What makes a good experience?

- I am involved as an **active partner in my care**.
- I am treated as an **individual** – my needs, values and preferences are respected.
- There is a recognition that I am the **expert on me**.
- I am able to access services when I need them, and my care is **coordinated**.
- I am asked about my **communication** preferences so that communication is tailored to me.
- I have access to the **information** I need, which is presented in a way that is right for me.
- I have access to the **support** I need and is right for me, including emotional and practical support, and I am able to involve my loved ones in decisions about me.
- The **environment** in which I receive my care is clean and comfortable and makes me feel dignified.

**Abridged from:**
A growing body of evidence shows the relationship between aspects of patient experience and clinical quality

- Clinical services that are intentionally patient-centred (surgery, ITU, cardiology) achieve better clinical outcomes (Boore 1978; Hayward 1975; Shuldham 1999; Suchman 1993)

- Effective doctor-patient communication promotes compliance in medication + more active self-management of long-term chronic conditions (Bauman et al 2003)

- Anxiety and fear delay healing but are allayed by emotional and psychological support (Cole-King and Harding 2001; Norman 2003; Weinman et al 2008)
Cancer care – a rising bar:


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<table>
<thead>
<tr>
<th>Indicator</th>
<th>Indicator full name (CPES 2015 Qu No in brackets, and amended wording where applicable)</th>
<th>CPES 2014 result</th>
<th>CPES 2015 result</th>
</tr>
</thead>
<tbody>
<tr>
<td>Overall experience of care</td>
<td>CPES Qu 70 (59): Overall how would you rate your care?</td>
<td>89% excellent or very good</td>
<td>Mean 8.7 94% scored 7 - 10</td>
</tr>
<tr>
<td>Provision of information: given name of CNS</td>
<td>CPES Qu 21 (17): Were you given the name of a Clinical Nurse Specialist who would support you through your treatment?</td>
<td>89%</td>
<td>90%</td>
</tr>
<tr>
<td>Provision of information: easy to contact CNS</td>
<td>CPES Qu 22 (18): How easy is it for you to contact your Clinical Nurse Specialist?</td>
<td>73%</td>
<td>87%          <em>(Scoring options changed. Data not comparable)</em></td>
</tr>
<tr>
<td>Involvement in decisions: care and treatment</td>
<td>CPES Qu 20 (16): Were you involved as much as you wanted to be in decisions about your care and treatment?</td>
<td>72%</td>
<td>78%</td>
</tr>
<tr>
<td>Care transition: given contact after patient left hospital</td>
<td>CPES Qu 54 (39): Did hospital staff tell you who to contact if you were worried about your condition or treatment after you left hospital?</td>
<td>94%</td>
<td>94%</td>
</tr>
<tr>
<td>Care transition - support from GP during treatment</td>
<td>CPES Qu 64 (53): Do you think the GPs and nurses at your general practice did everything they could to support you while you were having cancer treatment?</td>
<td>66%</td>
<td>63%</td>
</tr>
<tr>
<td>Interpersonal relations, respect and dignity</td>
<td>CPES Qu 52 (37): Were you treated with respect and dignity by the doctors and nurses and other hospital staff?</td>
<td>84%</td>
<td>87%</td>
</tr>
</tbody>
</table>
Scores for involvement in decisions and support from GP were significantly lower for other ethnic groups.

Cancer Dashboard indicators*

- Overall, how would you rate your care? (average score)***
  - White British: 8.7
  - Other ethnic groups: 8.3

- Were you involved as much as you wanted to be in decisions about your care and treatment?***
  - White British: 78%
  - Other ethnic groups: 71%

- Were you given the name of a Clinical Nurse Specialist who would support you through your treatment?
  - White British: 90%
  - Other ethnic groups: 91%

- How easy or difficult has it been for you to contact your Clinical Nurse Specialist?***
  - White British: 87%
  - Other ethnic groups: 82%

- Overall, did you feel you were treated with respect and dignity while you were in hospital?***
  - White British: 88%
  - Other ethnic groups: 86%

- Did the doctors or nurses give your family or someone close to you all the information they needed to help care for you at home?***
  - White British: 94%
  - Other ethnic groups: 92%

- Do you think the GPs and nurses at your general practice did everything they could to support you while you were having cancer treatment?***
  - White British: 63%
  - Other ethnic groups: 57%

Options that do not provide any information on positive or negative experience (e.g. “don’t know / can’t remember”) are excluded from the scores.

** Includes other white backgrounds
*** Statistically significant differences

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Learning disability: transforming care

Death by indifference
Following up the Treat me right! report

Connor Sparrowhawk was a fit and healthy young man, who loved buses, London, Eddie Stobart and speaking his mind.

Known as LB online, short for Laughing Boy, he also happened to have autism and epilepsy.

On the 19 March 2013, he was admitted to Slade House Assessment and Treatment Unit run by Southern Health NHS Foundation Trust. Tragically, after 107 days in the unit, he drowned in the bath on 4 July 2013. An entirely preventable death.

Twelve months later 107 days seeks to inspire, collate and share positive actions being taken to support JusticeforLB and all young dudes.

We want to harness the energy, support and outrage that has emerged in response to LB’s death and ensure that lasting changes and improvements are made.

justiceforLB@gmail.com #justiceforLB
http://107daysofaction.wordpress.com/
Learning disability: transforming care

Always Events

- Pilot work demonstrated that Always Events can significantly improve experience;
- Adaptable to context but approach accelerates improvement across whole Trust;
- Now joint programme with NHS Improvement;
- Methodology being rolled out as part of Transforming Care in a range of settings, from LD services to A&E.

NHS Quality Checkers

- Widely used in social care but very limited so far in NHS;
- Inclusion East won Excellence in Participation Award at Expo 2014;
- We have now adapted methodology to different clinical settings, drawing on evidence of higher mortality;
- Trials suggest approach improves experiences and supports better outcomes;
- Plans to roll out as part of Transforming Care.
‘How can we make ending your support from Learning Disability Services better for you?’

- A place or person to contact if we need help
- A fridge magnet telling me who to contact (I lose pieces of paper and business cards)
- A photograph of the new person coming to see me
- Warning in advance that my support will be ending and the person is leaving or being replaced
- Being told who you are going to see if the person you normally see is not available
- Keeping in touch with the service. Coffee mornings, catch up events
- The person leaving introducing me to another worker I can contact
Follow-up calls: summary findings

Q1 Were you told in enough time that you were ready to move on?

Q2 Were you involved in making choices about moving on?

Q3 Have you been told who to contact if you are worried about support with your health after you left the learning disability service at Bridge House?

Q4 Did you receive a card with the contact details for Bridge House?

Q5 Will you be coming to the Pop In and Chat Session?
Helping carers support patients

‘Modelling results indicate that approximately 5% more people with dementia would remain in the community from year 3 on and that 19.3% fewer people with dementia would die in institutions over fifteen years. During those years Minnesota could save $996 million in direct care costs.’


http://content.healthaffairs.org/content/33/4/596.abstract
NHS Commitments to Carers

Commissioning Principles

• Think Carer, Think Family; Make Every Contact Count;
• Support what works for carers, share and learn from others;
• Right care, right time, right place for carers;
• Measure what matters to carers
• Support for carers depends on partnership working;
• Leadership for carers at all levels;
• Train staff to identify and support carers;
• Prioritise carers health and wellbeing;
• Invest in carers to sustain and save;
• Support carers to access local resources.

MoU/ Integration

An integrated approach to identifying and assessing Carer health and wellbeing

Standing Commission on Carers
Surrey GP Carers Registration 2016

20% of adult carers are now registered with their GP

6,000 to 22,000 carers registered in 5 years
Support for family carers

- Between 2013-2016 the number of carers identified and referred to Salford Carers Centre rose from 4790 to 6650 – a 39% increase, up to some 28% of the carer population;
- Excellent impact in identifying young carers through schools;
- GPs have to offer carers health check to 80% of list in year 1 and 100% in year 2;
- Third-wave of Salford vanguard will integrate carers’ support into integrated care;
- A new service will provide an intensive support package alongside discharge planning and following discharge.
Sometimes the questions are complicated & the answers are simple

“I firmly believe it is not just about knowing someone's name, but it runs much deeper. It is about making a human connection, beginning a therapeutic relationship and building trust. In my mind it is the first rung on the ladder to providing compassionate care.”

Kate Granger, MD
Staff experience is crucial

- 59% of NHS staff feel able to make improvements in their areas of work - 17% do not;
- 69% feel confident in raising concerns - 9% do not;
- Significant variation between NHS Trusts and professional groups.

Source: NHS Staff Survey 2015

• Implementation of Freedom to Speak Up
• Commitment 6 of Nursing & Midwifery Framework: ‘We will actively respond to what matters most to our staff and colleagues.’
Thank you

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