NATIONAL QUALITY BOARD engagement exercise on the library of NICE Quality Standard NHS healthcare topics

1. I write with regard to the NATIONAL QUALITY BOARD engagement exercise on the library of NICE Quality Standard NHS healthcare topics.

2. The Royal College of General Practitioners is the largest membership organisation in the United Kingdom solely for GPs. Founded in 1952, it has over 42,000 members who are committed to improving patient care, developing their own skills and promoting general practice as a discipline. We are an independent professional body with enormous expertise in patient–centred generalist clinical care. Through our General Practice Foundation, established by the RCGP in 2009, we maintain close links with other professionals working in General Practice, such as practice managers, nurses and physician assistants.

3. The College welcomes the opportunity to respond to this consultation and we have answered the questions posed below. However, we do have a few broader comments which we would like to be considered.

4. 176 is a huge list of quality standards, and GPs and others working in primary care will have significant concerns that, while it will be feasible for a hospital department to focus on standards in their particular area, primary care staff will have to be mindful of the entire list; GPs in particular, as generalists, will have to focus on all areas not only as providers but now also as commissioners of healthcare. Depending on the
extent to which standards are applied as quality indicators this could amount to performance management overload for GPs and others in primary care.

5. It is also critical that any standards that are used to assess primary care providers (ie for care pathways that have an element in primary care) must have specific statements relating to the primary care end of the pathway. GPs will be very reluctant to accept standards that are drawn up wholly by bodies or specialists who have no direct experience of the conditions of general practice. Even more broadly, though the cross-cutting category is useful, the division of topics in the list by disease categories misses much of what primary care actually does – GPs deal with symptoms and people, and extrapolate from these to diseases. We would find it very helpful if you could be explicit about the extent to which the evidence base for the proposed standards is relevant to primary care.

6. Our responses to your questions, which represent the views of a number of our members, especially experts contributing to our Clinical Innovation and Research Centre rather than a developed RCGP policy position, are as follows:

1. **Are there any significant gaps or omissions in the proposed library? If so, what are they?**

   **Allergy** - As we said in our response to the Academy of Royal Medical Colleges earlier this year, the RCGP believes that allergy should be included as a category area in its own right. Although some areas where allergy may or may not figure have been included (e.g. drug allergy, failure to thrive, constipation, etc.) under other category headings, allergy has not been considered in the comprehensive manner it merits.

   Allergic conditions often commence in early childhood and may, particularly in those with more severe disease, involve a number of organ systems. This often results in patients receiving multiple referrals and overall poor coordination of care. These clinical challenges are it seems being replicated in the approach to allergy in formulating these proposed Quality Standards. This is an area that really would benefit from more comprehensive treatment, rather than the piecemeal approach currently being proposed.

   We suggest that the new topic ‘End of life care for infants, children and young people’ should also include neonates as the issues relating to treatment of neonates on special care baby units may be very different from older children in hospice situations.
2. Of the topics in the proposed library, are there any aspects of the care pathway or clinical area that it would be particularly important for the Quality Standard to address?

**Allergy** - As demonstrated by professional and parliamentary reviews, allergy is currently poorly managed in both primary and generalist secondary care settings resulting in poor patient experiences, avoidable consultations/hospital admissions and unnecessary costs to the NHS.

In order to improve the management of people with allergic disease, there is a need for Allergy Quality Standards in the following disease areas:

- Allergic conjunctivitis
- Allergic rhinitis
- Anaphylaxis,
- Angioedema
- Asthma
- Eczema
- Food allergy
- Urticaria
- Venom Allergy

**Pain** - We are pleased to see that pain management is highlighted as a new area for a National Quality Standard.

**Obesity** - Obesity, although now divided appropriately into childhood and adult topics, does not convey the full impact that an unhealthy lifestyle has on disease and it risks focusing clinical endeavour too fixedly on BMI change. This means that wider health gains from overall lifestyle change may not receive due recognition and support from health professionals. We would like to see at least a modification of the Obesity title to imply a wider remit of health gain, e.g. ‘Adult weight and lifestyle management’. A new additional heading of Fitness Promotion would be even better.

The benefit of a separate ‘Fitness Promotion’ category would be to tackle the crucial impact of fitness (independently of co-existing obesity) in relation to heart disease and stroke, falls prevention, rehabilitation after orthopaedic surgery, mental health including depression, essential hypertension, childhood obesity, adult obesity. In fact, few conditions fail to be improved by an exercise component, yet clinical confidence in promoting fitness – particularly following
illness - is low. Although there is a comment in the Background information document about quality standards for social care and public health not being dealt with in this exercise, the College believes that clinicians, and hence patients, would benefit from seeing fitness promotion as a specific clinical topic worthy of focus. The library of NICE Quality Standard NHS healthcare topics would be an excellent way to raise its profile.

It is encouraging to see Nutrition support in Adults being included. This should be a priority, because various commissioning groups are currently looking at reducing SIP feed prescribing, but there is no current consensus about ensuring that nutritional care is improved, particularly where SIP feed prescribing is being discouraged. A ‘food first’ approach requires guidance, educational resources and training. Awareness of screening tools for malnutrition is low, yet malnutrition is widespread and has a big impact on secondary care in particular.

The College believes there is a need to contain the number of guidance documents impacting on primary care and suggests that Lipid modification and Familial hypercholesterolaemia could be combined under one topic?

**Musculoskeletal** - The College agrees with the topic choice, but suggests that 'gout' should be included.

**Respiratory** - We suggest including something about managing the child with acute respiratory distress.

On acute respiratory infection, the current standard only refers to pneumonia, and excludes mild self-limiting conditions etc. We suggest including standards for "cough" and Breathlessness".

3. **Are there any other cross-cutting topics that address health improvement and / or patient experience issues for which a Quality Standard would be of benefit?**

We believe that allergy is a prime example of a clinical area that would benefit from a cross-cutting standard. This is because the manifestations of allergy in individuals tend to evolve over time (e.g. progression from eczema to allergic rhinitis to asthma) and because allergic co-morbidity is so common.

4. **Which are the topics where the interface with social care is particularly important and should be considered in developing the quality standard?**
**Long term disorders** - Particularly children with long term disabilities (clinical guidelines);

**Cross cutting** - We suggest domestic violence, children and young people’s patient experience;

**Service delivery** - We suggest vulnerable children and families (hard to engage, frequent movers, missed appointments), meeting with health visitors and social care to discuss common concerns with these families; also suggest Child Maltreatment recording and coding (following guideline);

We believe children with learning disability, behavioural management and mental health disorders should be included as topics and suggest the following as a library that could be used as a framework for child health.

**Children and Young people**

**Congenital and peri-natal problems**

Children with congenital disorders, disabilities and syndromes including sensory impairment, cranio-facial defects, cardiovascular, respiratory and gastrointestinal anomalies

Technology dependent infants and children

Children with complex needs

Children requiring long-term palliative care

Malignant disease in infancy

**Mental Health**

Children and young people with troubled behaviours

Children and young people with sexually disturbed behaviours

Children and young people placed within the Youth Justice System

**Auto-immune and inflammatory disorders in infancy, childhood and adolescence**

Joint and muscle inflammatory disorders
Inflammatory bowel diseases

Ophthalmic complications of inflammatory and auto-immune disorders

**Gynaecology and Andrology in childhood and adolescence**

Gynaecological problems in childhood and adolescence including congenital anomalies, ovarian cysts, menorrhagia, pregnancy

Male congenital anomalies, benign and malignant neoplasia of genitalia

**Service delivery**

Child and adolescent incontinence and stoma services

Reconstructive surgery for congenital anomalies and trauma induced deformities

5. **What are your views on the Quality Standards published to date?**

We believe they are generally good and comprehensive and particularly appreciate the effort made to include young people and children by splitting topics (eg self harm, pain management, medicines adherence). The Picker Institute standards to frame the QS could work as follows:

- Involvement in decisions and respect for preferences
- Clear comprehensible information and support for self care
- Emotional support, empathy and respect
- Fast access to reliable health advice
- Effective treatment delivered by trusted professionals
- Attention to physical and environmental needs
- Involvement of and support for family and carers
- Continuity of care and smooth transitions

7. On the topics, we have a couple of minor points. We understand that ‘Failure to Thrive’ is now called ‘Faltering Growth’ and would prefer the term ‘Safer Prescribing’ to ‘Safe Prescribing’.

8. Finally, we would like to add that we would be very keen for early central representation and input on the NICE process.
Yours sincerely

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Honorary Secretary of Council