



# RARE DISEASES, COMPLEX CONDITIONS AND THE LIMITS OF LOCALISM

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**H**ealth policy in recent years has been much concerned with localism and rightly so for, in most cases, it makes sense to determine and deliver services as close to patients as possible.

The Specialised Healthcare Alliance, however, is concerned with medical conditions where rarity or complexity mean that services need to be planned at regional or even national level, with clinical expertise often concentrated in a small number of tertiary centres. In particular, we are concerned that what is right for the majority of the NHS doesn't prejudice standards at the specialised end of the spectrum.

As a starting point, it's important to understand that, while we may not need to call on specialised services personally, they matter to us all. The number of rare diseases is legion and can strike any family, from cystic fibrosis to haemophilia to progressive supranuclear palsy, the devastating effects of which were so movingly portrayed by Julie Walters in the recent BBC film 'A Short Stay in Switzerland'. Similarly, if we suffer serious burns or spinal injury the chances are we'll need specialised care.

Cumulatively, a lot of people depend on specialised services, which account for about 10 per cent of the NHS budget. They may involve minorities but it would be foolish to treat them as a minority issue. The Alliance is therefore looking for all parties to support the following objectives:

**Ministerial responsibility** – Ministers shouldn't be second guessing NHS management and clinicians but, in a taxpayer funded system, specialised services are notable by their absence from portfolios. This needs to be rectified with a particular Minister sponsoring specialised services as a mark of their importance to the NHS as a whole;



**Carter reforms** – the NHS can be better at changing policy than changing practice. It is essential that the excellent Carter reforms of specialised commissioning are fully implemented, including the definition of services, the designation of providers and the pooling of budgets to share risk between Primary Care Trusts;

**Regulatory oversight** - The Care Quality Commission needs to take an active interest in Specialised Commissioning Groups given their importance to the wider NHS and to review particular patient pathways in more detail;

**Ethical consistency** – whether the result of a road accident or a rare genetic condition, specialised care often involves great clinical severity and high cost. Difficult funding decisions need to be reconciled with the public's wish to help wherever possible. This needs to be reflected in an ethical framework, applied consistently across the NHS.

*ARMA-Arthritis Care-BAPEN-Behcet's Syndrome Society-Bliss-Bowel Cancer UK-British Liver Trust-British Paediatric Rheumatology Group-British Polio Fellowship-British Society for Rheumatology-Child's Liver Disease Foundation-CLIMB-Children's Heart Federation-Contact a Family-Cystic Fibrosis Trust-GBSSG-Haemophilia Society-Hepatitis B Foundation UK-Kidney Alliance-Limbless Association-Lymphoma Association-Macmillan Cancer Support-MS Society-MS Trust-Muscular Dystrophy Campaign-National AIDS Trust-National Kidney Federation-National Voices-Neurofibromatosis Association-National Rheumatoid Arthritis Society-Niemann Pick Association-PINNT-Primary Immunodeficiency Association-Progressive Supranuclear Palsy Association-Pulmonary Hypertension Association-Rarer Cancers Forum-Rare Disorders Alliance-Scleroderma Society-Sickle Cell Society-Sign-Speakability-Spinal Injuries Association-Terrence Higgins Trust*