annual health check and some GPs are ahead of the game on this. One parent carer reported that her daughter had already had a health check at 14. It is hoped that health checks will pick up health problems that may have gone unnoticed or undiagnosed.

#### **Areas for Improvement**

- GPs sometimes lacked knowledge about specialist services

Parent carers reported having to 'fight' to be referred to specialists or that GPs knew nothing about the variety of specialist services which might be available. Parent carers may find visiting their GP so stressful and demoralising that they avoided taking their young person to their GP. This sometimes resulted in a child becoming very ill before their parent accessed medical health. Some parent carers reported going to A&E as an alternative.

- Prescription errors

Parent carers reported incidences where the GP had written a prescription for their child which was inaccurate. Medication and dosages had been changed by specialist consultants who had not communicated this change to the GP. There seemed to be an understanding that parent carers would update the GP which was felt inappropriate. One parent carer reported that her GP was brilliant at double checking medication but that the labels on the bottles of medicine were often out of date and inaccurate.

- Inconsistency across the city

Whilst some parent carers reported that they had a very good relationship with their GP, others find it problematic. One parent reported that her son, who was on the autistic spectrum, did not have a community paediatrician and that she only took him to the GP if he was 'really ill' as he had little understanding of her son's complex needs. Also, out of hours doctors didn't always know the family history and needed to ensure that they respect the views of parent carers. When visiting the surgery, parents reported differing experiences of their initial contact with reception staff. There was a lack of understanding and, as one parent put it a "can't do" attitude.

"My son has a very complex health problem. Our GP knows him really well. But the problem is when you see a locum GP out of hours. Our son needs antibiotics at the first sign of a chest infection as, otherwise, it can turn into a life threatening problem and he ends up in hospital for weeks needing suction. A locum GP told us that he was not 'ill' enough for antibiotics."

“My GP is very helpful but there is little recognition of the emotional and mental problems that go with a disability, both for the young person and the parent. Also, appointment times are too short when your child has such complex difficulties. GPs need improve how they signpost to other agencies”

“I am hugely worried about transferring care to the GP. My son is unable to wait in a waiting room, there is no disabled parking at my GP and he has not specialist knowledge of learning disability. One parent I know had an awful experience when her child had to stay in the car, as they were restrained, in order to be seen by their GP.”

- Some GPs do not 'take care' of the whole family

Many GPs do not realise that they have a statutory responsibility for the health of parent carers.

When young people reach 18 the main professional becomes the GP. In the lead up to this, if families and young people have not built up a relationship with their GP this transition is problematic because the GP does not always have enough understanding and knowledge about their complex medical condition. This did not give families confidence in the GP's ability to look after their young person. Challenges were also faced by parents whose children were 16 and had learning difficulties. They were not able to take responsibility for their own health needs and parents found that professionals who lacked knowledge in this area were asking them to do things they were not allowed to do.

### Parent Carer Recommendations about GPs

- A route map of services that will give GPs information and points of referral to specialist services when a parent goes to them for a consultation. This information also needs to be given to the parent so that they have a clear idea of possible wider medical concerns. Information could be provided by Amaze.

- Disabled children need to be prioritised

Waiting times should be reduced. Disabled parking bays need to be provided routinely outside GP surgeries. If access is not possible, then provision needs to be made for disabled patients to park in the private GP car park.

- Home visits given routinely to children with disabilities and SEN who find it difficult to successfully visit the surgery. More thought must be given to out of hours GP services to allow families that have difficulty accessing the services during the day time to go to the GP when the surgery is also less busy.

- Training for GPs and families on power of attorney/mental capacity act so that families are clear about their responsibilities and GPs do not put families in a difficult position by asking them to make decisions for their young person that they have no power to act on in the eyes of the law. GPs also need to be given the parent journey training alongside other professional so that they can empathise with families who have a caring role.

- A holistic approach needed by all GPs.

They have a duty to look after parent carers too and should routinely look at their health/coping capacity. GPs should produce a protocol to ensure that the needs of the wider family are taken in to consideration when a young person visits the GP.

- Transparency and communication

Eligibility for referrals needs to be clearly explained to parents. All communication from specialist consultants should be routinely copied to parents and the child's GP. There needs to be really careful monitoring of medication and communication between the parent, GP and the pharmacist. This is particularly pertinent when new medications are introduced or doses are changed. GPs, pharmacists and specialist consultants need to routinely review the medication and ensure all labels are up to date and accurate. Many children receive respite care in other settings and inaccurate labelling could lead to medication errors resulting in serious harm. Information stored in the All About Me document needs to be transferred so that it includes the out of hours service provided by the GP.

- Health reforms- need a parent voice

The new CCG is currently consulting on how to engage patient populations and are keen to develop Patient Participation Groups (PPGs) at GP practice level. Amaze has fed into this consultation that it is very unlikely PPGs will be accessible to parent carers so there needs to be other attempts made to hear their voices. We suggest Amaze and the PaCC can represent parent carer views on a city-wide basis and we should be invited onto key strategic decision making groups where possible to present these views and be influential at service design.

• Extend examples of good practice that are making a real difference to all GP surgeries.  
Code of practice for disabled children and their families to be disseminated throughout.

• GPs who are responsible for a child with a learning difficulty or other special need that do not have a specialist paediatrician, need extra support and training.

They are the key person and need to be supported to fulfil this role. This group should be earmarked and liaise with each other and access specialist training (e.g.: training on the autistic spectrum, how children with communication difficulties express pain and so on...). This could be done through the Nurse Consultant at RACH.



## 5. Conclusions and Parent Carer's Key Recommendations

So what are the priorities for parents? Often, it is not blue sky stuff, such as a magical cure or revolutionary new treatment, but the less measurable, subtler nuances of care. Parents, who are at the coal face after all, experience the care, rather than live it. It is an emotional journey that is their daily life.

### a) Parent Participation

i. A seat for parent carer (PaCC) representatives on the new Health And Wellbeing Board, Children's Committee, and Clinical Commissioning Group's Children's Review Board. The parent carer voice needs to be represented at the highest level in order to work in partnership to drive improvement in health services for the most vulnerable children in our local community. This is a vital starting point.

ii. Recognise the value of parent participation and partnership working and invest in it  
As mentioned earlier in the report, the PaCC (receives some funding for its engagement activity via the PCT (now emerging CCG) but this contract will expire at the end of March'13. It is vital that the CCG can replace and if possible increase this funding so that this group of disadvantaged children can be well represented by their parent carers.

Indeed we are keen to reach more families who are not currently engaged with the work of PaCC and Amaze to improve our ability to represent the full diversity of needs across the City, but additional funding is required to do so. We believe Public Health should match the investment in the PaCC that the PCT/CCG makes in order for us to help them in their target to reduce health inequalities for this group further.

iii. Recognise and value the parent carers' role as child's keyworker in health care provision  
Our comments come from our proven expertise of being the 'key worker' and deliverers of health care, therapies, education and emotional care to our children 24/7, 365 days a year, for their childhood, through their adolescence and often for many decades of their adult lives.

Navigating the health care system is not a skill that parents of disabled children are born with. It is one that they have to learn 'on the job' (a job they did not apply for...). They find that, not only do they need to adjust to new parenthood but they need to adjust to their role as a 'parent carer'. Parents describe themselves as having to be multi-skilled and have almost super human powers of resilience.

iv. CAMHS Parent Carer review  
Parent carers need to work in partnership with CAMHS to review transparency and communication across the service at all tiers.

v. Service evaluations and user satisfaction surveys  
It is good practice for 'customers' to be asked what they thought about a particular service and all health services should be asking for feedback as a matter of course. A standardised form could be developed and then rolled out across all services, including health. These would need to be allowed to be completed anonymously and sent into a centralised research team and results presented to the new Health and Well-Being board.

In addition, all the health services discussed here should be encouraged to invite pairs of parent carers to independently assess their service using the Partnership Charter. CAMHS has already asked and is due to be evaluated in the autumn of 2012. The (0-3) star ratings should also be made public and presented to the Health and Well-Being Board, Children's Committee and other key groups and communicated to families via the Amaze newsletter and most importantly by the service itself.

“I am my daughter’s nurse, her psychologist, her OT, her speech and language therapist, her gastroenterologist, her epilepsy specialist, her teacher, her advocate, her pharmacist, her PA... I am everything in my daughter’s world and it takes enormous amounts of energy and resilience to keep everything together. Sometimes, I just want to be her mummy.”

## **b) Increased resource for services**

### **i. Bolster Community Support**

Support in the community is very powerful, supports the principles of early intervention and is cost effective. For example, a specialist epilepsy nurse (which Brighton & Hove does not have in paediatrics) would give much needed support in the community. This would cut down visits to A&E, 999 calls, the input needed by community paediatricians and greatly reduce stress levels within families who have children with very complex epilepsy. The community nursing team gives invaluable support to children and keeps them out of hospital but they are under resourced and sometimes can't make it to families when needed. Specialist Health visitors are a key professional at the very early stages and offer vital 'early support' but there are only two of them and many children cannot access their help. We need more specialist nurses and specialist health visitors (with greater focus on disabled children) working in the community to support our most vulnerable families optimise their health chances.

### **ii. Paediatric Disability Liaison Post at the RACH**

Parents need somebody to liaise with over their child's stay in hospital. At the moment, the hospital experience is not consistent. Such a post would greatly improve the experience of children with disabilities and young people and their families. This would reduce complaints and reduce stress levels in already over stretched services.

### **iii. Where necessary parents should be allocated a key worker**

However, parents feel they are often expected to bring everything together, in a 'key worker' type role, and this is not always possible e.g. many parent carers might also have a disability or health concern of their own, there are other siblings to care for etc. Indeed, the ability of a parent carer to navigate all the health services their child needs, might be more or less do-able depending on where they are on their carer journey'.

As such, some parent carers are unable to take on this keyworker role and in some instances this is not appropriate. This will be even more necessary with the implementation of the new Single Plan.

### **iv. The need to invest in parent carers' resilience**

We also need to be very mindful of the health of the whole family. Families who have a child or young person with a disability or special need experience immense levels of stress. Research by Contact a Family reveals that 49 per cent of the parents surveyed had been to their GP about feelings of depression and isolation and received either medication or counselling. In Brighton & Hove, 52 per cent of all carers have been treated for stress related illness.

Many parent carers in the PaCC have attended the Amaze 'Looking After You' and 'Insiders' Guide – Building Resilience' 6 weeks courses which have been highly evaluated as invaluable by parent carers as they tackle feelings of isolation and provide techniques and strategies for dealing with everyday situations, asking for help and building their family's resilience. The PaCC would like to see these courses being built into the Amaze core funding so they can be offered to families each year, and delivered in 'harder to reach' neighbourhoods where families may be more at risk of crisis.

## **c) Improved Communication and Transparency**

### **i. Improved Communication about services, eligibility and waiting lists**

Parents would like to see improved communication between GPs, consultants, hospital departments and families. Parent carers would like to be routinely copied in to any correspondence written by these professionals. They would also like to be kept informed of the eligibility criteria for services provision and the length of waiting lists so that expectations of service delivery times can be realistic. Parent carers are still 'in the dark' across many services about who is and who isn't eligible and how long they will have to wait to receive a service. This needs to be urgently tackled so that there is absolute transparency for families from the outset. Greater transparency of the services provided will ultimately lead to increased confidence in the system and fewer complaints.

“As a Parent Carer, years are spent in an adrenalin-fuelled, ‘flight or fight’ mode. Life is truly a rollercoaster of emotion. I have seen many families break down under the stress of it all and most of my friends, who are parent carers, are on (or have been on) antidepressants and have regular counselling to cope with the immense pressures they face parenting their child.”

ii. Therapy waiting times

This is still a problem despite therapy services being the subject of the first PaCC report in 2009 and subsequent internal and external reviews following this. We need to reduce waiting times urgently and be transparent with families about why the waiting times are so long.

iii. Training opportunities extended to all staff in the health care profession

The PaCC would like to see the ‘Parent’s Journey’ adapted into mandatory training for all health care professionals working with children with disabilities and complex health needs. This will give professional a much better understanding of the context that being a parent carer has e.g. practical difficulties as well as emotional and physical demands. This would result in fewer complaints and much improved communication between the medical profession and families.

iv. GPs and transition

There needs to be a city wide code of good practice for GPs on disabled children’s transition. Too many GPs lack an understanding of their young people who have a disability or special need and this can be calamitous when they take over their ‘care’ at 18.

**Content provided by parent carers, compiled by:**

Amanda Mortensen – Chair of PaCC  
Debbie Collins – Amaze Parent Participation Officer  
Rachel Travers – Amaze CEO

July 2012



## Appendices

### Appendix 1

#### Partnership Charter Outline

The Parent Carer Partnership Charter comprises 4 staged elements, each the result from extensive consultation and each supported by full documentation. They are:-

- Partnership Standards short checklist
- Parent carer star assessments
- Partnership Standards full checklist
- Disabled Children Integrated Services action planning strategy

Under each of the core offer standards the Parent Carer Partnership Charter sets out delivery milestones in three categories; 'at basic stage', 'in development', and 'advanced' – to give clarity to local areas about what they need to do in order to meet the core offer standards. The milestones:

- 'at basic stage' will have been met by local areas just beginning to think about and plan services that deliver on the core offer.
- 'in development' will relate to local areas that have progressed further and have many of the necessary elements in place.
- 'advanced' will have been met by local areas who are fully delivering on the core offer standards, with families firmly at the heart of their service planning and delivery.

This document will continue to be updated as practice develops.

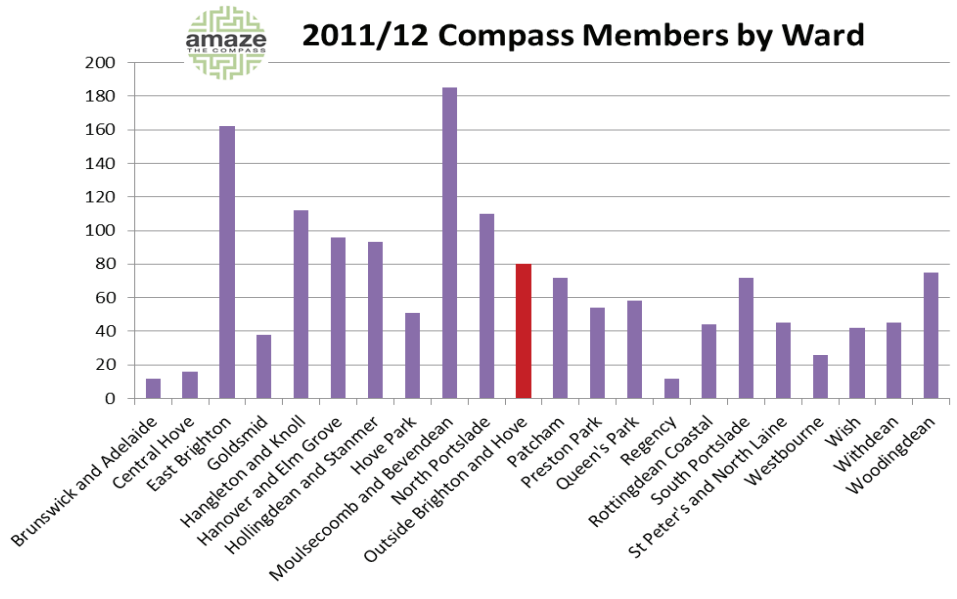
The aim is to provide a constructive vehicle for on-going improvement in quality of partnership working between families of disabled children and service providers across all sectors. The function of the Partnership Standards is to provide an agreed baseline of good practice in partnership working and offer a constructive framework for on-going service improvement.

#### Key Features and Characteristics

The key elements which we believe are integral to the Parent Carer Partnership Charter and which we believe define it as a product are:

- a. Defining and agreeing the standards and process in partnership with parents right from the start of the project
- b. Training up of parent ambassadors to carry out the assessments, with this role being paid for in line with the Amaze Parent Engagement Policy, recognising parents as equal professionals. The Parent Ambassadors are suitably supported, supervised and accountable.
- c. Positive assessment approach focussing on identified strengths as well as areas for development and allowing for the development of a relationship and dialogue between professionals and parents
- d. The assessment findings are published in a transparent way including an agreed plan of actions with commitment where improvements are needed

## Appendix 2



## Appendix 3

Key senior officers/professionals attending the 'Talk Health' event were:

### For RACH:

Janet Lee  
Linda Gilmour

### For CAMHS:

Tim Ojo  
Peter Joyce

### For Seaside View:

Jenny Brickell  
Sian Bennett  
Tracey Young

### For GPs:

Dr Xavier Nalletamby





**Amaze** provides information, advice and support for parents of children with special needs and disabilities in Brighton & Hove.

**The Parent Carers' Council** is the local forum and voice representing the views of parent carers on services their disabled children receive. It is supported by Amaze.

**information - advice - support - Parent participation**

# about Amaze and the PaCC

- Parent-led independent charity since 1997
- Mission - empowerment of parents and building their capacity and resilience
- Provide information, support and advice services to parents of disabled children e.g. 4,000 calls per annum to helpline (86% increase in 5 years)
- Manage city's disability register – The Compass – has in depth details of 1,800 children
- Support the PaCC – the local forum for parent carer, now 190 parent members and 7 partner organisations
- Parent representatives are supported to sit on 12+ strategic, partnership, decision making, boards and subgroups across the city
- Reports published:
  - More Therapies 2009
  - Education and Special Educational Needs 2010
  - Talk Health 2012



*“To be a good supporter of your child, you need great support yourself”.*





# Focus on health

- High cost, high incident users of health services
- A range of different health services are required including universal services, specialist services and condition specifics
- Services *must* actively seek the views of these young patients, and their parent carers, to ensure that their experience of health services are as positive as possible and achieve:
  - More efficient use and targeting of scarce health resources
  - Improved quality and ‘fit’ of service
  - Greater user satisfaction with services and fewer complaints
- Should be a focus on reducing health inequalities (as far as possible) in this population
- Feed into the City’s Joint Strategic Needs Assessment (JSNA) and new Health and Well-Being Board



*“I wouldn’t swap you for the world... except for when you wake up at midnight... 2.15am... 3.30am... 4am”*



# A Personal Story



# Talk Health – key findings

## 1) RACH +ve

**+ve:** RACH was a fantastic resource to have on doorstep, without having to travel out of area. New children’s A&E department very well received.

**+ve:** Very positive about the community nursing team

**+ve:** Departments providing an exceptional service



*“I was at crisis point when I found Amaze, support from this organisation has literally changed our lives, we owe them so much!”*



# Talk Health – key findings

## 1) RACH -ve

- ve: Monitored for long periods of time before any firm 'diagnosis'
- ve: Mixed wards and transition anxiety
- ve: Communication between different professionals was often poor
- ve: Have to repeat their 'story; over and over again
- ve: Some nurses lacked basic disability awareness or understanding of parent carer experiences in hospital
- ve: Some consultants could be patronising or distant



*"I was at crisis point when I found Amaze, support from this organisation has literally changed our lives, we owe them so much!"*



# Talk Health – key findings

## 1) RACH - suggestions

- ? Parking priority should be given to those with a disabled badge allowing them to queue jump
- ? Parent carer involvement in regular groups
- ? Parent journey training for all
- ? ‘All About Me’ Documents
- ? Disabled children given priority
- ? Specialist disability liaison nurses



*“I was at crisis point when I found Amaze, support from this organisation has literally changed our lives, we owe them so much!”*



# Talk Health – key findings

## 2) CAMHS +ve and -ve

**+ve:** The service is listening to parent carer concerns and is keen to develop its partnership working with parents to improve the service.

**-ve:** The waiting time for an assessment is too long (and no support is given in the meantime)

**-ve:** Parents were not empowered or treated as equals in their child's care

**-ve:** Transparency was poor



*“We spend a lot of time feeling as if we are in a parallel universe and that we’re on the outside of life looking in.”*



# Talk Health – key findings

## 2) CAMHS - suggestions

- ? Better information
- ? Extend the CYPOSC user satisfaction survey
- ? Transparency about pathways of care and waiting times.
- ? Training for psychiatrists in the parent journey
- ? Autism specialist needed
- ? Behaviour network for children with severe behavioural difficulties



*“We spend a lot of time feeling as if we are in a parallel universe and that we’re on the outside of life looking in.”*



# Talk Health – key findings

## 3) Seaside View +ve

- +ve:** The coordination and communication between professionals at Seaside View was very good
- +ve:** Personable and approachable staff
- +ve:** Excellent team of paediatricians
- +ve:** Keyworkers and Specialist Health Visitors



*“Being a parent to my child is an honour and a pleasure – although my child has turned my life upside down we wouldn’t have had it any other way.”*





# Talk Health – key findings

## 3) Seaside View -ve

**-ve:** Lack of transparency about waiting times

**-ve:** Could improve signposting

**-ve:** Huge delays in equipment

**-ve:** Significant problems still exist with the provision of therapies (communication, transparency, waiting times)



*“Being a parent to my child is an honour and a pleasure – although my child has turned my life upside down we wouldn’t have had it any other way.”*



# Talk Health – key findings

## 3) Seaside View - suggestions

- ? Trial innovative approaches to reduce waiting times e.g. Therapy Assistants
- ? Transparency about waiting times and eligibility and provision of exercises/advice whilst waiting
- ? Information at Seaside View is good but could be better



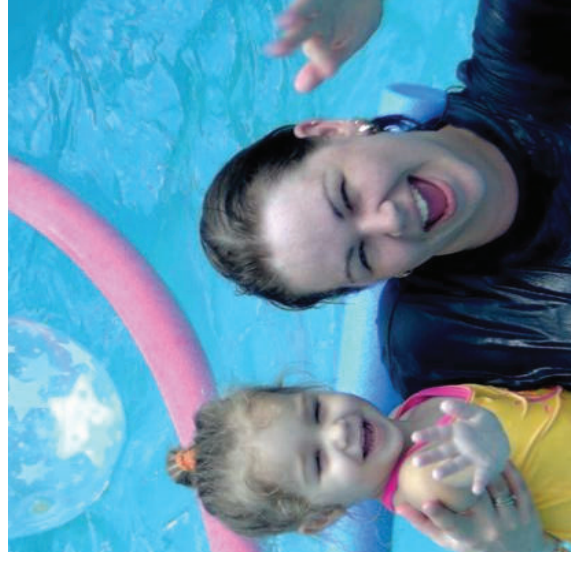
*“Being a parent to my child is an honour and a pleasure – although my child has turned my life upside down we wouldn’t have had it any other way.”*



# Talk Health – key findings

## 4) GPs +ve and -ve

- +ve:** Innovative local solutions
- +ve:** GPs see the family as a whole
- +ve:** Some GPs are taking annual health checks seriously
- ve:** GPs sometimes lacked knowledge about specialist services
- ve:** Prescription errors
- ve;** Inconsistency across the city
- ve;** Some GPs do not ‘take care’ of the whole family



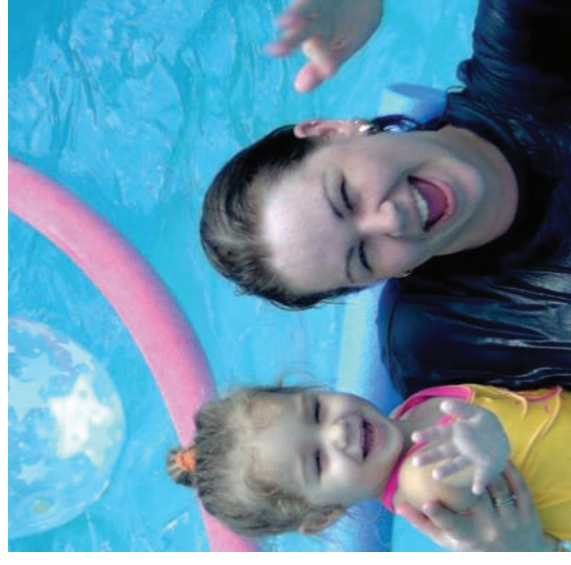
*“A look, a cry, a reach, the stamping of feet... you become a communication detective when you have a child with speech difficulties.”*



# Talk Health – key findings

## 4) GPs – suggestions

- ? Consistency of how families are treated – Partnership Charter for GPs
- ? A route map of services available
- ? Home visits given routinely to children with disabilities
- ? Training for GPs and families on power of attorney/mental capacity act
- ? A holistic approach needed by all GPs
- ? Eligibility for referrals needs to be clearly explained and all communication routinely copied to parents
- ? Amaze and the PaCC can represent parent carer views on a city-wide basis (unlikely to participate in PPGs)



*“A look, a cry, a reach, the stamping of feet... you become a communication detective when you have a child with speech difficulties.”*



# C&YP Health Outcomes Forum

**HOF and Kennedy report very similar things as PaCC:**

## Challenges

- Health outcomes for C&YP are poor esp C&YP with disability
- C&YP and families struggle to get voice heard
- Training in paediatrics is poor esp. for GPs
- Care is not joined up and focuses on the system rather than individual
- C&YP low priority for GPs
- Wide variations in care



*“Sometimes we want to do things that other families take for granted. Other families have to accept that we are a little bit different.”*



# C&YP Health Outcomes Forum

## Recommendations:

- Put C&YP and families at heart
- Services need to demo how they listen to C&YP and families
- More paediatric training for all health services
- Better integration between hospital and community nurses (esp complex needs so can treat at home)
- Tightening drug procedures incl. drug errors
- More integration betw. Health, Education, Social Care
- Local Healthwatch to reflect C&YP issues
- Services to identify CYP with LT conditions, disabilities, SEN etc



*“Sometimes we want to do things that other families take for granted. Other families have to accept that we are a little bit different.”*



# To sum up...

## Further improve (and fund) Parent Carer Participation:

- Representation at H&WB board, CCG, RACH.
- Gateway funding
- Ask for service user and parent feedback

## Increased resource for services

- Paediatric and parent carer training for medical staff
- Paediatric Disability Liaison post
- Sussex-wide Epilepsy Nurse
- Access to therapy services

## Improved communication & transparency

- Between services and to parents

## HWOSC

- To champion our recommendations?
- To refer to H&WB next meeting?



*“Sometimes we want to do things that other families take for granted. Other families have to accept that we are a little bit different.”*







# HEALTH & WELLBEING OVERVIEW & SCRUTINY COMMITTEE

## Agenda Item 30

Brighton & Hove City Council

<b>Subject:</b>	<b>Performance and Quality in Primary Care</b>		
<b>Date of Meeting:</b>	<b>11 September 2012</b>		
<b>Report of:</b>	<b>Strategic Director, Resources</b>		
<b>Contact Officer:</b>	<b>Name:</b>	<b>Kath Vlcek</b>	<b>Tel: 29-0450</b>
	<b>Email:</b>	<b>Kath.vlcek@brighton-hove.gov.uk</b>	
<b>Ward(s) affected:</b>	<b>All</b>		

### FOR GENERAL RELEASE

#### 1. SUMMARY AND POLICY CONTEXT:

- 1.1 The Health Overview and Scrutiny Committee (HOSC) received a report on GP Performance at its September 2011 committee meeting. There were a number of issues that remained outstanding, so it has returned to the Health and Wellbeing Overview & Scrutiny Committee (HWOSC)
- 1.2 The Clinical Commissioning Group is due to take on responsibility for assessing GP performance and quality from April 2013. They will be doing so using a 'scorecard' system.

#### 2. RECOMMENDATIONS:

- 2.1 That Members note and comment on the contents of this report and its appendices.
- 2.2 That Members agree to take up the offer of a seminar on performance and quality in Primary Care hosted by the CCG.

#### 3. RELEVANT BACKGROUND INFORMATION/CHRONOLOGY OF KEY EVENTS:

- 3.1 The Health Overview and Scrutiny Committee (HOSC) heard about GP Performance at their September 2011 committee meeting. There were a number of issues that remained outstanding so it has returned to the Health and Wellbeing Overview & Scrutiny Committee (HWOSC), which has superseded the HOSC.
- 3.2 The minutes of the September 2011 HOSC say:

35.1 *This item was introduced by Ms Elizabeth Tinley, Service Lead, Brighton & Hove City Primary Care Contracts and Commissioning Directorate, Sussex Commissioning Support Unit.*

35.2 *Members agreed that they were disappointed that this report did not include information on the performance of individual GP practices in the city and asked for a paper to be circulated including this material.*

35.3 *Members also asked for some work to be done mapping the relative performance of city GP practices against areas of deprivation across the city – i.e. to ascertain whether GP practice performance was significantly correlated with deprivation etc – and requested that this be circulated alongside information on comparative performance.*

35.4 *In response to a question from Cllr Robins on the use of locums by individual GP practices, members were told that PCTs had no power to influence the use of locums by GP practices – the practice rather than named GPs is contracted to provide services. However, Ms Tinley agreed to find out whether information on locums was nonetheless collated, and, if so, whether there was any correlation between locum use and performance.*

35.5 *In answer to a question from Mr Hazelgrove on Patient Groups, members were informed that patients could choose to establish their own groups, although this could cause problems as the groups had to be fully representative of the practice population rather than a self-selecting sample.*

35.6 *The Chair thanked Ms Tinley for her contribution.*

35.7 *That the committee should receive additional information on:*

- (a) comparative performance of each city GP practice*
- (b) mapping of GP performance against city demographics*
- (c) use of locums and its correlation (if any) with GP practice performance.*

3.3 The Clinical Commissioning Group is due to take on responsibility for assessing GP performance and quality from April 2013. They will be doing so using a 'scorecard' system.

3.4 Information on the scorecards is available on <http://www.brightonandhove.nhs.uk/localservices/gp/NHSBrightonandHove-GPbalancedscorecard.asp>

3.5 The CCG has offered to host a seminar for HWOSC members on performance and quality in Primary Care to provide further time for discussion and detailed questions on the data and its implications,

#### **4. COMMUNITY ENGAGEMENT AND CONSULTATION**

- 4.1 None to this report for information.
- 4.2

#### **5. FINANCIAL & OTHER IMPLICATIONS:**

- 5.1 None to this report for information.

Legal Implications:

5.2 None to this report for information.

Equalities Implications:

5.3 None to this report for information but the appendices from the CCG are focussed on GP performance and on inequalities.

Sustainability Implications:

5.4 None to this report for information.

Crime & Disorder Implications:

5.5 None to this c report for information.

Risk and Opportunity Management Implications:

5.6 None to this report for information but the appendices from the CCG are focussed on GP performance and on any risk that may ensue.

Public Health Implications:

5.7 None to this report for information but the appendices from the CCG are focussed on GP performance and consequently on public health.

Corporate / Citywide Implications:

5.8 None to this report for information.

**6. EVALUATION OF ANY ALTERNATIVE OPTION(S):**

6.1 None to this report for information.

**7. REASONS FOR REPORT RECOMMENDATIONS**

7.1 The HOSC had queries that remained outstanding so it was referred on to HWOSC for information.

7.2 Members who were on HOSC may have already attended a workshop on GP performance, which is a significant issue, so it was felt appropriate to offer the same opportunity to newer members.

## **SUPPORTING DOCUMENTATION**

### **Appendices:**

1. GP Performance and Quality Scorecard Presentation handout
2. Example of a scorecard
3. Example of GP practice profile
4. GP taxonomies
5. GP Scorecard newsletter

### **Documents in Members' Rooms**

None.

### **Background Documents**

None.

**NHS**  
Brighton and Hove  
Clinical Commissioning Group

# Improving Quality in General Practice Brighton and Hove

## The GP Scorecard




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**NHS**  
Brighton and Hove  
Clinical Commissioning Group

# Contents

- Improving Quality of Primary Care - part of CCG Business
- Changes to NHS Commissioning 2013 - who does what in the new world
- Brighton and Hove – GP Scorecard Process
- Key Findings – Data Analysis & Lessons Learnt
- Next Steps




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**NHS**  
Brighton and Hove  
Clinical Commissioning Group

## Improving Quality of Primary Care - part of CCG business?

- CCG responsibility to improve health care - secure the best outcomes within the resources available
- UK has a strong primary care based system with relatively high levels of patient satisfaction.
- International evidence suggests the strength of a primary care is linked to overall population health.
- Primary care accounts for 9 out of 10 patient contacts, but hospital care and specialist services is where most NHS expenditure is focussed.




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Clinical Commissioning Group

### Improving Quality of Primary Care - part of CCG business

- Most of CCG's service redesign focus:
  - shifting to primary care based models of care
  - avoiding the need to go to hospital
- Primary care – multiple small providers
  - **Wide variation** in effectiveness & delivery of primary care at an individual practice level
  - GP practices now plays an increasingly important role in co-ordinating the provision of patient care.




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**NHS**  
Brighton and Hove  
Clinical Commissioning Group

### Changes to NHS Commissioning - April 2013

- The newly reformed NHS requires GPs to play a key role as commissioners, as well care providers.
- The **National Commissioning Board** will be responsible for commissioning primary care and managing each practice contract, but
- Under the Health Act **CCG's** have a duty to **"assist and support the National Commissioning Board to improve the quality of primary care:**
  - Promoting quality improvement
  - Reviewing and benchmarking practice performance
  - Enabling peer review and challenge




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**NHS**  
Brighton and Hove  
Clinical Commissioning Group

### GP Scorecard Process

- Nationally one of the most used approaches to driving forward quality improvement in general practice - collection and analysis of a range of clinical, quality and performance data to form **GP scorecards.**
- Brighton and Hove introduced a Quality and Performance Framework for Primary Care in 2009/10;
  - Key element - GP Scorecard to driving quality improvement forwards
- Piloted with 25% of practices.




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Brighton and Hove  
Clinical Commissioning Group

### GP Scorecard Process

- In 2010/11 - learning from the pilot informed the full roll-out across the City:
  - **Practice Profiles** were produced to contextualise the data.
  - Individual practice visits took place to agree **Practice Development Plans**.
  - **Public facing scorecards** were included on the PCT website.
- In 2011/12 a CCG steering group - Public Health, Clinical Quality, Primary Care Commissioning and Business Intelligence - set up to ensure systems developed were in-line with the emerging CCG environment.
- The group concluded the process should be adapted for 2011/12, in particular to provide greater focus on **peer review** and support.




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Brighton and Hove  
Clinical Commissioning Group

### Peer Review Workshops

- February and March 2012 - all Practices in Brighton & Hove (GPs, Practice Managers and Practice Nurses) were invited to attend **scorecard workshops** made up of small groups of practices.
- Individual Practice Scorecards, Practice Profiles and Patient Surveys were provided in advance of the workshops to aid planning and discussion.
- The aim was to provide a non-judgemental, supportive environment to share good practice and to consider individual practice development needs.




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**NHS**  
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Clinical Commissioning Group

### GP Scorecard

- The data is broken down into key areas:
  - Contractual Requirements and Premises
  - Priority Standards and Services
  - Access
  - Patient Experience
  - Quality & Outcomes Framework (QOF)
  - Public Health Information
  - Prescribing
- 59 different indicators are included
- Practices are rated A, B or C for each area & given an overall rating.




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The GP Scorecard



Brighton and Hove

GP Scorecard 2011/12, Albion Street

Overall Score: B (7 out of 116, 70%)	East: C63/100							
<b>11 Compliance with GP Contract and Regulatory Requirements</b>								
11.1 Compliance with GP Contract	100%	A	100%	N/A	100%	N/A	100%	N/A
11.2 Regulatory Requirements	100%	A	100%	N/A	100%	N/A	100%	N/A
<b>12 Electronic Patient Records (EPR)</b>								
12.1 EPR available	100%	A	100%	N/A	100%	N/A	100%	N/A
12.2 EPR available within 5 days	100%	A	100%	N/A	100%	N/A	100%	N/A
12.3 EPR available in 3 days	100%	A	100%	N/A	100%	N/A	100%	N/A
<b>13 Access to services</b>								
13.1 Access to services	84.2%	B	74.8%	A	74.8%	A	84.2%	B
13.2 GP appointment within 5 days	84.2%	B	74.8%	A	74.8%	A	84.2%	B
13.3 GP appointment in 3 days	84.2%	B	74.8%	A	74.8%	A	84.2%	B
13.4 Access to services with waiting times	84.2%	B	74.8%	A	74.8%	A	84.2%	B
<b>14 Patient Experience</b>								
14.1 Overall patient satisfaction	81.2%	B	77.5%	A	77.5%	A	81.2%	B
14.2 Overall satisfaction with care	81.2%	B	77.5%	A	77.5%	A	81.2%	B




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Overall Results

- 17 Practices Scored A
- 25 Practices Scored B
- 5 Practices Scored C
- **Total 47 practices**




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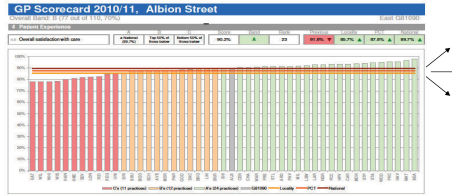
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Overall satisfaction with care

• 19 practices scored lower than national average: 11 East, 3 West, 5 Central




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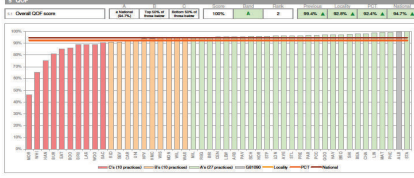
## QOF Scores



14 practices scored lower than national average: 6 East, 4 West, 4 Central

Brighton and Hove  
Clinical Commissioning Group

GP Scorecard 2010/11, Albion Street



National  
PCT

Practices QOF scores vary between 462 & 1000 points




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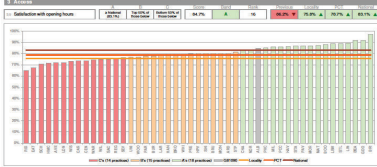
## Satisfaction with Opening Hours



14 practices scored lower than national average: 6 East, 4 West, 4 Central

Brighton and Hove  
Clinical Commissioning Group

GP Scorecard 2010/11, Albion Street



National  
PCT




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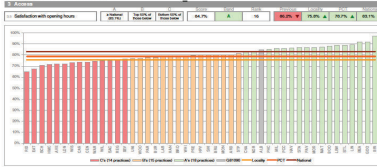
## Ability to See Own GP



16 practices scored lower than national average: 6 East, 4 West, 6 Central

Brighton and Hove  
Clinical Commissioning Group

GP Scorecard 2010/11, Albion Street



National  
PCT




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# Analysis

- No particular pattern in terms of Locality – although more West practices were higher scoring
- No particular pattern in terms of deprivation – although the lowest 2 scoring practices had the highest level of deprivation.
- The lowest 5 scoring practices were all small practices
- No identifiable patterns in terms of scores and Taxonomy of General Practice



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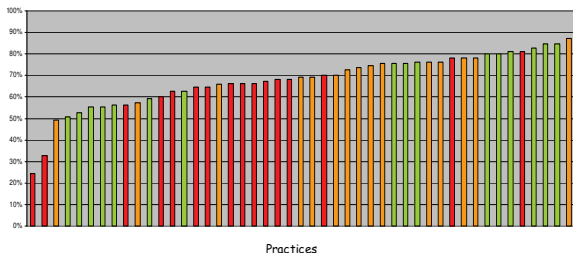
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## Score by Locality

Each practice has an overall percentage score: East, West, Central



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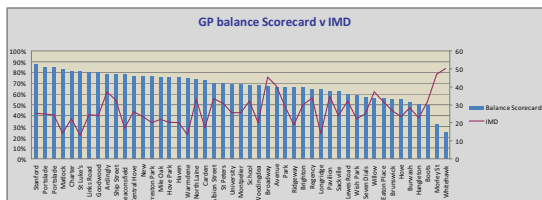
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## Score By Index of Deprivation

(High IMD = higher deprivation)



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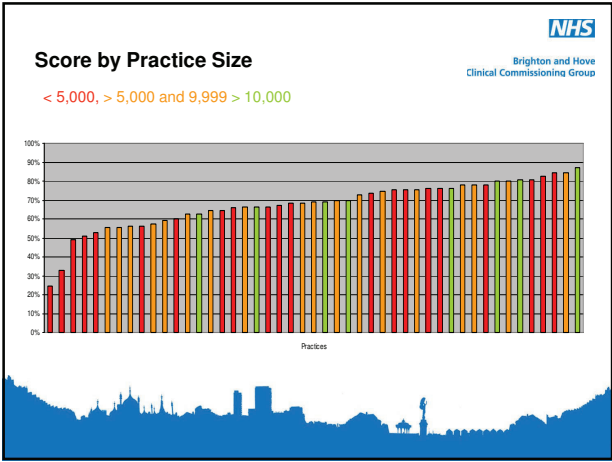
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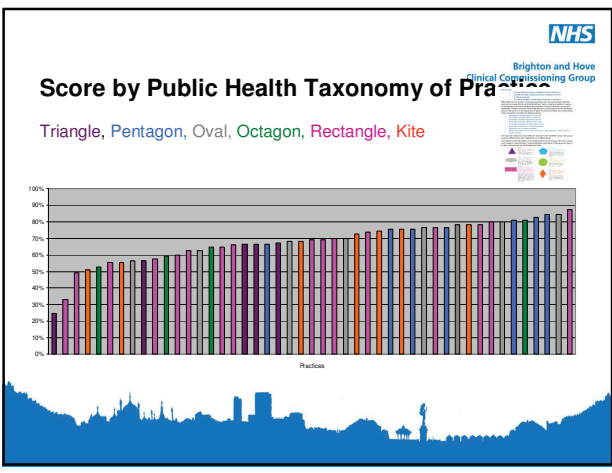
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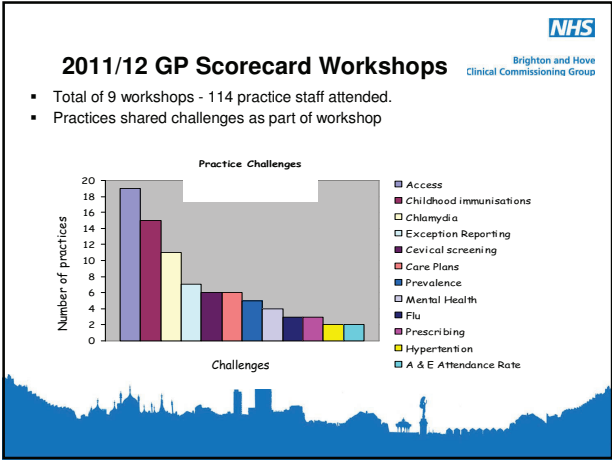
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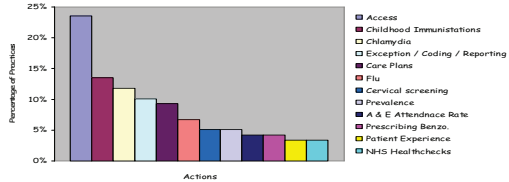
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**GP Scorecard Workshops**   
Brighton and Hove  
Clinical Commissioning Group

- Practices were required to submit Action Plans to address the practices challenges; common themes are shown below:



Access  
 Childhood Immunisations  
 Chlamydia  
 Exception / Coding / Reporting  
 Care Plans  
 Flu  
 Cervical screening  
 Prevalence  
 A & E Attendance Rate  
 Prescribing Benzos  
 Patient Experience  
 NHS Healthchecks

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**GP Scorecard Newsletter**   
Brighton and Hove  
Clinical Commissioning Group



- June 2012 - newsletter was sent to practices which summarised the key findings:
  - 'Top Tips' from the workshops.
  - The contact details of practices willing to offer additional peer support.
  - The evaluation summary.
  - Responses to organisational issues.
  - The next steps.

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**Summary**   
Brighton and Hove  
Clinical Commissioning Group

- From 2010/11 to 2011/12, **13 practices moved up at least one band, 31 stayed in the same band and 3 moved down.**
- The 2011/12 feedback was positive with all 47 practices commenting about the benefit of peer review and support.
- The latest - Practice Profiles and Public Scorecards will be added to the CCG website in September
- CCG - as apart of authorisation process – establishing a dedicated primary care team - GP clinical lead will be recruited.
- Further plans to improve quality will be developed in the Autumn – once new team established.

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## Further Information

- New National Guidance – Securing Excellence in Primary Care
  - Management & safe transfer of functions
  - Main components of the new primary care commissioning system - who will do what.
- <http://www.commissioningboard.nhs.uk/files/2012/06/ex-comm-pc.pdf>
- B&H Scorecards – Link to CCG Web-site
- <http://www.brightonandhove.nhs.uk/localservices/gp/NHSBrightonandHove-GPbalancedscorecard.asp>



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# The shape of general practice in Brighton & Hove

Over the years within Brighton & Hove we have tended to compare general practices with other practices based within the same locality (East/Central/West). This has meant that some practices have been compared with others with very different populations. Clustering practices according to the characteristics of the practice population allows indicators of need and health outcomes to be compared more appropriately.

## Practice classifications with no Brighton & Hove practice



### Circle

High percentage under 15 years. Very high percentage of Black population and higher than average Asian population. High deprivation.



### Square

Practices with a smaller than average list size, a high percentage of the population aged under 15 years old and fewer aged 65 years or older. A very high proportion of the population from Asian ethnic groups and a higher than average proportion from Black ethnic groups. Very high levels of deprivation.



### Hexagon

Located in towns or urban fringe settlements with low deprivation and few people from Asian and Black ethnic groups.



### Crescent

Located in villages, hamlets and isolated settlements with a smaller than average list size and a higher proportion of the population aged 65 years and older. Few people from Asian and Black ethnic groups and low levels of deprivation.

The Yorkshire and Humber Public Health Observatory produced general practice classification groups in February 2011 for all practices across England. The groups were based upon practices having similar characteristics according to the following indicators:

- Percentage of population aged 0-4 years old
- Percentage of population aged 5-14 years old
- Percentage of population aged 65-84 years old
- Percentage of population aged 85 years or older
- Percentage of population from Asian ethnic groups
- Percentage of population from Black ethnic groups
- Deprivation score for practice population
- Whether the practice was in an urban area, town or urban fringe area or village, hamlet or isolated settlement

A 'two-step cluster analysis' was used to identify the 'best match' of the classification groups. Each group is designated by a different shape and in England there are ten different shapes/groups.

Within Brighton & Hove practices fall into six of these ten groups. We have no square, circle, hexagon or crescent practices – these classifications are either more rural or have higher proportions of people from Black and minority ethnic groups.

The group descriptions of Brighton & Hove practices are shown. **These groupings are used throughout this report.** The Station Practice and New Larchwood have not been included in the classification as they were newly established at the time the classification was created and there was insufficient information to include them.

More information is available at: [www.apho.org.uk/pracprof/](http://www.apho.org.uk/pracprof/)

## Practice classifications for Brighton & Hove practices



### Triangle

Practices with a high percentage of children (under 15 years old) and very high levels of deprivation.

Broadway Surgery; Park Crescent Health Centre; The Avenue Surgery; Willow Surgery; Whitehawk Medical Practice



### Oval

Practices with a higher percentage of older people (aged 65 years and older) with slightly higher levels of deprivation.

Eaton Place Surgery; Ardingly Court Surgery; Sackville Road Surgery; St Peter's Medical Centre; Portslade Health Centre; Central Hove Surgery; School House Surgery; Links Road Surgery



### Rectangle

Practices with a very low percentage of people under 15 years and a lower proportion of older people (65 years and older) and an above average proportion of the population from Asian and Black ethnic groups. Average levels of deprivation.

Boots North Street Practice; Stanford Medical Centre; Montpelier Surgery; Seven Dials Medical Centre; Pavilion Surgery; Lewes Road Surgery; University of Sussex Health Centre; Albion Street Surgery; North Laine Medical Centre; Brunswick Surgery; Regency Surgery; Goodwood Court Medical Centre; BHH Morley Street; Ship Street Surgery



### Pentagon

Practices with an average proportion of the population in younger and older age groups and generally low deprivation.

Preston Park Surgery; Charter Medical Centre; Mile Oak Medical Centre; Ridgeway Surgery; The Haven Practice; Portslade County Clinic; Matlock Road Surgery



### Octagon

Practices with a high percentage of the population aged 65 years and older and low levels of deprivation.

Saltdean and Rottingdean Medical Practice; Wish Park Surgery; Burwash Road Surgery; St Luke's Surgery



### Kite

Practices with large average list sizes, an average proportion of the population under 15 years old, a higher proportion aged 65 years and older, and low levels of deprivation.

Hove Medical Centre; Carden Surgery; Warndene Surgery; Beaconsfield Surgery; Woodingdean Surgery; Hove Park Villas Surgery; Hangleton Manor Surgery





## Workshop Top Tips

### Exception Reporting

How to reduce it?

*"When QoF target is met don't exempt more patients, that way patients remain on the QoF alert system and reminders won't disappear"*

### QoF

How to maximise points?

*"Opportunistic actions; ensure your clinical system is set to produce reminders and prompts"*

### Childhood Immunisations

How to increase uptake?

*"Offer appointments around nursery and school pick up times"*

### Flu Vaccinations

How to increase uptake?

*"Frequently monitor uptake with a prominent early campaign targeted at larger groups"*

### Cervical Screening

How to increase uptake?

*"Ask your Receptionist or Nurse to telephone the patient saying Dr... has specifically asked me to contact you"*

### Access

How to improve it?

*"Look at the split between pre-bookable and on the day Appointments, then work out the best solution for your practice. Embrace technology and consider, online, email and text message booking and an answer machine for cancellations"*

## Introduction

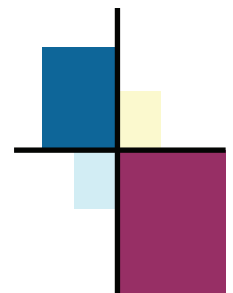
This year the GP Scorecard was overseen by a steering group that included the Clinical Commissioning Champions, Clinical Commissioning Group, Primary Care Team, The Commissioning Support Unit, Primary Care Quality Team and Public Health.

It was agreed that the 2012/2013 scorecard and profile would be produced with as little change as possible to ensure consistency and enable year on year comparison.

This year there was a change to the format of discussions; rather than individual practice meetings, the practices were brought together in small groups to look at practice level priorities and to work towards a 2012/13 Practice Development Plan.

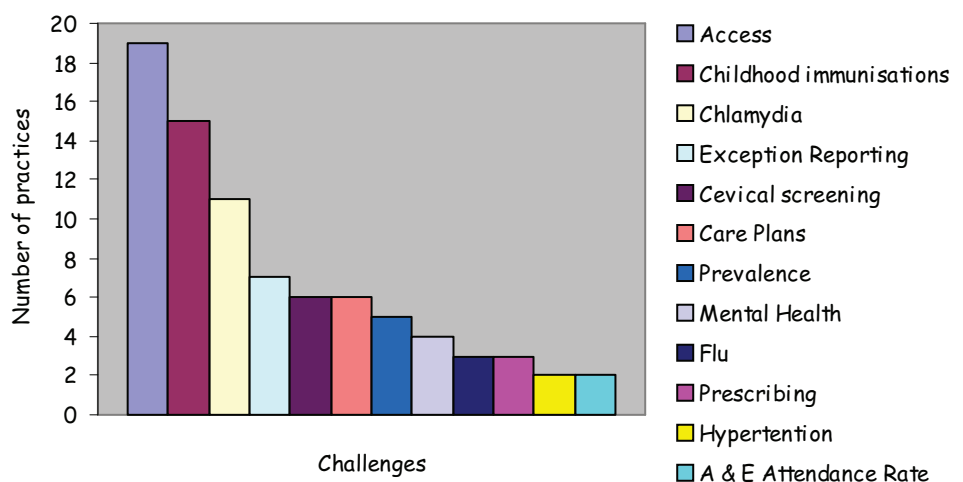
The aim of the workshops was to provide a non-judgmental, supportive environment to enable sharing of good practice and to consider practices' development needs.

All the practices in Brighton & Hove took part and submitted action plans for 2012/13. This report summarises how practices evaluated this year's process and some of the common themes and good practices that emerged.



## Practice Challenges

Prior to the workshop meetings practices were asked to identify 2 practice strengths and 2 practice challenges. The bar chart below shows the challenges practices identified and the number of practices experiencing them.



## Need advice or support completing your action plan?

If so, your colleagues might be able to help. The practices below are willing to offer guidance with the following:

### Access

University of Sussex Health Centre  
 Email: [lindsay.coleman@nhs.net](mailto:lindsay.coleman@nhs.net)  
 Telephone: (01273) 249006

### Childhood Immunisations

Warmdene Surgery  
 Email: [susan.harries@nhs.net](mailto:susan.harries@nhs.net)  
 Telephone: (01273) 545906

### Exception Reporting

St. Peter's Medical Centre  
 Email: [heather.dilks@nhs.net](mailto:heather.dilks@nhs.net)  
 Telephone: (01273) 606006

### Flu Vaccinations

Central Hove Surgery  
 Email: [amanda.jones20@nhs.net](mailto:amanda.jones20@nhs.net)  
 Telephone: (01273) 744927

### Cervical Screening

Preston Park Surgery  
 Email: [tricia.gibbons@nhs.net](mailto:tricia.gibbons@nhs.net)  
 Telephone: (01273) 542791

### Prevalence

Hove Medical Centre  
 Email: [vanessa.elliott@nhs.net](mailto:vanessa.elliott@nhs.net)  
 Telephone: (01273) 413666

### Benzodiazepine Prescribing

Park Crescent Health Centre  
 Email: [carol:whitney@nhs.net](mailto:carol:whitney@nhs.net)  
 Telephone: (01273) 523633

### Patient Experience

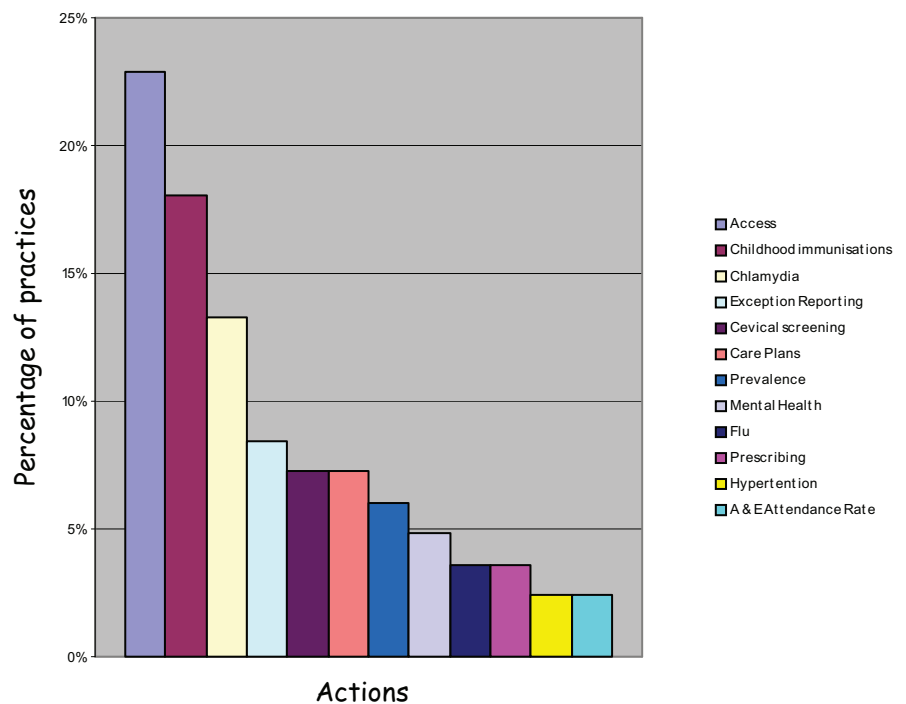
Mile Oak Medical Centre  
 Email: [rick.jones@nhs.net](mailto:rick.jones@nhs.net)  
 Telephone: (01273) 426210

### NHS Health Checks

Albion Street Surgery  
 Email: [ninagraham@nhs.net](mailto:ninagraham@nhs.net)  
 Telephone: (01273) 605497

## Practice Action Plans

After the workshop meetings practices were asked to write and submit practice action plans which addressed the practices challenges. The bar chart below shows the percentage of practices that included an action i.e. 'access' in the practice action plan.

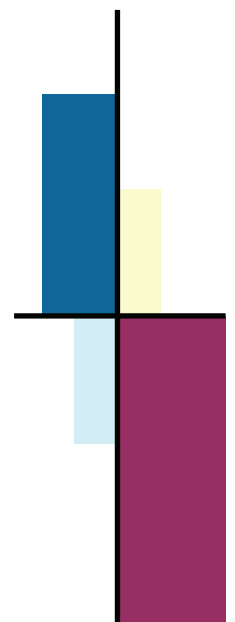


## Workshop Evaluation

In total 9 workshops were held, 3 for each locality with 114 practice staff participating.

The evaluation feedback was extremely positive with many participants commenting on the benefits of meeting with other practices to discuss issues and share ideas.

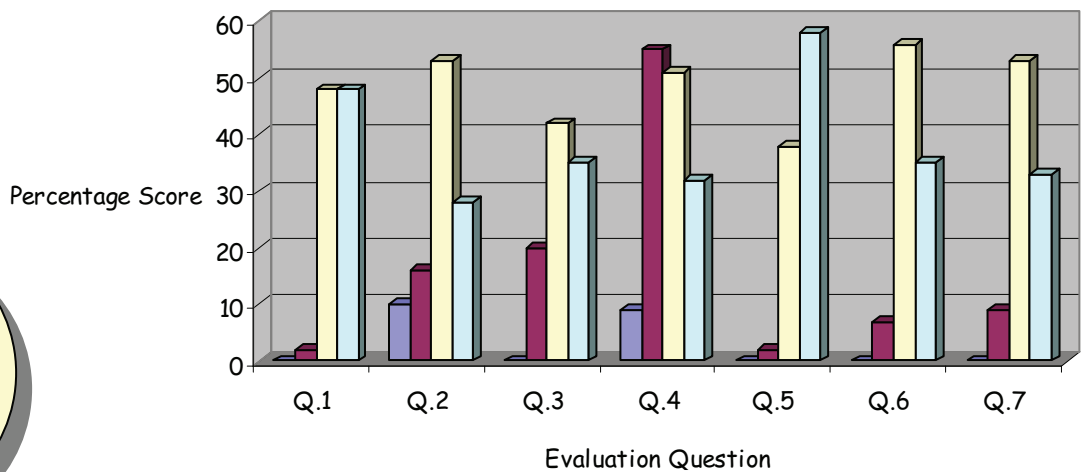
For each of the 7 evaluation questions the response on average was either 'good' or 'excellent' with very few participants rating the any part of the process 'average' or 'poor'.



The evaluation questions covered the following aspects of the workshop process:

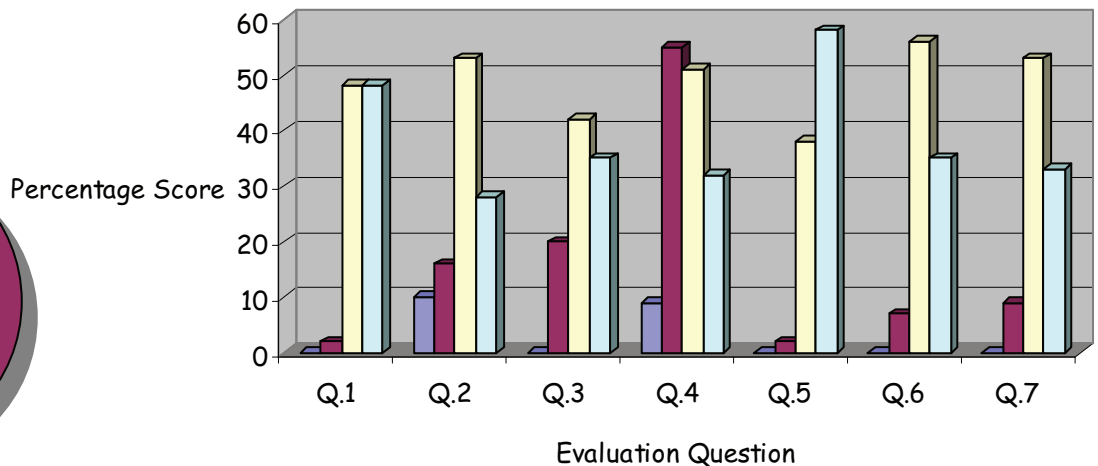
- Q.1 Welcomes, introductions and scene setting
- Q.2 Public Health presentation on using the scorecard to improve patient outcomes
- Q.3 Key messages from the scorecards and practice profiles
- Q.4 Presenting and discussing practice strengths
- Q.5 Presenting and discussing practice challenges
- Q.6 Action points identified from discussion
- Q.7 Next steps - Practice Action Plans

**Evaluation Summary West Locality**



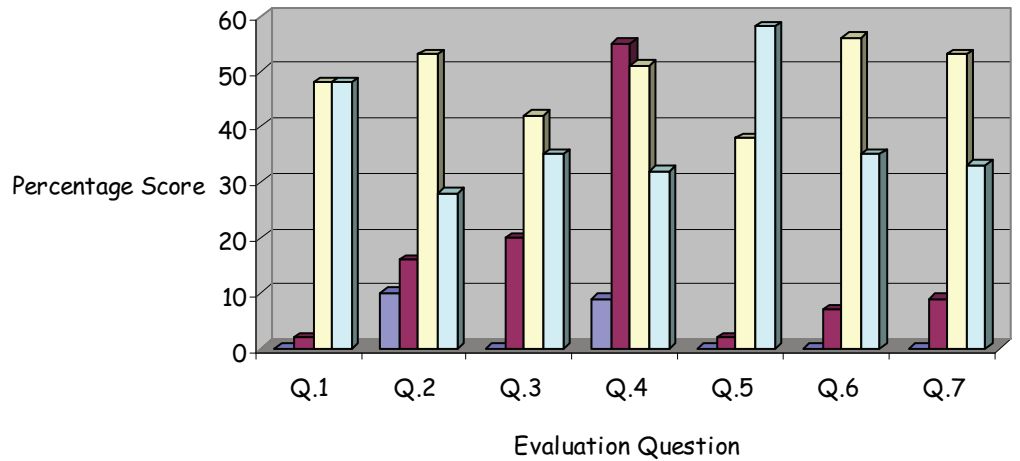
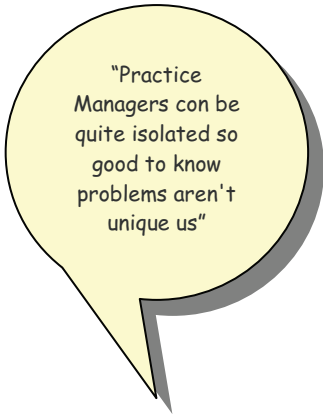
"Great to share experiences and practical Solutions; very useful session"

**Evaluation Summary Central Locality**



"Great to find out what other surgeries are doing and comparing; feels supportive"

## Evaluation Summary East Locality



## Practice Issues

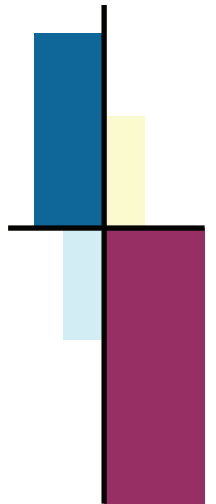
During the workshops a number of issues were raised by practices and since then the following has been done to address these:

**Health Visiting:** A number of practices raised concerns about access to an identified Health Visiting Team. A workshop focussing specifically on Health Visiting was included in the city-wide PLS event in June.

**Lack of training opportunities:** Lots of concerns around the recent changes and reduction in primary care education and training were raised; these concerns have now been fed into the Clinical Education and Training Committee.

**Pressures on practice time:** Practice staff articulated there were increased competing expectations on their time and felt planning around external events and workshops could be improved. A practice calendar will soon be available on the PCT website extranet.

**Sussex Interpreting Service:** Quite a number of practices raised concerns about the quality of this service; this has been fed into the CSU to inform contract discussions.



## Next Steps

The Public Scorecard is now being updated with new data and will be circulated to practices at the end of June. Practices will then have 2 weeks to refresh the profile before its published in mid July.

Your Business Support manager or Clinical Champion will be in touch at the end of September to check how your action plan is going and offer support if needed.

# HEALTH & WELLBEING OVERVIEW & SCRUTINY COMMITTEE

## Agenda Item 31

Brighton & Hove City Council

<b>Subject:</b>	<b>Mental Health Beds Update (September 2012)</b>		
<b>Date of Meeting:</b>	<b>11 September 2012</b>		
<b>Report of:</b>	<b>Strategic Director, Resources</b>		
<b>Contact Officer:</b>	<b>Name:</b>	<b>Kath Vlcek</b>	<b>Tel: 29-0450</b>
	<b>Email:</b>	<b>Kath.vlcek@brighton-hove.gov.uk</b>	
<b>Ward(s) affected:</b>	<b>All</b>		

### FOR GENERAL RELEASE

#### 1. SUMMARY AND POLICY CONTEXT:

- 1.1 This report provides an update on monitoring of the temporary reduction of in-patient mental health beds at Mill View hospital.
- 1.2 **Appendix 1** to this report contains information, supplied by Brighton & Hove Clinical Commissioning Group (CCG), relating to the ongoing work of the independent Clinical Taskforce established to monitor the impact of the temporary bed reductions.

#### 2. RECOMMENDATIONS:

- 2.1 That the Health & Wellbeing Overview & Scrutiny Committee considers and comments on this report and its appendix.

#### 3. RELEVANT BACKGROUND INFORMATION/CHRONOLOGY OF KEY EVENTS:

- 3.1 Sussex Partnership NHS Foundation Trust (SPFT), acting in agreement with Brighton & Hove Clinical Commissioning Group, plans to reduce its acute mental health bed capacity in Brighton & Hove by around 18 beds; arguing that more effective community mental health services, coupled with more efficient discharge planning, will mean that it can provide a better quality service to local people with fewer acute beds.
- 3.2 Aspects of this plan have been presented both to the Brighton & Hove Health Overview & Scrutiny Committee (HOSC) and to the Health and Wellbeing Overview & Scrutiny Committee (HWOSC) on several occasions.

3.3 The HOSC was updated on the work of the Clinical Taskforce at its 21 March and 09 May 2012 meetings, the HWOSC received updates on 12 June and 24 July 2012. On all occasions members were informed that the Taskforce's targets had not been attained. At the July meeting, the HWOSC was informed that the clinical decision was , despite this consistent failure to hit targets, to maintain the bed closures and to further invest in community services.

#### **4. COMMUNITY ENGAGEMENT AND CONSULTATION**

4.1 None has been undertaken in compiling this update.

#### **5. FINANCIAL & OTHER IMPLICATIONS:**

##### Financial Implications:

5.1 None to this update – members are not being asked to make any decision which might have financial implications.

##### Legal Implications:

5.2 None to this update

##### Equalities Implications:

5.3 None to this update

##### Sustainability Implications:

5.4 None to this update

##### Crime & Disorder Implications:

5.5 None to this update

##### Risk and Opportunity Management Implications:

5.6 None to this update

##### Public Health Implications:

5.7 None to this update

##### Corporate / Citywide Implications:

5.8 None to this update

## **6. EVALUATION OF ANY ALTERNATIVE OPTION(S):**

- 6.1 At some point, should performance continue to be below target, the HWOSC may wish to reconsider its approval of the temporary bed closure at Mill View hospital – i.e. should it become evident that there is no realistic prospect in the short term of SPFT managing with fewer local beds without impacting on the level of care provided to local people.

## **7. REASONS FOR REPORT RECOMMENDATIONS**

- 7.1 This is an ongoing issue which the Council's statutory health scrutiny committee has been monitoring for some time. As the HWOSC is assuming statutory health scrutiny responsibilities, it makes sense for it to continue its predecessor's activities in this important area.

## **SUPPORTING DOCUMENTATION**

### **Appendices:**

1. Mental Health Acute Beds - September Update from the CCG.
2. Mental Health Acute Beds - June Update from the CCG

### **Documents in Members' Rooms**

None

### **Background Documents**

None





## **Mental Health Acute Beds**

### **HWOSC Update - September 2012**

#### **1. Purpose of the Paper**

The purpose of this paper is to update the HWOSC regarding proposals to invest further in community mental health service to support the whole system programme of work to reduce the number of acute mental health beds in Brighton and Hove.

#### **2. Background**

Previous papers have described the rationale for the proposals and the agreed local approach to ensure the arrangements are implemented safely. The HOSC at its meeting in January 2012 gave support to proceed with a temporary phased reduction in bed numbers with the agreement that a Clinical Review Group would oversee the process and provide updates to the HOSC (which has now been superseded by the HWOSC). The last detailed update paper was provided in June 2012 and should be used as a reference document to this paper. The paper is detailed in Appendix A.

#### **3. Progress**

- 3.1 The purpose of the Clinical Review group is to assess the point at which there have been sufficient system changes to enable 19 beds in Brighton and Hove to close on a permanent basis. The group has met a total of six times and has agreed a set of metrics to measure the system readiness to function safely and effectively with fewer beds. The metrics were detailed in Appendix A of the June 2012 paper.
- 3.2 Since the last written report provided to the HWOSC in June 2012 the Clinical Review Group has met twice further.

#### **4. Decision to Invest Further in Community Mental Health Services**

- 4.1 At its meeting on 17 July the Clinical Review Group undertook a detailed option appraisal to assess whether the beds should re-open or whether further investment in community services was necessary to help support people's care in out of a hospital settings.
- 4.2 On balance the clinicians recommended that the preferred option was to invest further in community services and not to re-open the beds at this stage. The key elements of the debate that informed the decision are as follows:
  - National best practice is that people should always be cared for in the least restrictive setting and the minimum disruption to their lives.

## Appendix 1

- Patient preference in the main is for care in the community rather than in hospital settings.
- Clinicians felt that there are still a number of patients admitted to Millview Hospital who would be better cared for in the community if additional resources were available
- There is scope to make further improvements in community services to provide more care outside hospital as an alternative to inpatient admission

- 4.3 The group agreed that specific additional investment proposals for community services would be developed and a decision made on preferred investment proposals at the next meeting on 17 August.
- 4.4 The investment proposals are **in addition** to the investment plans already agreed including the intensive day care facility for people with personality disorder development and increased supported accommodation options. Plans for both of these developments are in place to deliver service changes by the summer of 2013.
- 4.5 The investment proposals are also **in addition** to new investment the Clinical Commissioning Group have made in relation to the Audacious Goal programme to improving urgent care services and reduce reliance on emergency services at the Royal Sussex County Hospital (A&E and unplanned hospital admission services). The service changes agreed as part of this Audacious Goal programme of work are to enhance the Brighton Urgent Response Service (BURS) by developing a 24/7 urgent response that patients/carers/ambulance will be able to access directly. The service will include a 24/7 phone line and 7 day a week rapid access clinics. This value of this investment is an additional 391k with the enhanced BURS service due to commence by 1 December 2012 at the latest.

## 5. Specific Investment Proposals

- 5.1 At its meeting on 17 August the Clinical Review Group considered proposals for additional investment in community services.
- 5.2 **Crisis Resolution Home Treatment Team.**  
The group agreed the priority area for investment was an investment of 429k in additional staffing (nursing, medical and support workers) in the **Crisis Resolution Home Treatment Team (CRHT)**. This represents a 28% increase in resource over and above the existing investment of 1,531k.
- 5.3 The CRHT is a team for adults with severe mental illness (e.g. schizophrenia, manic depressive disorders, severe depressive disorders) with an acute psychiatric crisis. It provides a seven day a week crisis support and home treatment as an alternative to hospital admissions for a period of up to six weeks. The specific investment areas agreed are:
- Additional night time senior nursing cover

- Additional nursing resource to help support early discharge from hospital
- Additional weekend medical cover.

5.3 The decision was informed by a number of factors:

- There is a wealth of national research & evidence that demonstrates that a responsive CRHT can significantly reduce bed use, particularly in terms of supporting patients in the community to help admission avoidance<sup>1</sup>
- Latest bench-marking undertaken against nationally recommended staffing and caseload indicators has identified Brighton and Hove having lower staffing levels than indicated for our population need.
- National best practice is that people experiencing severe mental health difficulties should be treated in the least restrictive environment with the minimum disruption to their lives. This is based on research that has shown that most service users and carers prefer community based treatment and that clinical and social outcomes are at least as good as those achieved in hospital.<sup>2</sup>
- Length of stay in hospital should be the minimum time required to address the reason for admission, and there is potential to expand the current early discharge arrangements to 7 days a week.

5.4 In summary the investment decision was made on the basis that the current CRHT resource is less than indicated for the Brighton and Hove population and on the basis of the available evidence that CRHT's have positive outcomes in terms of patient satisfaction and clinical care and that they can support a reduction acute mental health bed usage.

5.5 The additional investment was made in context of some further changes to the working practice of the CRHT to maximise the productivity and efficiency, for example use of geographical caseload zoning to minimise staff travel and clinical handover time.

### 5.6 Other Investment Proposals

In addition to the approval to invest further in the CRHT, the Clinical Review Group agreed that further changes to the system should be considered including whether any additional investment in terms of the community mental health teams was necessary. Effective and timely discharge from the CRHT to the community mental health teams (the Assessment and Treatment Service (ATS) is essential to ensure whole system working. The Group agreed to consider a specific proposal in terms of additional investment in the ATS and the impact this would have on bed usage at its next meeting on 18 September.

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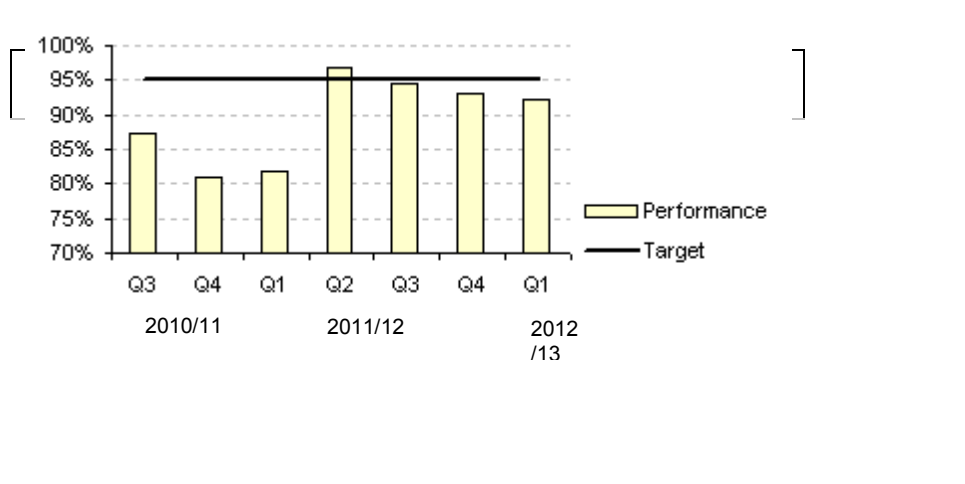
<sup>1</sup> (Glover et al, (2006) Crisis Resolution/Home Treatment Teams and Psychiatric Admissions in England.

<sup>2</sup> Department of Health, (2001) The Mental Health Policy Implementation Guide)

## 6. Update on Performance

6.1 The performance metrics were reviewed by the Clinical Review Group at the meetings on 17 July and 17 August. Key headlines are as follows.

6.2 **Access to Acute Mental Health Beds within the City.** The latest data for Quarter 1 2012-13 (April to June 2012) shows that 92% of people have been able to access a bed within the City. This is slightly below the target of 95%.



6.3 There have been no additional complaints or Serious Untoward Incidents in relation to the beds.

6.4 The hospital re-admission audit described in the June HWOSC report is in progress and the results will be reviewed at the September meeting

6.5 Plans are in place for additional patient and staff satisfaction audits, in relation to the additional .

## 7. Summary

7.1 The Clinical Review Group has agreed to additional investment in the Crisis Resolution Home Treatment Team to provide more support as an alternative to hospital admission. It will take approximately 10 weeks to recruit additional staff to the Team and the planned changes will take effect from November 2012. The Clinical Review Group anticipate being able to evaluate the changes at the end of January 2013.

7.1 This is alongside other changes planned including:

- Enhanced 24/7 Brighton Urgent Response Service
- New Intensive Day Facility for people with Personality Disorder
- Increased Supported Accommodation Options

## Appendix 1

- 7.2 The Clinical Review group has also agreed that the staffing of the Churchill Ward (Nevill Hospital) should be relocated to staff the Meridian Ward at the Millview Hospital. This move is planned to take place in October 2012 and will enable the benefits of the newly refurbished ward to be experienced by patients and the benefits around team working and consolidation of clinical expertise to be realised. The spare capacity in terms of beds will be maintained at Churchill ward and reviewed by the Clinical Review Group until any final decision to close beds. The option of re-opening beds will therefore be maintained until this point.
- 7.3 A further progress will be provided to the HWOSC next meeting including any additional investment agreed by the Clinical Review Group at its meeting on 18 September.



# Mental Health Acute Beds

## HOSC Update - June 2012

### 1. PURPOSE OF THE PAPER

The purpose of this paper is to update the HOSC regarding the proposals to reduce the number of acute mental health beds in Brighton and Hove.

### 2. BACKGROUND

Previous papers have described the rationale for the proposals and the agreed local approach to ensure the arrangements are implemented safely. The HOSC has given its support to proceed with a temporary phased reduction in bed numbers with the agreement that a Clinical Review Group will oversee the process and provide updates to the HOSC.

### 3. PROGRESS

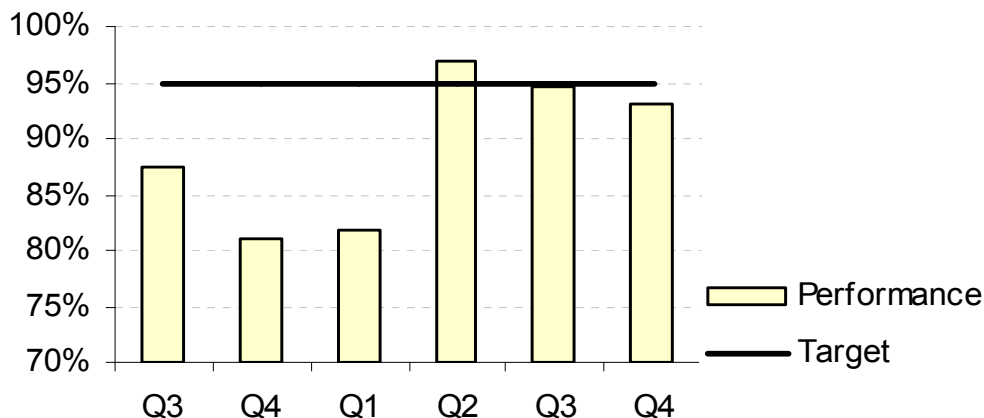
3.1 The Clinical Review group have held four meetings to date. The purpose of the group is to assess the point at which there have been sufficient system changes to enable 19 beds in Brighton and Hove to close on a permanent basis.

3.2 The Clinical Review Group has agreed a range of clinical metrics that will be monitored and measured to assess whether the system is ready for the beds to close. The metrics are detailed in Appendix A. An update on progress against key metrics are as follows:

#### 3.3 Access to Beds in Brighton and Hove.

One of the key metrics is that **95%** of residents are able to access a bed within the City. This equates to no more than 3 Brighton and Hove residents being admitted out of area at any one time (excluding female psychiatric intensive care where there is no local facility). The data contained in figure 1 plots the trend from Q3 2010 (September to December 2010) until the most recent quarter (January to March 2011). It shows that during the most recent quarter that this target has not yet been achieved – the proportion of bed occupancy within Brighton and Hove is at **93%**. There is also softer intelligence that some residents who agree to an informal admission, chose not to enter hospital treatment, if the available bed is not within Brighton and Hove. A potential negative impact is that a patient's condition could deteriorate whilst they are waiting for a local bed to become available and it may take longer for them to recover once they are admitted.

**Figure 1: Proportion of Occupied Bed Days that are located within Brighton and Hove**

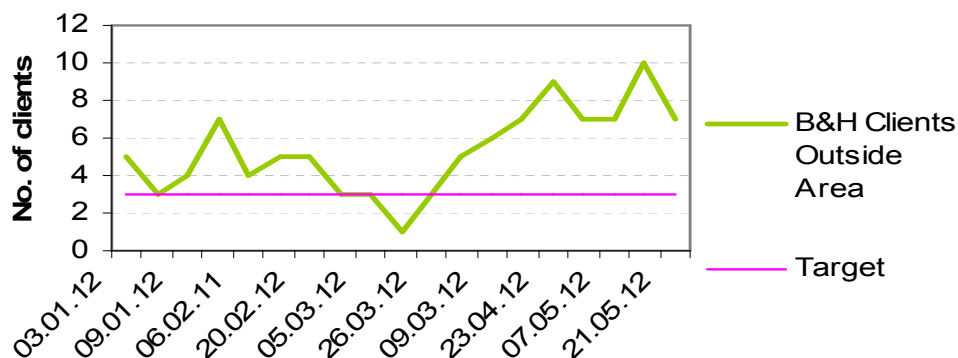


Note

Data excluded female psychiatric intensive care unit – as there is no local facility.

More detailed data for the period since January 2012 (figure 2 below shows that the target of no more than 3 Brighton and Hove residents has only been achieved for 5 out of the 19 weeks (26% of the time). However it needs to be recognised that within the data for admissions outside Brighton and Hove included are small numbers of people where this is appropriate e.g. (a patient still registered with a Brighton and Hove GP but living in another part of Sussex, or because they are member of Millview Hospital staff, or because of patient choice).

**Figure 2: Number of B&H Residents Admitted Out of Area**

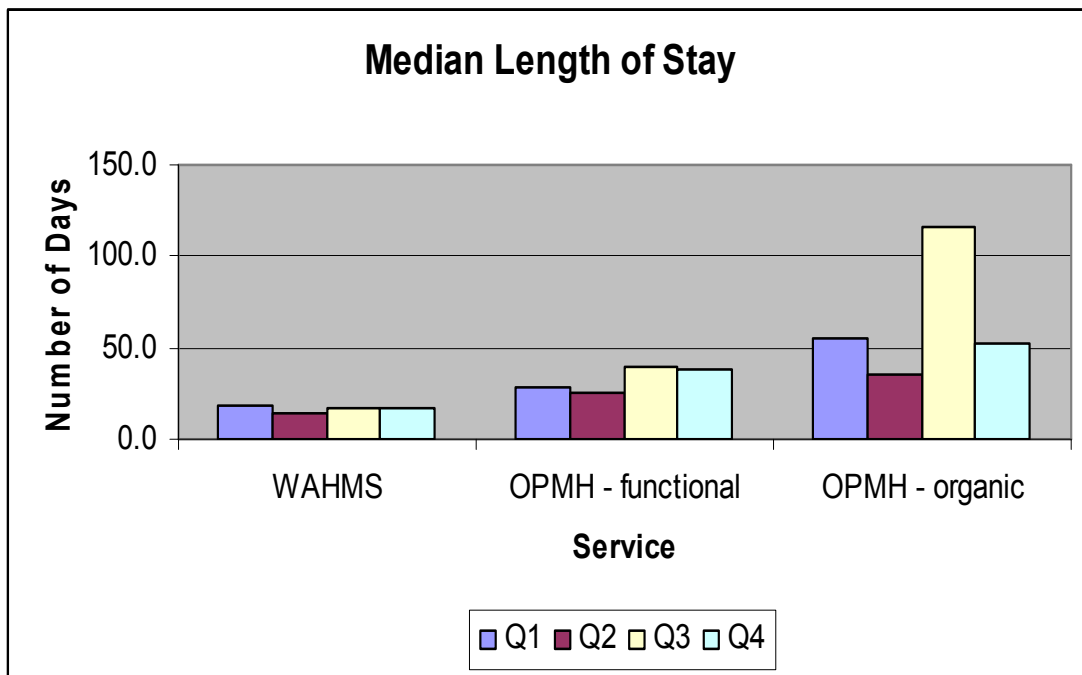


**3.4 Length of Stay**

Median Length of stay has fluctuated, with increases shown in older people services for the last two quarters of 2011-12. The data is detailed below in Figure 3.



**Figure 3: Median Length of Stay**



Notes

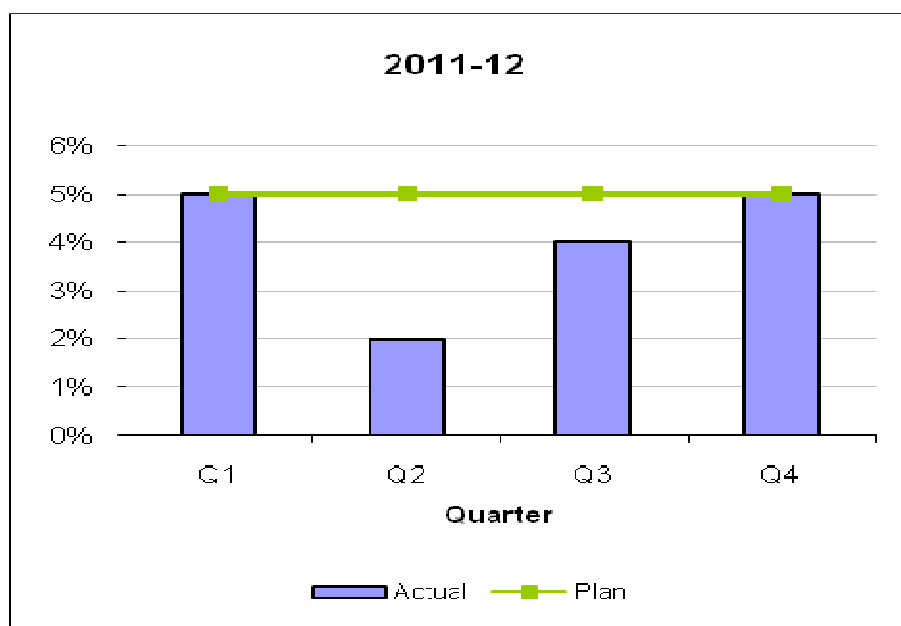
WAHMS – Working Aged Mental Health Service

OPMH – Older People Mental Health Service

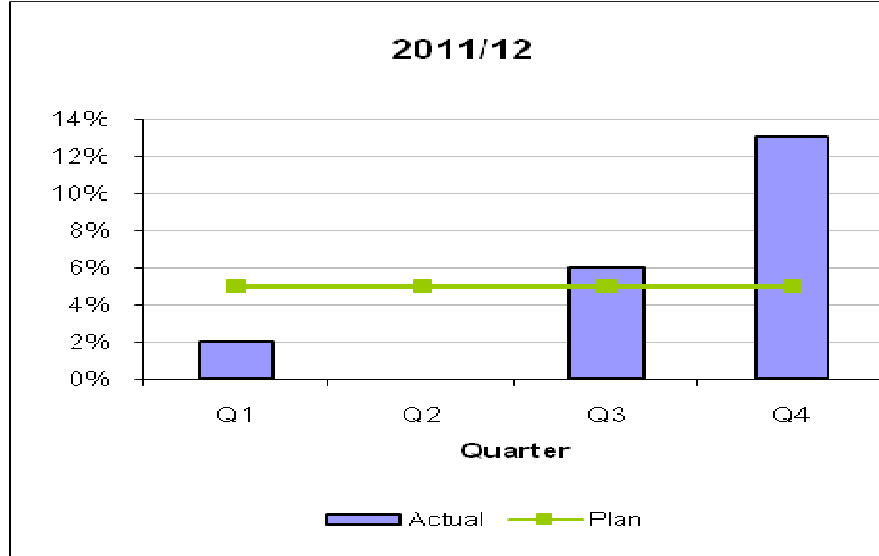
**3.5 Delayed Transfer of Care**

The target is for delayed transfers of care to be no more than 5%. For working aged service the figure has stayed at 5% or below during 2011-12, but for older people the target has not been achieved for quarters 3 and 4 of 2011-12. Lack of suitable supported accommodation remains one of the key reasons for delayed transfer of care.

**Figure 4 – Delayed Transfer of Care – Working Age Services**



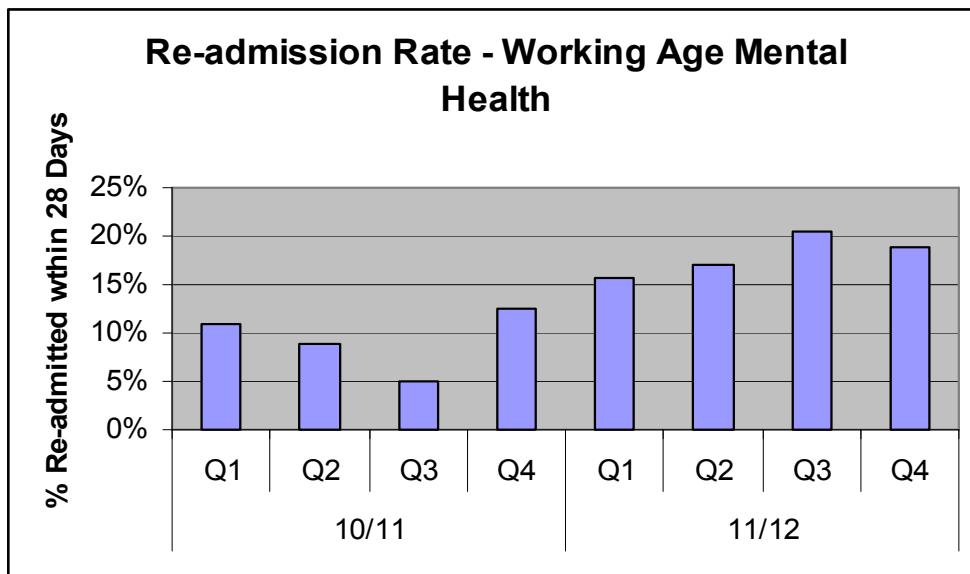
**Figure 5 – Delayed Transfer of Care – Older People Services**



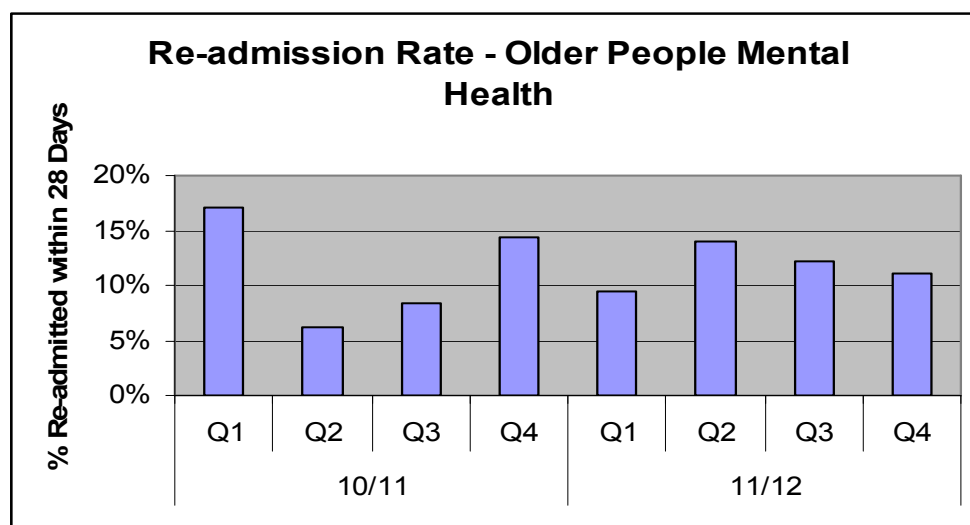
**3.6 Re-admission Rates**

Re-admission rates appear to have increased in 2011-12 compared with the previous year for working age services (figure 6). The pattern appears to be more variable in older people services (figure 7). Sussex Partnership Foundation Trust (SPFT) is undertaking a more detailed clinical audit to examine and understand this issue in more detail.

**Figure 6 – Re-admission Rates – Working Age Services**



**Figure 7: Re-admission Rates – Older People Services**



### 3.7 Complaints & Serious Untoward Incidents (SUI's)

Over the period September 2011 to April 2012 a total of 31 complaints were received by SPFT relating to Millview Hospital and urgent care services in Brighton and Hove. Three of these related to access to beds

- Long wait in A&E for assessment and delay in admission due to bed availability.
- Two people raised concerns about admission outside of Brighton and Hove.

All three complaints have been investigated and responded to.

In addition there has been a recent unexpected death of a patient being care for by the crisis team. This SUI is in the process of being investigated. Part of the scope of this investigation will include attempting to establish whether the incident had any connection with inpatient bed availability.

## 4. PLANS TO ENHANCE COMMUNITY MENTAL HEALTH SERVICES

There a further updates to report on two important ongoing pieces of work that will contribute to the reduction in number of admissions and the length of stay:

- ### 4.1 Development of a community based service for people with personality disorder.
- We have reached agreement to develop a new community based facility which will help support people with personality disorder in the community and prevent some hospital admissions. The new service will start in April 2013. SPFT will provide the overall management of the service as well as the clinical aspects of service delivery. The CCG is currently inviting bids via our Commissioning Prospectus for the community and voluntary sector to provide a range of supporting activities such as peer support and volunteering opportunities, and a range of social and therapeutic activities.

**4.2 Improvement of Supported Accommodation** Delayed transfers of care due to housing still remains a significant issue. Bench-marking work undertaken in 2012 has identified opportunities to secure improved value for money from the funding available for mental health accommodation support. During 2012 the CCG plan to under-take a procurement process and re-commission an increased number of units of supported accommodation to help prevent delayed transfers of care due to insufficient support accommodation. It is anticipated that increased accommodation units will be available from June 2013.

**4.3** In addition to the updates on these two developments, SPFT have undertaken a review of the crisis resolution home treatment team (CRHT) and the team will be working more closely with the wards to help facilitate early discharge from hospital. These changes will be introduced on a three month pilot basis and the effectiveness will be evaluated.

## **5. SUMMARY**

Since January 2012, 15 beds have been temporarily closed at Millview Hospital whilst we have been testing out the safety of the system in terms of operating with fewer beds and also to undertake refurbishment work. A range of metrics have been agreed via the Clinical Review Group and it is evident that the targets have not yet been achieved. The two key developments that have been identified as supporting the bed closures (increased units of supported accommodation and a community based personality disorder service) will not be available until 2013. The fundamental question for the Clinical Review group to consider and agree at the next meeting on 3<sup>rd</sup> July is whether the beds should re-open until these key developments are in place.

## **6. RECOMMENDATION**

The recommendation of the clinical review group is that the system is not yet ready to close beds on a permanent basis. The clinical review group at its' next meeting on 3<sup>rd</sup> July will consider whether the beds should re-open until further improvements to community mental health support services are in place.

## Appendix A

### CLINICAL METRICS

	Description	Target
1	Access to Bed in Brighton & Hove	95% of patients able to access bed in the City
		Length of wait for CRHT assessment
		Length of time between the decision to admit & the time a bed is identified
2	Average Length of Stay	WAHMS 28 days
		OPMH - functional 50 days
		OPMH - organic 60 days
3	Median Length of Stay	WAHMS
		OPMH - functional
		OPMH - organic
4	Admission Rates	WAHMS 73 per 100,000 weighted population
		OPMH - functional 48 per 100,000 weighted population
		OPMH - organic 106 per 100,000 weighted population
		Variation in admission rate over the course of the year
5	Re-admission Rates	No increase in the emergency re-admissions rates (no of emergency re-admissions within 28 days)
6	Delayed Transfer of Care	Less than 5%
7	Impact on Recovery Teams	7 Day Follow Up from discharge from CRHT
8	Impact on CRHT Team	CRHT caseload To be agreed following output of CRHT review
9	Number of complaints	
10	Number of Adverse Incidents	
11	Number of SUI's	



# HEALTH & WELLBEING OVERVIEW & SCRUTINY COMMITTEE

## Agenda Item 32

Brighton & Hove City Council

<b>Subject:</b>	<b>Local Implementation of 111 Services and Associated Change to Out of Hours</b>		
<b>Date of Meeting:</b>	<b>11 September 2012</b>		
<b>Report of:</b>	<b>Strategic Director, Resources</b>		
<b>Contact Officer:</b>	<b>Name:</b>	<b>Kath Vlcek</b>	<b>Tel: 29-0450</b>
	<b>Email:</b>	<b>Kath.vlcek@brighton-hove.gov.uk</b>	
<b>Ward(s) affected:</b>	<b>All</b>		

### FOR GENERAL RELEASE

#### 1. SUMMARY AND POLICY CONTEXT:

- 1.1 '111' is the new NHS service to deal with emergencies that do not require a 999 response.
- 1.2 This item will explain the local plans for implementing the nationally agreed service model and how this will impact upon local GP out of hours services.
- 1.3 **Appendix 1** to this report includes further information supplied by the Brighton & Hove Clinical Commissioning Group.

#### 2. RECOMMENDATIONS:

- 2.1 That the HWOSC:  
  
Considers and comments on the report

#### 3. RELEVANT BACKGROUND INFORMATION/CHRONOLOGY OF KEY EVENTS:

- 3.1 NHS 111 is a new service that is being introduced to make it easier to access local NHS healthcare services when medical help is needed but it is not a 999 emergency situation. NHS 111 is intended to be a fast and easy way to get the right help throughout the day and night.
- 3.2 The NHS 111 service is staffed by a team of fully trained advisers, supported by experienced nurses. They will ask questions and then give the healthcare advice needed or direct the patient straightaway to the local service that can help best, ranging from A&E, an out-of-hours doctor, a walk-in centre, a community nurse, an emergency dentist or a late-opening chemist.
- 3.3 From 19th March 2013, the NHS 111 service in Sussex will be provided by a partnership between South East Coast Ambulance Service NHS Foundation Trust (SECAmb) and Harmoni.

#### **4. COMMUNITY ENGAGEMENT AND CONSULTATION**

- 4.1 None to this report for information but the national pilot has involved consultation with stakeholders.

#### **5. FINANCIAL & OTHER IMPLICATIONS:**

- 5.1 None to this report for information.

Legal Implications:

- 5.2 None to this report for information.

Equalities Implications:

- 5.3 None to this report for information.

Sustainability Implications:

- 5.4 None to this report for information.

Crime & Disorder Implications:

- 5.5 None to this report for information.

Risk and Opportunity Management Implications:

- 5.6 None to this report for information.

Public Health Implications:

- 5.7 The report focuses on how the nationally agreed '111' service will impact upon local GP out of hours services.

Corporate / Citywide Implications:

- 5.8 None to this report for information.

#### **SUPPORTING DOCUMENTATION**

##### **Appendices:**

1. NHS 111 – 'when it's less urgent than 999'

##### **Documents in Members' Rooms**

1. None



## **Background Documents**

1. None
- 2.



## **NHS 111 – ‘when it’s less urgent than 999’**

### **Context**

The development of NHS 111 as a new national NHS service, providing a telephone advice line for patients with urgent health problems which require assessment but which are not so serious as to require a 999 call, was identified in the White Paper, *Liberating the NHS*. The service will be available free to callers, 24 hours a day, 7 days a week, 365 days a year and will absorb the calls currently going to NHS Direct and our GP OOH services. NHS 111 makes it easier for people to access local NHS healthcare services

NHS 111 will incorporate services already offered by NHS Direct and the telephony components of the GP OOH services.

### **When to contact NHS 111?**

- Need medical help fast but its not a 999 emergency
- Don't have a GP or know how to access healthcare
- Think you need A&E or other urgent care service
- Need health information, reassurance or advice on what to do next

### **What will NHS 111 do?**

- Clinical assessment without the need for a call back
- Dispatch an ambulance without delay
- Refer callers to services with appropriate skills and capacity to meet their needs
- Provide information / advice to callers who can care for themselves
- Transfer clinical assessment data to other providers / book appointments where appropriate
- Provide a Professional Support Line

### **Mobilisation in Sussex**

In order to be as efficient as possible, a single procurement across Kent, Surrey and Sussex was conducted in order to secure a high quality service that is value for money.

From 19th March 2013, the NHS 111 service in Sussex will be provided by a partnership between South East Coast Ambulance Service NHS Foundation Trust (SECAmb) and Harmoni. Assessment of the bidders was carried out by a panel including a number of GPs against a rigorous set of criteria to determine which bidder was best able to deliver the service to the standard required for patients in our health economy.

When someone phones 111, a trained call handler, supported by appropriate health professionals, will provide them with a clinical assessment using NHS Pathways at the first point of contact, without the caller having to wait for a call back. NHS Pathways will be underpinned by a local 'Directory of Services' (DoS), which will provide the call handler with real time information about local services available to support a particular patient.

GPs and other health professionals will also be able to phone 111 or use a web based version of the DoS to get real time information on available services.

The new NHS 111 service will provide telephone triage and assessment, both in and out of hours, and will advise the patient or direct to the most appropriate local service available including GP Practices.

The current professional support line function that is currently provided by HERMES will also be incorporated into the 111 service.

### **What are the benefits?**

The benefits of 111 are:

- Improved access to urgent care services
- Improving efficiency of NHS services
- Increasing public satisfaction & confidence in using NHS services
- Enables design and commissioning of more effective and efficient services

### **Out of Hours Service (OOH)**

The current OOH contract is being extended for 6 months and the CCG procuring a new service to start on 1st October 2013. It is expected that there may be an increase in OOH activity as a result of NHS 111 but these numbers have not yet been quantified. Mitigation of possible increases in OOH will be through the population of the Directory of Services to its maximum potential.