CHILDREN & YOUNG PEOPLE’S HEALTH OUTCOME FORUM:

How will this impact on disabled children?

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Co-Chair, Children and Young People’s Health Outcomes Forum
CHILDREN & YOUNG PEOPLE
HEALTH OUTCOME FORUM

ROLE:

The Forum was launched on 26 January and will be reporting to the Government with independent advice later this year on:

• the health outcomes that matter most for children and young people
• how well these are supported by the NHS and Public Health Outcomes Framework
• how the different parts of the health system will contribute and work together in the delivery of these outcomes
CHILDREN & YOUNG PEOPLE’S HEALTH OUTCOME FORUM:

From February to April -

• the Forum will develop outcome indicators and measures
• Will meet with children, young people, parents, carers, doctors, nurses and other professionals involved in providing care to children
• Will start to meet key individuals

From March to May -

• The forum will develop its views of system requirements; the ‘strategy’ and outputs

End of June -

• The Forum will report back to the Government and publish their recommendations.
WHAT WE ALL HAVE TO DO

- Develop a suite of outcome indicators / measures
- Develop our thoughts about the ‘system’ and what will realistically support delivery of these outcomes
- Engage with listening to children, young people, families, professionals
- Identify, meet, listen to and influence key individuals and a range of organisations
- Produce outputs that will create positive change and improvement
Children and Young People’s Health Outcomes Forum

‘No decision about me without me’

Life Course

Premature/ LBW
Early Years
School child
Teenager
Young Adult

Key Themes

Promoting Health
Acute illness
Long term condition
Disability
Palliative Care
Mental Health
Looked after children

Cross cutting Issues 1

Integrating services
General Practice
Safeguarding
Transition to adult services
Technology
Choice
Information and data

Cross cutting Issues 2

Education & Workforce development
Clinical leadership
Aligning NHS, PH and care outcomes
Levers of funding – PbR / CQuiNs
Networks – local / hub; specialised; national
7 key principles are proposed to underpin the development of the NHS outcomes Framework

- Accountability and transparency
- Balanced
- Internationally comparable
- Focussed on what matters to patients and clinicians
- Promoting excellence and equality
- Focussed on outcomes that the NHS can influence but working in partnership with other public services where required
- Evolving over time
NHS Outcomes Framework

1. Domain 1: Preventing people from dying prematurely
2. Domain 2: Enhancing quality of life for people with long-term conditions
3. Domain 3: Helping people to recover from episodes of ill health or following injury
4. Domain 4: Ensuring that people have a positive experience of care
5. Domain 5: Treating and caring for people in a safe environment of protecting them from avoidable harm

NICE Quality Standards
(Building a library of approx 150 over 5 years)

3. Commissioning Outcomes Framework
4. Commissioning Guidance
5. Provider payment mechanisms
   - tariff
   - standard contract
   - CQUIN
   - QOF

6. Commissioning/Contracting
   - NHS Commissioning Board - certain specialist services and primary care
   - GP consortia - all other healthcare services
Vision: To improve and protect the nation’s health and wellbeing and improve the health of the poorest fastest

Outcome 1: Increased healthy life expectancy
*Taking account of the health quality as well as the length of life.*
(Note: This measure uses a self-reported health assessment, applied to life expectancy.)

Outcome 2: Reduced differences in life expectancy & healthy life expectancy between communities
*Through greater improvements in more disadvantaged communities.*
(Note: These two measures would work as a package covering both morbidity and mortality, addressing within-area differences and between area differences)
## Developing a Patient Centred Outcomes Approach

<table>
<thead>
<tr>
<th>Patient Questions /Statements</th>
<th>Pathway Stage</th>
<th>Outcome measures / Indicators</th>
</tr>
</thead>
<tbody>
<tr>
<td>How do I stay healthy?</td>
<td>PREVENTION</td>
<td>Immunisation rates</td>
</tr>
<tr>
<td>How do I stay out of hospital?</td>
<td>HEALTH PROMOTION</td>
<td></td>
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<tr>
<td>I have a problem – can you help me?</td>
<td>PRESENTATION</td>
<td>Out of hours attendances at ED (A and E)</td>
</tr>
<tr>
<td>How quickly?</td>
<td>ASSESSMENT /DIAGNOSIS – REFERRAL(S)</td>
<td>Time 1st symptom to diagnosis – Long term condition</td>
</tr>
<tr>
<td>What is wrong with me?</td>
<td>DISCUSSION ABOUT DIAGNOSIS AND MANAGEMENT OPTIONS</td>
<td>Patient /parent reported experience</td>
</tr>
<tr>
<td>How quickly can I find out?</td>
<td></td>
<td></td>
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<tr>
<td>Am I in the right place?</td>
<td></td>
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<tr>
<td>Are you the best person for me to see?</td>
<td></td>
<td></td>
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<tr>
<td>I need clear and accurate information, delivered with empathy. Can you help me decide what is best?</td>
<td>DISCUSSION ABOUT DIAGNOSIS AND MANAGEMENT OPTIONS</td>
<td></td>
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<tr>
<td>What choices do I have?</td>
<td></td>
<td></td>
</tr>
<tr>
<td>I want best treatment. How do I know I am getting it?</td>
<td>INTERVENTION(S) MANAGEMENT / TREATMENT – IMMEDIATE /ACUTE</td>
<td>Hospital acquired infection rates</td>
</tr>
<tr>
<td>How does it compare with elsewhere?</td>
<td></td>
<td></td>
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<tr>
<td>What are the effects of treatment?</td>
<td></td>
<td></td>
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<tr>
<td>How do I know I am getting best treatment? How do I maintain normality?</td>
<td>INTERVENTION(S) MANAGEMENT / TREATMENT – LONG TERM CONDITION</td>
<td>International comparator benchmarking eg survival</td>
</tr>
<tr>
<td>How can I prevent getting worse / returning to hospital? Might this include self-treatment?</td>
<td>END OF LIFE CARE</td>
<td></td>
</tr>
<tr>
<td>How does it affect my daily living? What kind of choices do I have?</td>
<td>OFF TREATMENT - FOLLOW UP - DISCHARGE</td>
<td>Emergency admission rates</td>
</tr>
<tr>
<td>Do I need to watch out for anything?</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Can I just come back if I have a problem again? Would I benefit from being reviewed?</td>
<td></td>
<td></td>
</tr>
<tr>
<td>How do I stay healthy and out of hospital?</td>
<td>PREVENTION</td>
<td>Long term complication rates</td>
</tr>
</tbody>
</table>
Overarching themes and emerging issues – from all groups (1)

• These may form the basis of overarching outcome measures, which seek whole system input and commitment to deliver.

• These include:
  o Measures of children, young people and parents being empowered to make choices, through better information, building resilience and self-esteem
  o Patient experience measures routinely including young people in all healthcare settings
Overarching themes and emerging issues – from all groups (2)

- Measure of time from first presentation to NHS service to established diagnosis for a range of conditions
- Internationally comparable outcomes for a range of conditions e.g. mortality / HbA1c
- Safety outcomes of relevance to children and young people
<table>
<thead>
<tr>
<th>Outcome</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>A: 1- 4</td>
<td>Generic Outcomes/Life Goals</td>
</tr>
<tr>
<td>1</td>
<td>Educational attainment and progress</td>
</tr>
<tr>
<td>2</td>
<td>Pupil absence</td>
</tr>
<tr>
<td>3</td>
<td>Quality of life of child, young person or their family</td>
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<td>4</td>
<td>Emotional wellbeing</td>
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<tr>
<td>B: 5 -10</td>
<td>Process/Patient Experience</td>
</tr>
<tr>
<td>5</td>
<td>Time taken to diagnosis</td>
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<tr>
<td>6</td>
<td>Key worker – coordinator of care</td>
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<tr>
<td>7</td>
<td>Integrated care – a single plan</td>
</tr>
<tr>
<td>8</td>
<td>Knowledge and understanding to enable the child or young person to manage their condition</td>
</tr>
<tr>
<td>9</td>
<td>Provision of a service for each disease/disorder/condition over a lifetime</td>
</tr>
<tr>
<td>10</td>
<td>Transition, Independent living and autonomy</td>
</tr>
</tbody>
</table>
### Examples of specific diseases, disorders and conditions

<table>
<thead>
<tr>
<th>C: 11 - 25</th>
<th>Examples</th>
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</tr>
</thead>
<tbody>
<tr>
<td>11</td>
<td>Acquired brain injury</td>
<td></td>
</tr>
<tr>
<td>12</td>
<td>Cerebral Palsy</td>
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<tr>
<td>13</td>
<td>Feeding/swallowing problems</td>
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<tr>
<td>15</td>
<td>Diabetes</td>
<td></td>
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<tr>
<td>16</td>
<td>Asthma</td>
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<tr>
<td>18</td>
<td>Palliative care: Improving the quality of end of life experience</td>
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<tr>
<td>19</td>
<td>Palliative care: Improving symptom management</td>
<td></td>
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<tr>
<td>20</td>
<td>Supporting continence</td>
<td></td>
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<tr>
<td>21</td>
<td>Cancer</td>
<td></td>
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<tr>
<td>22</td>
<td>Atopic excema</td>
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<tr>
<td>24</td>
<td>Epilepsy</td>
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</tbody>
</table>
THE NEW SYSTEM

Department of Health

NHS

NHS Commissioning Board

Monitor (economic regulator)

CQC (quality)

HealthWatch

Clinical Commissioning Group

Providers

Public Health England

(Local health improvement in LAs)

Local authorities (via health & wellbeing boards)

Local HealthWatch
System challenge: Disabled Children

• Defining and agreeing national leadership and accountability
• Understanding and ensuring effective local integration
• Ensuring effective commissioning pathways
• Ensuring patient voice for disabled children, young people and families
• Understanding and harnessing the role of regulators and quality
What have we done

• Met with each part of the system in turn
• Started to develop commissioning pathways
• Looked at roles of Health and Well Being Boards
• Met with Ministers re: Healthwatch and patient voice and looked at the Constitution
• Met with Regulators
Key linkages for disabled children

• Alongside more work on managing meds in schools /school health services and role of school nursing
• Guidance on access to education for children with medical need
• Looking at developments in AQP
• Cross over with next steps
• Ensuring linking into the CAMHS agenda
Links to Next Steps progress document: requests of the forum (1)

- Recommendations from Outcomes Forum and early findings from the Green Paper pathfinders will be considered and used to inform the Children and Families Bill on joint commissioning.
- Reflect on the NHS Future Forum’s recommendations on Integrated Care and link to own recommendations and outcomes for disabled children and those with SEN.
Links to Next Steps progress document: requests of the forum (2)

• To consider the routes of redress available to children, young people and their families as part of the Outcomes Forum’s recommendations.

• NHS Future Forum working group asked to look at securing improvements for this group of children as part of its work considering how the constitution can be strengthened.
Developing recommendations

• Work in progress but;
• Use of NHS Unique identifier
• Maximising use of NHS Constitution
• On workforce and levels of skills
• On Children’s Networks
• Children and young Peoples intelligence forum
Supporting Children with additional needs—information and data (1)

• The absence of high quality data on children with disability, life limiting conditions and complex needs must be addressed as a matter of urgency.

• This makes both service planning and improving outcomes for these children difficult. A task force should be established immediately to identify solutions to this problem.

• Children with complex chronic conditions or life limiting conditions must have a care plan which is electronically accessible from all care settings.
Supporting Children with additional needs-information and data (2)

• Introduce clinical coding into outpatient settings in order to track and improve outcomes for children with complex conditions and long term disabilities.

• Improve the coverage, content and shared standards of locally held disability registers.
Health and Wellbeing Boards and Children

Signposts to Resources

- The Department of Health Children and Young People’s Health Outcomes Strategy (due to be published in July 2012)
- A plethora of Local Government Association resources, collated by the LGA (links to be provided by Sam)
- Local authority child health priorities (published by the Child and Maternal Health Observatory - ChMat) – www.chimat.org.uk/profiles
- The NHS Atlas of Variation in Healthcare for Children and Young People - www.chimat.org.uk/variation
- NHS Confederation review of policy documents on children and young people’s health and wellbeing (to be posted on the Knowledge Hub)
- Assured Safeguarding - GP and Health Leader Edition (safeguarding advice for GP and health leaders developed by the East Midlands group of Directors of Children’s Services) – www.jnep.com
- Commissioning Child Health and Wellbeing Services (information and guidance framework developed by the East of England Strategic Network for Child Health and Wellbeing Commissioning Champions) - EOE Info and guidance framework
- National Institute for health research (for health related research materials) – www.nihr.ac.uk

The Spectrum of Children’s Health Needs
(taken from the project scope of the NHS Children and Young People’s Health Outcomes Forum)

- Health promotion and improvement
- Primary Care
- Children with poor mental health
- Urgent Care for Children with acute illness
- Children with long term conditions
- Children with complex health needs
- Children with disabilities
- Looked after children
- Palliative care
- Ensuring the use of medicines for children optimises health outcomes
- The health sector’s contribution to safeguarding children
- The health sector’s contribution to support for troubled families

Vision
That Health and Well-Being Boards make an effective contribution to improve health and well-being outcomes for children and young people.

Key Questions and Challenges for Boards

- Does the Health and Wellbeing Board link effectively with the local Children's Trust and Safeguarding Board to ensure cohesive governance and leadership across the children’s agenda?
- Does the Health and Wellbeing Board have an agreed process to ensure children’s issues receive sufficient focus?
- Has the Health and Wellbeing Board contributed to defining the early help offer as recommended by Professor Munro?
- Is the Health and Wellbeing Board making appropriate use of local mechanisms to listen to the views of children and young people?
- Does the local Health and Wellbeing Strategy analyse and prioritise the health needs of children and describe success?
- Has the Health and Wellbeing Board agreed models of local integration which are proven to work?
- Has the Health and Wellbeing Board got an agreed method of engaging with schools?
- Has the Health and Wellbeing Board got a clear plan to maximise the use of public assets (children’s centres, schools, youth services, health centres etc.) to improve health outcomes for children?

Key Success Factors

- A local partnership, dedicated to children and young people (linked into the Governance of Health and Wellbeing Boards) is essential
- Commissioning of NHS services for children and young people must sit alongside commissioning of all services for children (the concept of holistic commissioning)
- Health and Wellbeing Boards should prioritise interventions for children and young people which are proven to work
- Commissioning of services should be informed by views of children and young people
- Health and Wellbeing Boards should ensure a focus on early intervention
And finally...

• The coming together of SEN Next Steps and the Forum gives us an unprecedented opportunity to bring together key systems around the needs of disabled children, young people and their families

• How are YOU going to help us maximise it