Cancer52 Response to Investing in Specialised Services – SUMMARY

Cancer52 represents 80 predominantly small cancer charities united by their vision of seeing a better future for everyone affected by rare and less common cancers. Given our membership, we are particularly concerned about ensuring that those with rare and less common cancers are not left behind.

Lack of clarity and lack of clear measurement of key factors that will drive decisions to invest

- Cancer52 is concerned about the policy and practice proposed by NHS England in their principles to guide investment decisions in specialised services. There is not enough clarity in how the principles will be applied and how key issues such as tackling inequalities and social impact will be measured. Inequalities directly affect our members; those diagnosed with rare and less common cancers now account for more than half of all cancer deaths.

NHS England needs to become more transparent and open and supported by the broader policy framework and funding for the NHS

- NHS England needs to demonstrate the transparency and openness that it aspires to and which is a cornerstone of their proposed approach to investing in specialised services. NHS England must also be inclusive and include reference to all relevant legislation and policies and guidance; not least the duty to promote research as enshrined in the Health and Social Care Act 2012.

The broader policy framework and politics of the NHS must also enable NHS England to do the best it can given the budget set for the NHS. The politicians that will make up the new Government later this year have a chance to demonstrate their commitment to the NHS with funding commitments in line with the needs of the patients treated by the NHS.

NHS England must add in appeal to their processes

- We see no clear opportunity for appeal in the processes outlined by NHS England. We see appeal as a crucial part of a ‘reasonable’ process and ask that NHS England set out how patients, patient organisations and others can appeal decisions made by NHS England about investment in specialised commissioning in the future.

NHS England must be aligned to ongoing work

- Much work is ongoing which may affect specialised commissioning ranging from the new Strategy for Cancer, which Cancer52 is pleased to be involved with, through to forthcoming Comprehensive Spending Review. There is also much complexity arising out of the NHS essentially having two National Tariffs and gain share arrangements in place. NHS England needs to set out clearly what all of this means to patients and the services that they will be receiving under the banner of specialised commissioning in the future.

NHS England must move beyond engagement to involvement

- NHS England should consider seconding in patients/those working for patient groups when considering investing in a new specialised service or treatment. NHSE should also clarify whether key groups, such as the Clinical Appraisal Panel, includes a lay/patient representative.

A planned review in 2 years

- NHS England should plan for a review of their approach to investing in specialised services in 2 years.

The NHS must also declare their interest in future consultations

- Cancer52 has provided details of support received from our pharmaceutical industry sponsors as part of our response. At the same time, NHS England and the NHS more widely should do the same in the future.

30 April 2015