

Development of a UK Haemophilia Data Managers' Programme of Education

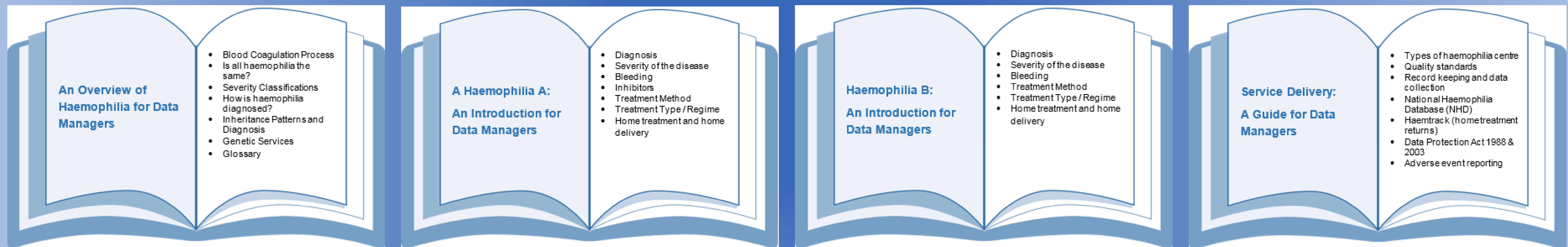
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UK National Haemophilia Database

Introduction and objectives:

Quality data collection is key in the current haemophilia environment. Acquiring optimum treatment is essential for patient care and accurate data collection has proven indispensable in the current climate of competitive resources. In 2015 the UKHCDO Haemophilia Data Management Working Party identified an education need for new and existing Data Managers employed in UK Haemophilia Centres. A greater understanding of the Haemophilia, and the workings of the United Kingdom Haemophilia Doctors' Organisation (UKHCDO) would improve the quality of the data. A UK Haemophilia Data Managers' Education Programme is due to commence in 2016.

Methods:

A series of booklets have been developed for Data Managers, aiming to provide specialist knowledge of Haemophilia without using clinical or nursing oriented language. Education days have been arranged to tutor on these subjects.



Simultaneously, a mentoring programme will be implemented, whereby new data managers will spend time at a Comprehensive Care Centre with a more senior data manager, who will also be available for advice and support as required.

Results and Conclusions:

This project is overseen, and all education tools approved, by the UKHCDO Data Management Working Party. All updated material will be reviewed by this Group. It is hoped that the results of this programme will lead to a greater understanding of the condition and enable data managers to submit high quality, accurate data at all times.

Good, reliable data collection is essential for all aspects of Haemophilia care, and it is important that those responsible for the input and analysis of the data receive appropriate training. Understanding the relevance and need for completeness of haemophilia data can only come through an enhanced educational programme endorsed and supported by lead clinicians and stakeholders.

