

PNH Alliance response to Department of Health Consultation: Liberating the NHS: commissioning for patients

Overview:

The PNH Alliance is a campaign group for Paroxysmal Nocturnal Haemoglobinuria (PNH), a very rare acquired bone marrow disease, which frequently leads to transfusion dependence and life threatening thrombosis. Services for PNH are currently commissioned nationally. We are pleased to provide this submission to the consultation process which will determine the future commissioning arrangements.

Since 2008 the National Commissioning Group (NCG) has designated 2 PNH sites in England – St James' University Hospital in Leeds and King's College Hospital in London. The principles of the NCG PNH services are:

- To provide a national, clinical and laboratory referral service to all patients with PNH in England.
- To provide funding for eculizumab (Soliris®) treatment for all appropriate patients.
- To provide comprehensive information and support.
- To oversee the administration of eculizumab (Soliris®) infusions to patients at their home where possible and supervise the home service team's work.
- To continue to share the care of referred patients with the referring haematology units.
- To provide ongoing education about PNH to other healthcare professionals.

The PNH Alliance will be submitting views on section 3 of this consultation, which refers specifically to specialised commissioning and commissioning for low volume services.

Section context: The underpinning principal and scope of GP commissioning is to devolve resources as close to the patient as possible. Consortia of GP practices will commission the majority of NHS services, managing combined budgets and working in partnership with both local authorities and patients. The NHS Commissioning Board, established to provide national leadership for quality standards, tariffs, and contracts will have responsibility for commissioning some services, such as primary medical care, family health services including community pharmacy, along with national and regional specialised commissioning.

Questions answered

In what practical ways can the NHS Commissioning Board most effectively engage GP consortia in influencing the commissioning of national and regional specialised services?

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How can the NHS Commissioning Board and GP Consortia best work together to ensure effective commissioning of low volume services?

Response

The PNH Alliance welcomes the commitment to ensure that national and regional services are commissioned by the NHS Commissioning Board with the support and engagement of GP Consortia.

The National Plan for Rare Diseases, agreed to at a Council of Ministers session in 2009, is fundamental to the future of commissioning services nationally and regionally and will act as a significant lever to ensure GP

Consortia are able to effectively support the commissioning of specialised services. There are over 6000 conditions recognised as rare affecting 3.5million people.

GP Consortia engagement is an essential requirement for these services to be commissioned and managed appropriately. For many patients their care will not be siloed into national, regional or local services. Treatment and care pathways will more often than not begin at a local level, even if nationally commissioned services are required. Indeed, patients with rare or complex conditions are likely to experience a mixture of both specialist and locally commissioned care.

There must therefore be clear understanding and co-ordination between all services commissioned by the NHS. An infrastructure that allows for this is essential.

Furthermore, ensuring that specialised services are available for as many conditions as is appropriate will mean that fewer patients will continue to experience the inequitable access to care.

Central leadership will also be key to GP Consortia and the NHS Commissioning Board working practically and effectively together for the organisation and delivery of specialised services. Therefore the PNH Alliance supports the creation of a National Clinical Director for Rare Diseases, as previously suggested by the Chief Medical Officer.

Final comment. From the experience of securing national funding for PNH services, increasing transparency in all decision-making on what will be commissioned nationally, regionally and locally will benefit clinicians and patients across England. The caveat remains that frequent changes to refine this decision-making process must be avoided.