



Picker Institute Europe's response to the Department of Health's Consultation on the NHS Outcomes Framework

September 2014

Picker Institute Europe

Picker Institute Europe is an international charity dedicated to ensuring the highest quality health and social care for all, always. We are here to:

- Influence policy and practice so that health and social care systems are always centred around people's needs and preferences
- Inspire the delivery of the highest quality care, developing tools and services which enable all experiences to be better understood
- Empower those working in health and social care to improve experiences by effectively measuring and acting upon people's feedback

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The Picker Institute Europe warmly welcome the Department of Health's consultation on 'Refreshing the NHS Outcomes Framework 2015-16' and we appreciate the opportunity to respond.

1. About the Picker Institute

The Picker Institute is an international charity dedicated to ensuring the highest quality health and social care for all. Our work is underpinned by a commitment to the principles of person-centred care and our core aims are to:

- influence policy and practice so that health and social care systems are always centred around people's needs and preferences;
- inspire the delivery of the highest quality care, developing tools and services which enable all experiences to be better understood; and
- empower those working in health and social care to improve experiences by effectively measuring, and acting upon, people's feedback.

We are experts in measuring patient experiences and in using the results to help care providers improve quality of care in areas that matter most to patients. We are pioneers of patient experience metrics and measurement in the UK and are internationally recognised for our work in developing, implementing and coordinating healthcare surveys and feedback tools for a range of organisations, including the Department of Health and NHS trusts. We also coordinate the NHS patient and staff survey programmes on behalf of the Care Quality Commission (CQC) and NHS England respectively. And we are renowned for providing follow-on improvement services to support organisations in using their patient experience data to make a positive difference.

As such we have expertise and insight in a number of the areas the Department of Health are consulting on, in particular:

- the effectiveness of using outcomes measures (in particular measures of experience) to drive improvements in care, and the robustness of these measures (questions 1, 18, 22, 23 and 24);
- development of appropriate indicators of patient experiences of care, including those for specific patient cohorts (questions 7, 11, 16, 17, 44 and 45); and
- ways to assess inequalities in care and parity of esteem between mental and physical health (questions 8, 12 and 14).

2. The effectiveness and robustness of outcomes measures

We recognise that significant benefits can accrue from outcome measures which are used to enhance accountability and incentivise care delivery that is aligned with national and local improvement goals. Indeed, evidence shows that the impact of improvement initiatives can be detected using outcome measures. We therefore welcome the efforts made by the Department of Health in this initiative to improve the scope and coverage of their outcome measures and develop new fit-for-purpose measures against which NHS England, commissioners, and through them providers of care, will be held to account.

In order that these benefits are realised, the measures must be well-designed and properly implemented, such that the risks of perverse incentives and unintended outcomes are minimised. This requires a number of equally important prerequisites:

- a clear definition of the set of outcomes to be encouraged, reflective of the things that matter most to patients;
- choice and development of actionable outcome indicators, based on accurate and reliable data, capable of measuring what is wanted in the most direct way possible;
- a rigorous performance monitoring and evaluation system capable of monitoring trends in indicators and evaluating the extent to which current performance meets, exceeds, or falls short of desired performance; and
- a transparent and robust link between successfully delivered outcomes and subsequent reward.

We agree that the indicator inclusion criteria presented in the technical appendix, based on the principles of '*outcomes focus*', '*parsimony*', '*clarity of purpose*', '*interpretable and actionable*', '*affordable*', '*additionality*' and '*feasibility*', are broadly sensible and largely cover the necessary prerequisites for effective indicators.

However, we believe that one amendment and one addition to the criteria would be valuable. First, we suggest that the importance of '*methodological and technical soundness*' merits its inclusion as a principle in its own right rather than as part of the broader '*feasibility*' criteria. We believe the risk of perverse incentives created by inaccurate or unreliable indicators is too great to merit their maintenance in the framework, and that more explicit commitment to a principle capturing indicator robustness should be made. We also believe that, as perverse incentives can also occur even when indicators are as accurate and reliable as possible, evaluation of the '*soundness*' criteria should include consideration of the indicator's intended and unintended impacts.

Second, we believe that the Department of Health could do much more to ensure that the outcome measures they include in their Outcomes Framework going forward are more closely aligned with the things that matter most to patients. We therefore believe an additional principle of '*person-centred*' should be included in the indicator inclusion criteria. As discussed in more detail in the following sections, we believe this should be achieved through greater use of appropriate patient experience indicators within the NHS Outcomes Framework.

The importance of experience as an outcome in its own right is understood in other sectors, where it is widely accepted that it is not possible to fully understand which aspects of service

can be improved without measuring the experiences of service users. Therefore we reiterate the importance, in keeping with Darzi (2009), of patient experience as an integral component of healthcare quality alongside safety and clinical effectiveness.

The Picker Institute's analysis of national patient survey results illustrates that whilst some metrics, typically in areas of policy focus, have shown improvements over the last 10 years, many areas of patient experience that matter most to patients have shown little movement. For example, since 2005 the proportion of hospital inpatients who stay on mixed sex wards has fallen from 22% to under 10%: this change has been driven by a policy commitment, set out in the NHS operating framework, to "*eliminate mixed sex accommodation*".¹ But in a 2006 study asking patients what aspects of inpatient care mattered most to them, not being in mixed sex accommodation was ranked as only the 62nd most important out of 82 statements.²

By contrast, one of the top-rated statements in that study was about doctors being able to give understandable answers to questions. But over the same time period the proportion of patients who "*always*" found doctors to give understandable answers rose only marginally, from 67% to 69%. There is therefore considerable scope for the NHS Outcomes Framework to drive significant improvements in these, and other, important areas.

However this requires not only that patient experience is acknowledged as one important foundation of the NHS Outcomes Framework but also that it is given *equal* status alongside clinical effectiveness and patient safety in the framework's development. We do not believe it has been given this status in the current consultation. For example, whilst the consultation asks for comments on the long term direction of travel for improving patient experience, this direction of travel appears to be based on patient safety rather than patient experience per se. Patient experience measures should be an area of development in their own right as well as potential indicators of safety issues.

Therefore we believe there is more that the Department of Health can do to exploit the ideal opportunity they have, through this refresh, to take a leadership role in ensuring system-level commitment to improving person-centred outcomes, in particular those related to patient experiences of care.

As highlighted above and elaborated on throughout this response, the Picker Institute have considerable expertise in this area and would welcome the opportunity to share this with the Department of Health as their work on the refreshed NHS Outcomes Framework progresses.

3. Appropriate indicators of patient experiences of care

3.1 Highlighting negative experiences

We read with interest the Department of Health's proposal to update Domain 4 of the NHS Outcomes Framework to emphasise the importance of patients reporting negative experiences of care. Whilst we understand the rationale behind this proposal, we highlight a number of issues that we believe deserve further consideration before a decision is taken to implement this proposal:

¹https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/216590/dh_131428.pdf

²http://www.nhssurveys.org/Filestore/documents/Findings_and_development_of_the_2006_Inpatients_Importance_study_final.pdf

- *Reliability of measurement* – An indicator of patient experience which is based on the most negative response categories may be less reliable than an indicator based on a fuller range of response categories. Its results may for example be skewed depending on the profile of respondents and the propensity of different groups of respondents to use different points on the rating scales. It could also perform poorly in terms of its ability to discriminate between trusts, although we recognise that it may be successful in pinpointing particularly problematic cases.
- *Incentives* – We are concerned that the proposed indicator could incentivise providers to improve their scores by introducing token initiatives designed to nudge responses away from the least positive categories, thereby influencing the indicator score with only minimal impact on patient experience. Intermediate response categories should not be seen as ‘good enough’, especially given that patient feedback is generally quite positive. Therefore providers should be encouraged as far as possible to maximise the proportion of responses in the most positive categories.
- *Use of results* – Given the issues identified above, an indicator based only on negative experiences of care would most appropriately be used only as an improvement tool. However, as we have observed with other indicators, once developed its results may nonetheless be used in a multitude of inappropriate ways that the indicator wasn’t designed for. This could create further perverse incentives.
- *Messaging* – We are also concerned that the proposed indicator would place undue focus on negative outcomes, potentially damaging morale among providers and further exacerbating a culture in which failures rather than successes are emphasised. We highlight that an inverse measure based on the most positive responses could be implemented that would use similar data but with a positive emphasis. However, whilst this may address messaging issues, clearly it would not address the other issues identified above.

3.2 Indicators relating to children and young people’s care

The Picker Institute’s comments regarding indicators for children and young people’s (CYP) care fall into two categories. First we respond to the Department of Health’s proposed long term direction of travel for CYP, before then commenting on their interest in developing an indicator relating to children’s access to age appropriate care.

3.2.1 Long term direction of travel

We welcome the Department of Health’s recognition of the importance of continuing to seek improvements in CYP indicators and of continuing to assess the robustness of current indicators. We also welcome their commitment to the development of new indicators which assess care from birth and align more closely with mental health priorities. However, whilst we endorse this overall direction of travel, we believe it is too vague and could be significantly improved in two areas.

First we believe it should differentiate between different areas of care received by CYP. CYP should not be viewed as one patient cohort in itself, rather it comprises different groups of young patients with as full a range of care needs across different environments as their adult counterparts. We would therefore have welcomed explicit acknowledgment of this through a stated direction of travel for indicators within these different groups.

We were particularly disappointed to see that the direction of travel did not include for example any reference to a children's outpatient indicator. We highlight that in 2011 the Department of Health had planned to include an indicator in this area³ so we view the omission of this in the current direction of travel as a disappointing backward step. As the Department will be aware, this is an area in which the Picker Institute have already demonstrated their particular expertise and we would welcome the opportunity to continue discussions in this area.

Second we believe the direction of travel should set out the Department of Health's plans within each of the five domains. As such we were particularly disappointed that it did not include any plans for refinement and development of CYP patient experience indicators going forward. This is an area in which a rich source of tools and indicators already exist, and therefore in which there is vast scope to exploit these. For example, the Picker Institute have developed CYP patient experience tools in the following areas⁴:

- *acute inpatients* – we recently developed a survey which will be run as part of CQC's national patient survey programme later this year;
- *acute outpatients* – we developed a survey in 2009, funded by Sheffield Children's NHS Foundation Trust, which is now run as a voluntary survey each year with a number of NHS Trusts⁵; and
- *acute emergency department patients* – we developed a survey in 2011, which is also run on a voluntary basis each year with NHS trusts.

In 2011 we also developed a separate survey for neonatal care in conjunction with Bliss, the special care baby charity. This asks parents about their experiences of care on a neonatal unit. The survey was revised in 2013 and is now being implemented in 71 NHS Trusts nationally, with the help of funding from NHS England.

We are also currently developing additional CYP patient experience tools in the following areas:

- *CAMHS* – we will soon be commencing work to assess CYP experiences of mental health services;
- *transition* – a survey to assess the experiences of young patients as their care is transferred to adult services is currently under development and will soon be piloted; and
- *community healthcare* – a survey is currently being developed to assess child and family experiences of community paediatricians, occupational therapy, physiotherapy and speech and language services.

In summary, we believe the direction of travel for CYP indicators should be built on more specific recognition of the different types of CYP care set out above and that patient experience data provides a valuable source of information that could be more fully exploited.

³ <https://www.gov.uk/government/news/winners-of-innovation-in-outcomes-competition-announced>

⁴ These have both parent completion versions for children up to the age of seven and self-completion versions for children aged eight to 16.

⁵ This is the tool which won the 'Innovation in Outcomes' competition referred to above.

We have considerable expertise and insight in this area and would be happy to share this with the Department of Health going forward.

3.2.2 Children's access to age appropriate care

We welcome the acknowledgment in this consultation of the importance of access to age appropriate care for children. Our annual survey of paediatric inpatients and day-case patients demonstrates that age-appropriate wards are more important to young patients than gender-specific wards, particularly for teenagers (Tallett, 2013).⁶ However, whilst we recognise that children's experiences are better when they stay on dedicated teenage or paediatric wards, and so we understand the Department of Health's rationale for considering an indicator based on the proportion of children staying on an adult ward, we highlight a number of challenges with this indicator:

- *Drivers of age appropriate care* – There are many different factors which combine to determine the overall age appropriateness of care. These extend beyond the location of that care (i.e. a teenage, paediatric or adult ward) and include for example communication between the child and the care giver, information provided to the child, their involvement in decisions, the attention to their individual needs and the emotional support they're given. We are concerned that a focus on the location of care alone would mask the importance of these other components.
- *Resources* – Our work with trusts suggests that space and resources for dedicated teenage and paediatric wards are often limited and over-stretched. Therefore, whilst the indicator may be useful in highlighting this, its ability to drive improvements may be limited unless it is accompanied by a sector-wide commitment to address the root causes of problem areas identified.
- *Narrow focus* – The indicator only focuses on age appropriateness of inpatient care. As suggested above, age appropriateness of care is important across a range of settings including outpatient care, emergency care, CAMHS and community care as well as for young people with long-term health conditions as they transfer from CYP to adult care. Care within each of these groups needs to be age appropriate.

As discussed above, the Picker Institute are currently working on a tool to measure young people's experiences of transition between CYP and adult services. This includes a set of questions which ask teenagers specifically about their experiences of staying on an inpatient ward. This could be used in future to expand the focus of the indicator currently being considered and we would be pleased to share our thoughts on this with the Department of Health.

3.3 Mental health

Our comments regarding indicators for mental health care also fall into two categories. First we respond to the Department of Health's proposed long term direction of travel regarding mental health indicators. We then comment on their consideration of including an outcome specifically relating to children with mental health problems.

⁶ Tallett, A. (2013). Children's feedback can help improve healthcare provision. *Nursing Children and Young People*, 25 (2), 6-7.

3.3.1 Long term direction of travel

The Picker Institute wholeheartedly endorse the Department of Health's commitment to refine and develop existing mental health indicators and to incorporate more robust survey methodology to improve the measurement of mental health outcomes. However, mirroring our comments in relation to indicators for CYP care, we believe the direction of travel is far too vague. Although the Department has set out a brief direction of travel within each of the five domains, these do not provide sufficient detail for us to be able to offer a meaningful critique.

We were also disappointed that the direction of travel for Domain 4 appears to focus solely on the development of new measures of patient safety rather than patient experience. As highlighted above, it is widely accepted that patient experience should be afforded equal status alongside clinical effectiveness and patient safety in driving improvements in the quality of care. Therefore we believe that more weight should be placed on the development of measures of patient experience of mental health care as indicators in their own right as well as potential indicators of safety issues.

3.3.2 Children with mental health problems

The Picker Institute recognise the importance of including outcomes with a focus on children with mental health problems in the Outcomes Framework. We believe a positive experience of CAMHS for children and young people plays an important part in ensuring good adult health and social care outcomes. Our forthcoming CAMHS work measuring CYP experiences of mental health services illustrates the sector's enthusiasm in this area and the scope to further exploit the tools being developed.

Our expertise in this area gives us particular insight into some of the challenges associated with developing indicators focusing on children with mental health problems. These include for example:

- *Indicator reliability* – The relatively small population sizes of children with mental health problems may make it difficult to create reliable indicators. Unreliable indicators which fluctuate widely will at best be unhelpful and at worst, misleading in highlighting problem areas and focusing resources.
- *Confidentiality* – Small population and/or sample sizes can also create confidentiality issues. For example, in the national patient survey programme, results based on fewer than 30 respondents are currently suppressed.
- *The complexity of CAMHS service provision* – Moreover CAMHS service provision is complex, not least due to the number of professionals and other stakeholders involved, including schools, social workers, psychologists, occupational therapists, GPs, and of course, the families and service users themselves. This increases the complexity of indicator selection and development.

This is also an area in which we have particular expertise and insight, which we would be pleased to share with the Department of Health as their work to develop indicators in this area progresses.

3.4 Comorbidities

We agree with the Government's proposal to include comorbidities in the NHS Outcomes Framework. We welcome the Department of Health's acknowledgement in this consultation of the importance of patients being treated as whole people rather than as individual

conditions. This is central to the idea of person-centred care and represents a key point of difference from the medical model. People who use health and social care services have a strong desire to be treated as individuals and for their care to be coordinated and coherent. But, in practice, there is evidence that people with multiple comorbid conditions have poorer experiences of care⁷, and therefore this is an area especially worthy of closer attention.

Indicators relevant to comorbidities may already be included in the Outcomes Framework, for example those covering people with long-term conditions. We therefore recommend that the Department of Health consider, as part of the development process, how any new indicators (including that tentatively proposed in this consultation) may overlap with existing indicators.

We do not provide detailed comments in this response on the Department of Health's tentative proposal for an indicator on the quality of life for people with comorbidities. However, we highlight that this is another area where additional patient experience indicators may also be useful going forward. As an example, the Picker Institute's transition survey also looks at experiences of care in those that have one or more long-standing conditions and so could be used to compare the experiences of those with one long-standing condition with those with multiple long-standing conditions.

Our transition survey also asks questions on the extent to which patients are treated as individuals, whether care providers are sufficiently informed about patients' medical histories and whether appointments are scheduled so as not to interfere with patients' personal lives. Existing patient experience tools therefore already exist which fully recognise the needs of comorbid patients and we believe these could be exploited to a fuller extent going forward. We would be very happy to share our thinking in this area with the Department of Health.

4. Inequalities and parity of esteem

4.1 Inequalities

We restrict our comments in this section to the Department of Health's proposed selection criteria for inequalities indicators set out in the consultation and our views on effective ways to assess inequalities in care.

4.1.1 Selection criteria for inequalities indicators

We believe the selection criteria for inequalities indicators, based on '*major areas of inequality of outcome*', '*areas where the NHS could make a significant difference to inequalities*' and '*areas of policy interest*' are broadly sensible. However, we make two comments here.

First, conceivably it is possible for the NHS to improve inequalities in many areas and in many ways. Therefore we would have welcomed further clarification on how '*areas where the NHS could make a significant difference to inequalities*' may be determined.

Second, we believe that inequality indicators should not only focus on inequalities with respect to treatment but also those related to access. It is only through consideration of the experiences of, and outcomes achieved by, different cohorts, including not only groups receiving treatment but also those without access to treatment, that a more accurate picture

⁷ Hewitson, P., Skew, A., Graham, C., Jenkinson, C., & Coulter, A. (2014). People with limiting long-term conditions report poorer experiences and more problems with hospital care. *BMC Health Services Research*, 14(1), 33. doi:10.1186/1472-6963-14-33

of healthcare inequalities can be painted. Therefore we would have welcomed more clarification about how such a holistic view may be produced going forward, either through the NHS Outcomes Framework itself or through its closer alignment with the Public Health Outcomes Framework.

4.1.2 Assessing inequalities

As with the other areas discussed in this response, we highlight again the value of using patient experience metrics as one effective way to assess inequalities in care. This is another area in which we believe existing tools could be exploited to fuller effect, and new tools developed, going forward.

We highlight two ways in which patient experience could be used in this context in future. First existing tools could be used to compare the experiences of different cohorts of health service users, including vulnerable and marginalised groups. These tools include for example a survey developed by the Picker Institute in 2012 to measure the experiences of acute adult inpatients with learning disabilities. The survey, which was developed and subsequently piloted with Leeds Teaching Hospitals NHS Trust, contains 12 key experience questions in an easy-to-read accessible format.⁸

Second, more could be done to acknowledge and measure the experiences, or rather the lack of experiences, of vulnerable and marginalised groups who are not accessing appropriate health services.

Our expertise in measuring patient experience also gives us particular insights into some of the challenges associated with developing indicators focusing on vulnerable or marginalised groups. These include for example:

- *Incomplete data* – Practical difficulties often arise in terms of the information available to examine differences across groups. For example, ethnicity is not well recorded by NHS organisations, and we have previously found large differences between recorded ethnicity and self-reported ethnicity. We have also found similar issues in relation to learning disabilities. In the absence of complete data, it will be difficult to assess inequalities accurately. Therefore it would be useful if the Department would consider accompanying their work on assessing inequalities with actions designed to improve recording.
- *Differential reporting* – We do not currently know whether certain minority groups report worse experience because they are treated worse or because they respond differently to questions about their care, compared with majority groups. Research would be needed to ensure that conclusions drawn from survey data validly reflect inequalities in experience where these exist.
- *Unrepresentative samples* – As highlighted above, inequalities in access to services create a risk that the population using health services is not representative of the

⁸ Use of this tool in a format suitable for the target population yielded a successful response rate of 45% (using a postal methodology) and produced a number of interesting results. For example whilst a large proportion of respondents agreed that doctors and nurses were friendly, there was room for improvement in a number of areas related to staff communication with both patients and friends or family members.

population as a whole. Therefore the picture of inequalities painted by analysis of the outcomes of this subset could also be unrepresentative.

4.2 Parity of esteem

The Picker Institute wholeheartedly endorse the Department of Health's commitment to select a combination of physical and mental health indicators across domains as one way of helping to achieve greater parity of esteem between physical and mental health. However, whilst we welcome their initial proposals with respect to measuring mortality in people with mental illness and reflecting quality of life for people with mental illness in the Outcomes Framework, we highlight two omissions in their current approach to more accurately assessing parity of esteem.

First, we believe this is another area in which greater use of patient experience indicators should also have been given consideration. We believe access to mental health services and diagnostic overshadowing are two key ways in which the lack of parity of esteem between physical and mental health is currently manifesting itself in practice. These are both areas in which patient experience could be informative going forward. Indeed, previously published work by the Picker Institute shows how this can be accomplished and demonstrates how people with mental health conditions are significantly less likely to report being treated with respect and dignity in hospital settings.⁹

Second, we note that the Department of Health's approach appears to be directed primarily at *promoting* parity of esteem rather than *assessing* it. Whilst we agree that the promotion of parity of esteem is a necessary long term goal, we suggest that this goal also needs to be accompanied by a clear approach to assessing how far the sector is from delivering parity of esteem in the short term. We believe for example that there would be merit in the Department more clearly articulating the extent to which they believe it may be possible to narrow the gaps between key indicators over time.

5. Summary

We welcome the Department of Health's commitment to refreshing the NHS Outcomes Framework and we endorse their focus on using patient-reported experiences as a major part of the assessment of health service quality.

Effective use of patient experience data demands that it be appropriately robust and well used, in order that outcome measures are closely aligned with the things that matter most to patients. In some areas we believe there is more that could be done by the Department of Health to broaden the effective use of patient experience information and, in so doing, to give a stronger role to the voice of the people who use services.

Our response has highlighted the significant scope that exists to incorporate further effective measures of user experience within the NHS Outcomes Framework and a number of specific ways in which this could be achieved. We would be delighted to discuss these, and the wider use of patient experience information, with the Department.

⁹ Sizmur, S., & Körner, K. (2013). Equal rights, equal respect: an examination of differential inpatient experience. *Diversity and Equality in Health and Care*, 10(4), 237–248.

