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The Kidney Alliance is an umbrella group of patient and professional organisations working in renal care - Association of Renal Industry, Association of Renal Managers, British Association for Paediatric Nephrology, British Kidney Patient Association, British Renal Society, British Transplant Society, Kidney Research UK, National Kidney Federation, Renal Association, Renal Nutrition Group, Royal College of Nursing.

**Response to the consultation on Healthy Lives, Healthy People: Transparency in Outcomes**

***Question 1.*** How can we ensure that the Outcomes Framework enables local partnerships to work together on health and wellbeing priorities, and does not act as a barrier?

The outcomes framework needs to link closely to, and complement, that for the NHS, above and beyond situations where there is a formal shared outcome measure. It is likely there will be other similar frameworks relating to various elements on which public health will impact and it is important that these are aligned nationally and locally.

Thus, if teams at all levels are working towards aligned objectives in all areas (with no conflicts), they are naturally more likely to work in close co-operation.

Ensuring that there is understanding and support amongst patients and communities is also key to this approach.

Barriers will inevitably occur and it will be important to have mechanisms to identify where barriers exist and to resolve them.

***Question 2.*** Do you feel these are the right criteria to use in determining indicators for public health?

Concentrating on indicators where evidence-based interventions exist and where there are existing data collection systems may provide a starting point. However, this should not discourage the identification and targeting of indicators for which data collection and evidence-based interventions do not currently exist, if they are important to improve public health. We would hope to see a later phase of work identify any such areas and the requirements for their inclusion in national and local outcomes frameworks.

***Question 3.*** How can we ensure that the Outcomes Framework and the health premium are designed to ensure they contribute fully to health inequality reduction and advancing equality?

Close and careful monitoring at a detailed level to track improvements and the rate of improvements, including comparisons from one sub group to another is likely to be important.

It is important that such data are collected according to a rigid and consistent protocol so that they may be compared across different points of collection (for example one part of the country to another). This is a major undertaking and is likely to require new and additional data collection and management – it is unlikely that it can be properly measured using existing systems.

Ensuring a reduction in inequality in public health is likely to link closely to differences in the provision of health services. This point needs to be carefully considered. For example reductions in preventable deaths due to kidney disease may be linked to healthy lifestyles and diets and there already exist differences in provision of and ability to provide services in such areas. It is worth noting that while the consultation refers to ‘a reassertion of the voluntary sector’s critical role in connecting with communities’, the sector is under growing pressure from cuts in local funding and so its opportunity to play a full part in this area is restricted.

***Question 4.*** Is this the right approach to alignment across the NHS, Adult Social Care and Public Health frameworks?

We have some concerns as to where the needs of children will fit in. Children with kidney disease often have rather different or additional needs to adults and this may also the case in other disease areas. Therefore it will be important to ensure these are included.

***Question 5.*** Do you agree with the overall framework and domains?

We believe it is important to encourage improved disease awareness so that people are generally better informed through accurate authoritative information and more likely to recognise symptoms that should prompt them to seek earlier contact with health care professionals. Appropriate early presentation is important to the outcomes and cost effective treatment of many conditions and public health has a role to play in this.

This may be included in Domain Four or Five, but we believe that it is important this is included. Our experience in kidney disease is that generating understanding in the general community is an important challenge.

We note the indicator in domain 3 measuring self-reported wellbeing. We would like to see this expanded. For example assessments of wellbeing relating to broader aspects of public health as well as quality of life assessments of the impact of specific public health interventions – particularly where they relate to prevention, or early stage treatment, of long term conditions.

***Question 6.*** Have we missed out any indicators that you think we should include?

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Diabetes prevalence is included as a measure in domain 4, and mortality due to cardiovascular disease (including heart disease and stroke) is included under domain 5. There is a strong link between these conditions and kidney disease and we believe that it is important to Public Health outcomes that the prevalence of Chronic Kidney Disease should be included. Please also note comments on Question 5 above.

Under domain 3, there are proposed indicators for weight, which are presumably there to provide an indication of healthy eating. However, these will not provide a full picture. There are other aspects of diet that have enormous impact on public health: for example salt intake, which is closely associated with kidney disease and, through hypertension, with cardiovascular disease.

***Question 7.*** We have stated in this document that we need to arrive at a smaller set of indicators than we have had previously. Which would you rank as the most important?

We believe that lifestyle and diet-related indicators are important because they apply across many different disease areas.

As a general comment we note there are numerous indicators measuring mortality, some of which are shared with the NHS. For those that are shared, it will be difficult to determine the impact that public health has had, based on these indicators and we would like to understand more about the way in which greater clarity will be achieved.

***Question 8.*** Are there indicators here that you think we should not include?

No comment

***Question 9.*** How can we improve indicators we have proposed here?

Please refer to response to question 7. Where indicators are shared, it will be important to identify precisely how the public affairs component will be measured. The risks of not doing so include not only an unhelpful lack of clarity but also the possibility that this could work against team-based approaches caused by team members being unclear on what is expected of them and whether or not interventions had the intended effect.

Corresponding improvement indicators for public health might prove helpful.

***Question 10.*** Which indicators do you think we should incentivise? (consultation on this will be through the accompanying consultation on public health finance and systems)

No comment

***Question 11.*** What do you think of the proposal to share a specific domain on preventable mortality between the NHS and Public Health Outcomes Frameworks?

We believe that this proposal reflects the reality that preventable mortality is not completely addressed through health interventions and their effectiveness. However,

we believe that greater clarity is needed in how the health and public health elements contribute and fit together.

***Question 12.*** How well do the indicators promote a life-course approach to public health?
No comment

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