

Professor David Haslam
Chair
NICE

16 November 2017

Dear Professor Haslam

PROPOSALS FOR INCREASING CAPACITY WITHIN NICE'S TECHNOLOGY APPRAISAL PROGRAMME

The signatories to this letter wish to raise concerns about your consultation and to recommend a delay to ensure proper engagement through Patients Involved in Nice.

We recognise NICE's need to review its technology assessment processes but believe this should not be at the expense of engagement with patients and clinicians.

Paragraphs 21 and 29 of the consultation paper suggest that greater use of written submissions would allow HTA committees to have less patient and clinician representation at the meetings themselves, in the interests of efficiency.

We question whether it can be acceptable to reduce patient and clinician engagement in the committees. Nor do we think it helpful for proposals with potentially very significant implications for patient voice to be buried in a technical paper where they can be easily missed.

The paper itself is ambiguous as to NICE's intentions, provides no real justification for reducing patient and clinician representation, and does not explore the implications of such a reduction - for example how it would impact on the quality of decision making and on the transparency, accountability and contestability of the decisions made.

We think this is wrong and we would urge you to clarify your intentions in proper dialogue with interested parties through the offices of PIN. We also urge you to extend the consultation period to allow sufficient time for this dialogue to take place.

Yours sincerely

(signatories overleaf)

Karen Addington, Chief Executive, JRDF

Deborah Alsina MBE, Chief Executive, Bowel Cancer UK

David Barker, Chief Executive, Crohn's and Colitis UK

Lidia Best, Chair, National Association of Deafened People

Matthew Bezzant, Policy & Public Affairs Manager, NRAS

Antony Chuter, Chair, Pain UK

Steve Ford, Chief Executive, Parkinson's UK

Jess Hobart, Chair, UK Mastocytosis Support Group

Kate Hill, Trustee, June Hancock Mesothelioma Research Fund

Martyn Hooper MBE, Executive Chairman, Pernicious Anaemia Society

Stella Huyshe-Shires, Chairman, Lyme Disease Action

Helen Lee, Policy Manager, RNIB

Trudie Lobban, Founder and Trustee, Arrhythmia Alliance

Fiona Loud, Policy Director, Kidney Care UK

Jane Lyons, Chief Executive, Cancer52

Alex Massey, Policy Manager, MND Association

Susan Passmore, CEO, Prader-Willi Syndrome Association

Jonathan Pearce, Chief Executive, Lymphoma Association

Jeremy Taylor, Chief Executive, National Voices

Dr Susan Walsh, Director, Primary Immunodeficiency UK

Donna Wicks, Chief Executive, Hypermobility Syndromes Association

Sophie Wintrich, Chief Executive, MDS UK

Rose Woodward, Founder and Patient Advocate, Kidney Cancer Support Network