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
The Forum, jointly 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:
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 & 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 - 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.
Children and Young People’s Health Outcomes Forum
‘No decision about me without me’

**Key Themes**
- Promoting Health
- Acute illness
- Long term condition
- Disability
- Palliative Care
- Mental Health
- Looked after children

**Life Course**
- Premature/ LBW
- Early Years
- School child
- Teenager
- Young Adult

**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
The framework will be organised around 5 national outcome goals /domains that cover all treatment activity for which the NHS is responsible

How **EFFECTIVE** the care provided by the NHS is
What the patient **EXPERIENCE** is like
How **SAFE** the care provided is

The five domains will cover the range of activities that the NHS should be delivering for all patients

<table>
<thead>
<tr>
<th>Domain 1</th>
<th>Domain 2</th>
<th>Domain 3</th>
<th>Domain 4</th>
<th>Domain 5</th>
</tr>
</thead>
<tbody>
<tr>
<td>Preventing people from dying prematurely</td>
<td>Enhancing quality of life for people with long-term conditions</td>
<td>Helping people to recover from episodes of ill health or following injury</td>
<td>Ensuring people have a positive experience of care</td>
<td>Treating and caring for people in a safe environment and protecting them from avoidable harm</td>
</tr>
</tbody>
</table>

- **Effectiveness**
- **Patient experience**
- **Safety**
Preventing people from dying prematurely

**Overarching Indicator**
Frames NHS Commissioning Board’s broader responsibilities

**Improvement Areas**
Outcome Indicator
SofS holds NHS Commissioning Board to account for progress

**Supporting Quality Standards**
Support commissioning of high quality service

- **Heart disease**
  - e.g. premature mortality

- **Cancer**
  - e.g. 1 and 5 yr survival

- **Stroke**
  - e.g. premature mortality

- **Children**
  - e.g. infant mortality; Neonatal mortality and stillbirths

- e.g. Older people
  - e.g. healthy life expectancy age 65

A suite of Quality Standards will support the delivery of improved outcomes in this domain
Enhancing quality of life for people with long-term conditions

**Overarching Indicator**
- Frames NHS Commissioning Board's broader responsibilities

**Improvement Areas**
- **Outcome Indicator**
  - SofS holds NHS Commissioning Board to account for progress

**Supporting Quality Standards**
- Support commissioning of high quality service

**Children and Young People**
- e.g. Composite indicator based on Patient Reported Outcome Measures for a range of long-term conditions
- e.g. Unplanned hospitalisation for asthma, diabetes, epilepsy

**Working Age adults**
- e.g. ability to work
- e.g. avoidable admissions

**Older People**
- e.g. ability to live independently
- e.g. avoidable admissions

**A suite of Quality Standards will support the delivery of improved outcomes in this domain**
Helping people to recover from episodes of ill health or following injury

Overarching Indicator
Frames NHS Commissioning Board’s broader responsibilities

Improvement Areas
Outcome Indicator
SofS holds NHS Commissioning Board to account for progress

Supporting Quality Standards
Support commissioning of high quality service

A suite of Quality Standards will support the delivery of improved outcomes in this domain

Planned care
- e.g. PROMs for elective surgery

Unplanned care – children
- Emergency admissions for LRTI

Unplanned care – adults
- Outcome Indicator

Unplanned care – older people
- Outcome Indicator

e.g. Emergency hospital admissions for acute conditions usually managed in primary care;
and

- Emergency bed days associated with repeat acute admissions
Improvement Areas

Outcome Indicator

Overarching Indicator

Frames NHS Commissioning Board’s broader responsibilities

Supporting Quality Standards

SofS holds NHS Commissioning Board to account for progress

Support commissioning of high quality service

A suite of Quality Standards will support the delivery of improved outcomes in this domain

Ensuring people have a positive experience of care

e.g. Composite Patient Experience Indicator

e.g. A&E, in-patient, out-patient
   e.g. patient survey

e.g. primary care services
   e.g. patient survey

e.g. mental health services
   e.g. patient survey

e.g. maternity services
   e.g. patient survey

e.g. children and young people
   e.g. patient/parent survey

e.g. end of life care
   e.g. bereaved relative survey

e.g. mental health services
   e.g. patient survey

e.g. end of life care
   e.g. bereaved relative survey

SofS holds NHS Commissioning Board to account for progress

Support commissioning of high quality service

A suite of Quality Standards will support the delivery of improved outcomes in this domain

Ensuring people have a positive experience of care
Improvement Areas

Outcome Indicator

Overarching Indicator
Frames NHS Commissioning Board's broader focus

Improvement Areas

Outcome Indicator

Safe Treatment
  e.g. Never Events, VTE, Falls

Safe discharge
  e.g. Emergency Readmissions

Patient Environment
  e.g. minimising avoidable infections

Safety culture
  e.g. Openness about mistakes

Vulnerable Groups
  e.g. Maternity, Older People

Children
  Harm due to ‘failure to monitor’

Supporting Quality Standards
Support commissioning of high quality service

Supporting Quality Standards
A suite of Quality Standards to support delivery of improved outcomes in this domain

Treating and caring for people in a safe environment and protecting them from avoidable harm

e.g.
Number of incidents reported (rising);
and
Severity of harm (decreasing);
and
Number of similar incidents (decreasing)
OUTCOMES

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)

DOMAINS

DOMAIN 1: Improving the Wider Determinants of Health
Objective: Improvements against wider factors which affect health and wellbeing and health inequalities
Indicators Across the life course

DOMAIN 2: Health Improvement
Objective: People are helped to live healthy lifestyles, make healthy choices and reduce health inequalities
Indicators Across the life course

DOMAIN 3: Health Protection
Objective: The population’s health is protected from major incidents and other threats, whilst reducing health inequalities
Indicators Across the life course

DOMAIN 4: Healthcare public health & preventing premature mortality
Objective: Reduced numbers of people living with preventable ill health and people dying prematurely, whilst reducing the gap between communities.
Indicators Across the life course
# Improving the Wider Determinants of Health

## Objective

Improvements against wider factors which affect health and wellbeing and health inequalities

## Indicators

- Children in poverty
- *School readiness (Placeholder)*
- Pupil absence
- First time entrants to the youth justice system
- 16-18 year olds not in education, employment or training
- People with mental illness or disability in settled accommodation
- *People in prison who have a mental illness or significant mental illness (Placeholder)*
- Employment for those with a long-term health condition including those with a learning difficulty/disability or mental illness
- Sickness absence rate
- *Killed or seriously injured casualties on England’s roads*
- Domestic abuse
- Re-offending
- *The percentage of the population affected by noise (Placeholder)*
- Statutory homelessness
- **Utilisation of green space for exercise/health reasons**
- Fuel poverty
- *Social contentedness (Placeholder)*
- Older people’s perception of community safety (Placeholder)
## The Domains

### Health improvement

**Objective**
People are helped to live healthy lifestyles, make healthy choices and reduce health inequalities

**Indicators**

<table>
<thead>
<tr>
<th>Indicator</th>
</tr>
</thead>
<tbody>
<tr>
<td>Low birth weight of term babies</td>
</tr>
<tr>
<td>Breastfeeding</td>
</tr>
<tr>
<td>Smoking status at time of delivery</td>
</tr>
<tr>
<td>Under 18 conceptions</td>
</tr>
<tr>
<td><strong>Child development at 2-2.5 years (Placeholder)</strong></td>
</tr>
<tr>
<td>Excess weight in 4-5 and 10-11 year olds</td>
</tr>
<tr>
<td>Hospital admissions caused by unintentional and deliberate injuries in under 18s</td>
</tr>
<tr>
<td><strong>Emotional well-being of looked after children (Placeholder)</strong></td>
</tr>
<tr>
<td>Smoking prevalence – 15 year olds</td>
</tr>
<tr>
<td>Hospital admissions as a result of self-harm</td>
</tr>
<tr>
<td>Diet (Placeholder)</td>
</tr>
<tr>
<td>Excess weight in adults</td>
</tr>
<tr>
<td>Proportion of physically active and inactive adults</td>
</tr>
<tr>
<td>Smoking prevalence – adult (over 18s)</td>
</tr>
<tr>
<td>Successful completion of drug treatment</td>
</tr>
<tr>
<td>People entering prison with substance dependent issues who are previously not known to community treatment</td>
</tr>
<tr>
<td><strong>Recorded diabetes</strong></td>
</tr>
<tr>
<td><strong>Alcohol-related admissions to hospital</strong></td>
</tr>
<tr>
<td><strong>Cancer diagnosed at stage 1 and 2 (Placeholder)</strong></td>
</tr>
<tr>
<td>Cancer screening coverage</td>
</tr>
<tr>
<td>Access to non-cancer screening programmes</td>
</tr>
<tr>
<td>Take up of the NHS Health Check Programme – by those eligible</td>
</tr>
<tr>
<td>Self-reported well-being</td>
</tr>
<tr>
<td>Falls and injuries in the over 65s</td>
</tr>
</tbody>
</table>
## THE PUBLIC HEALTH OUTCOMES FRAMEWORK

### The Domains

<table>
<thead>
<tr>
<th>3</th>
<th>Health Protection</th>
</tr>
</thead>
</table>

#### Objective

The population’s health is protected from major incidents and other threats, whilst reducing health inequalities.

#### Indicators

- Air pollution
- Chlamydia diagnoses (15-24 year olds)
- Population vaccination coverage
- People presenting with HIV at a late stage of infection
- Treatment completion for TB
- Public sector organisations with board approved sustainable development management plan
- *Comprehensive, agreed inter-agency plans for responding to public health incidents (Placeholder)*
## The Public Health Outcomes Framework

### The Domains

<table>
<thead>
<tr>
<th>4</th>
<th>Healthcare public health and preventing premature mortality</th>
</tr>
</thead>
</table>

#### Objective

Reduced numbers of people living with preventable ill health and people dying prematurely, whilst reducing the gap between communities.

#### Indicators

- Infant mortality
- Tooth decay in children aged 5
- Mortality from causes considered preventable
- Mortality from all cardiovascular diseases (including heart disease and stroke)
- Mortality from cancer
- Mortality from liver disease
- Mortality from respiratory diseases
- Mortality from communicable diseases (Placeholder)
- Excess under 75 mortality in adults with serious mental illness (Placeholder)
- Suicide
- Emergency readmissions within 30 days of discharge from hospital (Placeholder)
- Preventable sight loss
- Health-related quality of life for older people (Placeholder)
- Hip fractures in over 65s
- Excess winter deaths
- Dementia and its impacts (Placeholder)
## Developing a Patient Centred Pathway

<table>
<thead>
<tr>
<th>Pathway Stage</th>
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</thead>
<tbody>
<tr>
<td><strong>PREVENTION</strong></td>
</tr>
<tr>
<td><strong>HEALTH PROMOTION</strong></td>
</tr>
<tr>
<td><strong>PRESENTATION</strong></td>
</tr>
<tr>
<td><strong>ASSESSMENT /DIAGNOSIS – REFERRAL(S)</strong></td>
</tr>
<tr>
<td><strong>DISCUSSION ABOUT DIAGNOSIS AND MANAGEMENT OPTIONS</strong></td>
</tr>
<tr>
<td><strong>INTERVENTION(S) MANAGEMENT / TREATMENT – IMMEDIATE /ACUTE</strong></td>
</tr>
<tr>
<td><strong>INTERVENTION(S) MANAGEMENT / TREATMENT – LONG TERM CONDITION</strong></td>
</tr>
<tr>
<td><strong>END OF LIFE CARE</strong></td>
</tr>
<tr>
<td><strong>OFF TREATMENT - FOLLOW UP - DISCHARGE</strong></td>
</tr>
<tr>
<td><strong>PREVENTION</strong></td>
</tr>
</tbody>
</table>
Patient Centred Pathway

At each Stage - I (the patient) need

- expertise in me (child/teenager)
- expertise in my likely condition
- things to happen quickly (rapid access)
- someone who explains to me or my family in a way I and they can understand
- dignity
- respect
- the opportunity to do things for myself
- best available treatment giving me best chance of getting better
- to be at home if possible - and if not to be in the best place for treating me.
- if in hospital that I am safe from harm (infections)
- someone who knows my family
- to have my opinion asked about the care I am receiving and how it can be improved.
## 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>
</tr>
<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></td>
<td></td>
</tr>
<tr>
<td>What is wrong with me?</td>
<td>ASSESSMENT /DIAGNOSIS – REFERRAL(S)</td>
<td>Time 1\textsuperscript{st} symptom to diagnosis – Long term condition</td>
</tr>
<tr>
<td>How quickly can I find out?</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Am I in the right place?</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Are you the best person for me to see?</td>
<td>DISCUSSION ABOUT DIAGNOSIS AND MANAGEMENT OPTIONS</td>
<td>Patient /parent reported experience</td>
</tr>
<tr>
<td>I need clear and accurate information, delivered with empathy. Can you help me decide what is best?</td>
<td></td>
<td></td>
</tr>
<tr>
<td>What choices do I have?</td>
<td>INTERVENTION(S) MANAGEMENT / TREATMENT – IMMEDIATE /ACUTE</td>
<td>Hospital acquired infection rates</td>
</tr>
<tr>
<td>I want best treatment. How do I know I am getting it?</td>
<td>INTERVENTION(S) MANAGEMENT / TREATMENT – LONG TERM CONDITION</td>
<td>International comparator benchmarking eg survival</td>
</tr>
<tr>
<td>How does it compare with elsewhere?</td>
<td></td>
<td></td>
</tr>
<tr>
<td>What are the effects of treatment?</td>
<td></td>
<td></td>
</tr>
<tr>
<td>How do I know I am getting best treatment? How do I maintain normality? How can I prevent getting worse / returning to hospital? Might this include self-treatment?</td>
<td>INTERVENTION(S) MANAGEMENT / TREATMENT – LONG TERM CONDITION</td>
<td></td>
</tr>
<tr>
<td>How does it affect my daily living? What kind of choices do I have?</td>
<td>END OF LIFE CARE</td>
<td></td>
</tr>
<tr>
<td>Do I need to watch out for anything?</td>
<td>OFF TREATMENT - FOLLOW UP - DISCHARGE</td>
<td>Emergency admission rates</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>
Developing a Patient Centred Outcomes Approach

How do I stay healthy?

I have a problem?

What is wrong with me?
How quickly can I find out?
Who is the best person to see?

Can you give me clear information, in a way that helps me decide what is best for me?

I want the best treatment?
How do I know I’m getting it?

How do I maintain normality?
Might this include treating myself?
How might it affect my daily living?
What kind of choices are there?

Do I need to keep watch on or do anything?
Would I benefit from being seen/assessed?

At each stage

1. What happens now?
2. What is needed?
3. Could it be better?
4. How might it be better? – describe it
5. What would it take?
6. What is the evidence for each of these questions/answers!!!
Wiring in system change

- Issues of accountability
- Multiple/fragmented commissioning
- JSNA
- Integration etc.....
- What would it take to build confidence?
For disabled children.....

• Key impact
• Long term conditions/disability a crucial focus of the forum
• Alongside more work on managing meds in schools /school health services etc
• Critical linkages with the Green Paper proposals
Find out more

• Updates on Children’s Forum, slidepack and feedback form available at
  • http://healthandcare.dh.gov.uk/category/children/
• For Green paper updates and responses see
  • www.councilfordisabledchildren.org.uk/greenpaperactivity