Letter in 'The Times' today – Monday, 09 January 2012

Sir,

At the start of 2011 National Voices and other patient charities warned that the Health and Social Care Bill did too little to ensure that patients would be properly involved in their healthcare. There were many later improvements to the Bill, but as we enter 2012 there are still some significant weaknesses, which the government could remedy with cross-party support.

This mammoth Bill, supposed to create an NHS where there is 'no decision about us, without us', contains no direct reference to the most effective forms of shared decision making with patients. These are: shared decisions about the most appropriate treatments, based on patient preferences and values as well as clinical knowledge; personalised care planning, where professionals help us organise care packages over time, including towards the end of life; and support for people to manage chronic conditions in order to maximise quality of life.

Promoting these three aspects of shared decisions is proven to create better health outcomes, with more appropriate treatment, a better experience of care, and better use of healthcare resources. The government accepts this evidence but has so far refused to refer specifically to these aspects of care because it 'could exclude' other (unspecified) types of patient involvement.

We strongly believe that without such clarity, the new care commissioners will not understand their general duty towards 'patient involvement'. They will confuse it with people's involvement in public consultations, and shaping the design of services.

'Patient involvement' is actually about the kind of care that they arrange for us – care which involves and supports us as full human beings, not 'units of disease', and gets the best value from expenditure.

With 70% of healthcare resources now being spent on chronic, long term conditions, this could be a missed opportunity of very significant proportions.

Signed by the following:

Samia al Qadhi	-	Chief Executive, Breast Cancer Care
Lesley-Anne Alexander	-	Chief Executive, RNIB
Malcolm Alexander	**-**	**Chair, National Association of Links Members**
Jenny Baker	-	Chief Executive, Brain Tumour UK
Peter Baker	-	Chief Executive, Men's Health Forum
Jon Barrick	-	Chief Executive, Stroke Association
Judy Birch	-	Volunteer Chief Executive, Pelvic Pain Support Network
Ailsa Bosworth	-	Chief Executive, National Rheumatoid Arthritis Society

Neil Churchill	-	Chief Executive, Asthma UK
Debbie Cook	-	Director, National Ankylosing Spondylitis Society
Fiona Copeland, Chair	-	Primary Ciliary Dyskinesia Family Support Group
Suzanne Dobson	-	Chief Executive, Tourettes Action
Graham Faulkner	-	Chief Executive, Epilepsy Society
Mark Flannagan	-	Chief Executive, Beating Bowel Cancer
Karen Friett	-	Chief Executive, Lymphoedema Support Network
Simon Gillespie	-	Chief Executive, MS Society
Mark Goldring	-	Chief Executive, Mencap
Lew Gray	-	Secretary, Transverse Myelitis Society
Gill Hadfield	-	Trustee, National Association of Deafened People
Malika Hamiddou	-	General Manager, CITAS
Joanna Hamilton-Colclough	-	Director, Migraine Action
Tanya Harrison	-	Chairperson, BRAME (Blue Ribbon for the Awareness of Myalgic Encephalomyelitis)
Jenny Hirst	-	Co-Chair, Insulin Dependent Diabetes Trust
Jeremy Hughes	-	Chief Executive, Alzheimer's Society
Chris James	-	Chief Executive, Haemophilia Society
Steve James	-	Group Chief Executive, Avenues
Robert Johnstone	-	Chair, Access Matters
Phil Lee	-	Chief Executive, Epilepsy Action
Peter Lyne	-	National Vice-President, Disabled Motorists' Federation
Chris Maker	-	Director, Lupus UK
Emma Malcolm	-	Chief Executive, Prostate Action
Farah Nazeer	-	Director of External Affairs, Motor Neurone Disease Association
David Orme	-	Co-Chair, Dudley LINk
Susie Parsons	-	Interim CEO, Arthritis Care
James Partridge	-	Chief Executive, Changing Faces
Hazel Pixley	-	National Secretary, Urostomy Association
Geoff Salmon	-	Director of Fundraising, National Tremor Foundation
Pat Schooling	-	Executive Director, Action Against Allergy
Owen Sharp	-	Chief Executive, Prostate Cancer Charity
Paul Springer	-	Director of Resources, Age Related Diseases and Health Trust
Jeremy Taylor	-	Chief Executive, National Voices
Chris Whitwell	-	Director, Friends, Families and Travellers
Arlene Wilkie	-	Chief executive, Neurological Alliance
Barbara Young	-	Chief Executive, Diabetes UK