

# Section 4

## Commissioning and the case for apheresis

This part of the toolkit describes commissioning for lipoprotein apheresis in the different countries of the UK.

***In 2008, NICE published a clinical guideline for the identification and management of familial hypercholesterolaemia (FH). The Guideline includes the following recommendations on the use of lipoprotein apheresis:***

*“Healthcare professionals should consider offering LDL apheresis for the treatment of adults and children/young people with homozygous FH...”*

*“In exceptional instances (such as when there is progressive, symptomatic coronary heart disease, despite maximal tolerated lipid-modifying drug therapy and optimal medical and surgical therapy), healthcare professionals should consider offering LDL apheresis for the treatment of people with heterozygous FH. This should take place in a specialist centre on a case-by-case basis and data recorded in an appropriate registry.”*

Despite these recommendations, justifying and maintaining funding for apheresis patients remains a critical issue.

This section of the toolkit provides information and resources that may help apheresis sites maintain funding for existing and future patients.

### England

At the time of writing, apheresis treatment is supported in England by funding from Clinical Commissioning Groups (CCGs). These are determined on a case by case basis. Readers wishing to make a case for a patient, please see Appendix 4.1 for an example of a letter making just such a case.

In England, the Prescribed Specialised Services Advisory Group (PSSAG) makes recommendations to Health Ministers concerning which services should come under the remit of the specialised services portfolio.

In 2014, the PSSAG recommended that services for homozygous familial hypercholesterolaemia (HoFH) should be commissioned by NHS England as part of the existing prescribed service, “adult specialist cardiac services”. NHS England provided a supportive response on consultation and in light of that, Ministers agreed with PSSAG’s recommendations and were content that the changes could be made through amendments to NHS England’s service description for adult specialist cardiac services, to come into effect from 1 April 2015.

Therefore, from 1 April 2015, as a recognised life-saving treatment, lipoprotein apheresis treatment may be supported under specialised commissioning.

However, this arrangement only covers those HoFH patients. It does not appear to include heterozygous FH patient with very high cholesterol who also benefit from treatment. It is important, therefore, to ensure that funding is secured from an appropriate source for all apheresis patients.

### Wales

In Wales, lipoprotein treatment is funded by Local Health Boards on a case by case basis.

### Scotland and Northern Ireland

At the time of writing, there is no unit offering lipoprotein apheresis treatment, although there would be patients who would benefit from the treatment.

### Appendix 4.1 - Letter to support referred patient

This appendix is an anonymised letter from Llandough Lipid Unit to the referring GP. It provides an example of information sent to a GP that explains the rationale for apheresis for this patient. The letter may prove useful to readers in seeking funding for their patients.

### Appendix 4.2 – Case studies

Several patients have kindly provided stories about their experience of apheresis treatment. These are illustrative cases that can help make the case for the importance of apheresis.

### Appendix 4.3 – Patient evaluation of the lipoprotein apheresis unit at Llandough Hospital

This is a study of patients' experiences of the apheresis unit at Llandough. The paper highlights a number of key issues, including the relief that many patients expressed at having access to a life-saving treatment. The study has proved useful to the lipid unit in adopting measures to improve its treatment systems. Since the paper describes patient perceptions, it has also proved useful in its communications with funders and other hospital departments. Other apheresis units may consider a similar study of their own patients' views.

### References

- <sup>1</sup> DeMott K, et al (2008) Clinical guidelines and evidence review for familial hypercholesterolaemia: the identification and management of adults and children with familial hypercholesterolaemia. London: National Collaborating Centre for Primary Care and Royal College of General Practitioners.