The Rotherham NHS Foundation Trust

NP029

The 'Photopheresis Passport'
The development of a patient held record

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Introduction

Patients with Graft-versus-Host Disease often present for Photopheresis (ECP) with complex healthcare needs. The presence of anaemia, thrombocytopenia and immunosuppression in these patients increases the incidence of associated complications. The insertion of a central venous catheter in those patients with insufficient peripheral venous access (25% of our patient group) presents further problems, the incidence of infective episodes and blocked catheter lumens potentially resulting in the deferral of treatment. However, following the completion of a central venous access device audit it was found that within our patient records there was insufficient documentation regarding central line insertion, care and routine maintenance. In addition, it was felt that communication between the referring transplant Trusts and ourselves was suboptimal.

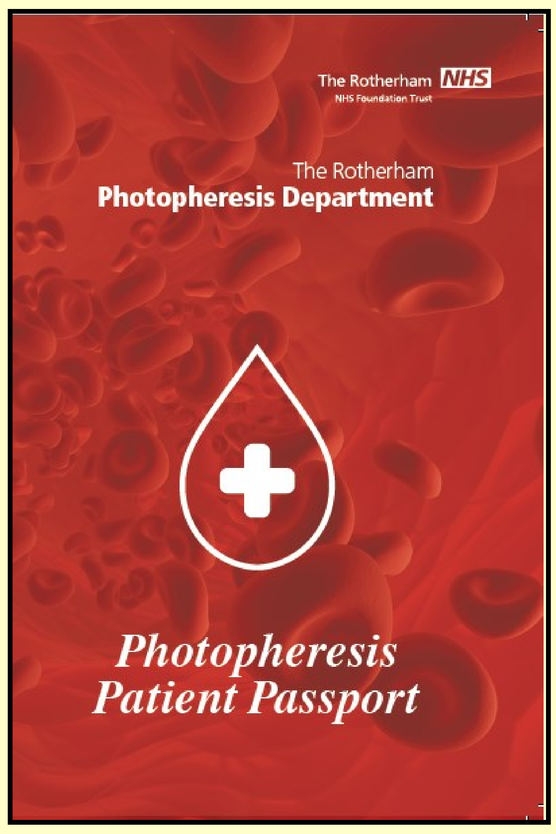
Objective/Aim

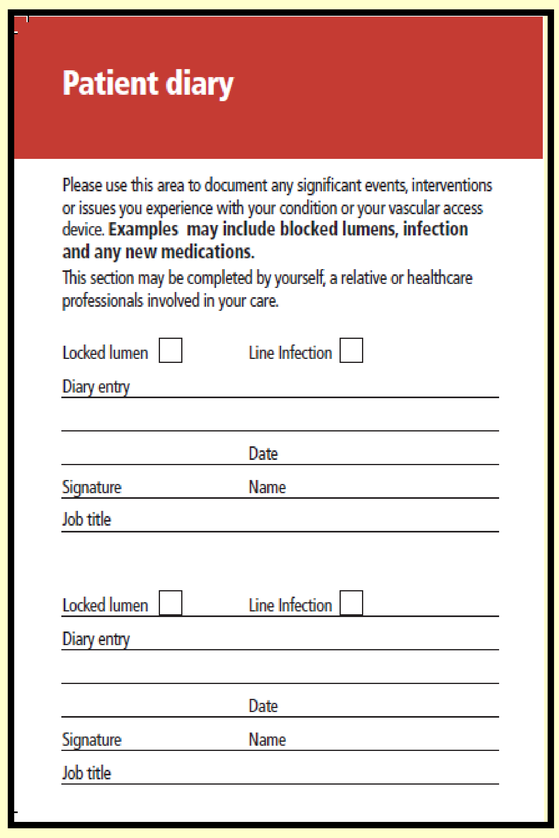
To develop and implement a 'Patient Passport' which will encompass all aspects of ECP treatment, enhancing multidisciplinary communication and encouraging the delivery of holistic patient care. This patient hand held record will compliment existing patient information utilised by the ECP department, aiming to bridge the communication gap and ensure excellence of care.

TOTAL NUMBER OF PATIENTS	36
Adult	29
Paediatric	7
DIAGNOSIS	
Graft-versus-Host Disease	30
Solid Organ Graft-versus-Host Disease	3
Cutaneous T-Cell Lymphoma	1
Scleredema of Buschke	2
LOCATION	
Treated at Rotherham Foundation Trust	29
Treated at Outreach Centre 1	3
Treated at Outreach Centre 2	4

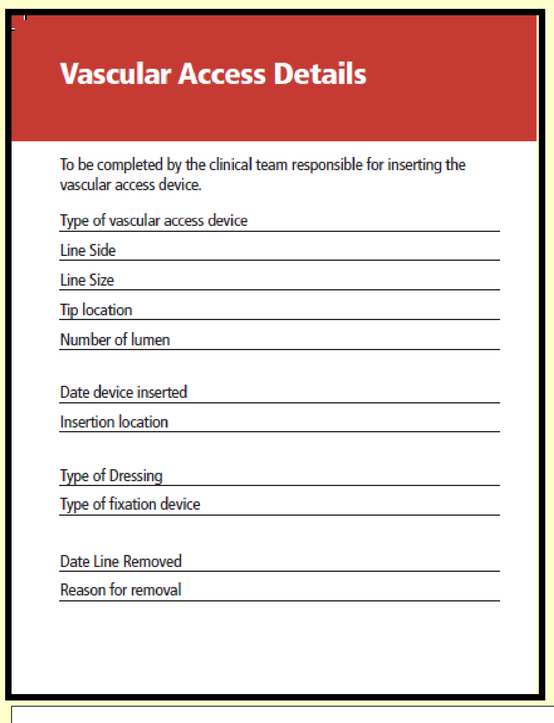
Table 1: Number of patients included within the central venous access device audit, their diagnosis and location.

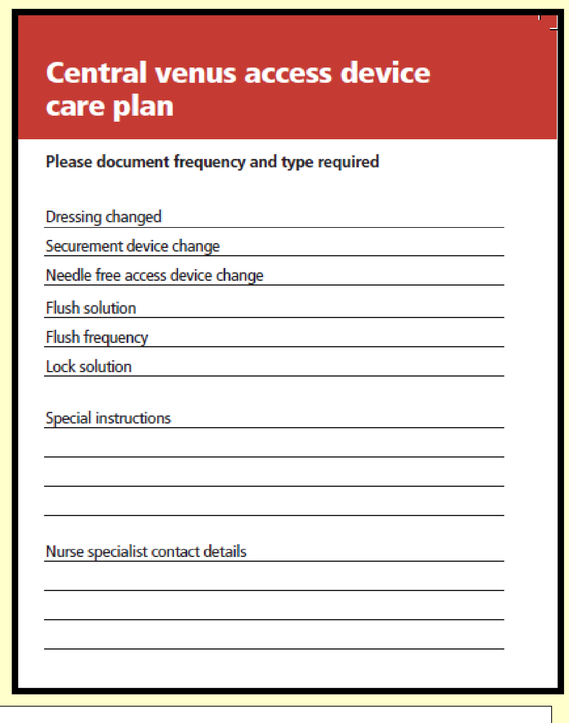
Results





The production of a patient held 'Photopheresis Passport'. The record includes sections for documentation of central line insertion together with ongoing care and maintenance of the central venous access device. In addition, patient demographic information, a patient diary, medication lists, blood results, treatment schedules and useful contact numbers are included





Method

A review of existing patient passports used within the NHS found wide variations in design and content. We were unable to find any document specifically pertaining to Photopheresis treatment. The requirements and aims of the document were discussed by the Photopheresis team following an audit of Central line device care, looking at incidence of infection, documented CVAD information, nursing care and lock devices. We found that details regarding line insertion and care was often absent, which could be attributed to a lack of consistent communication between the referring Trusts and ourselves.

A draft document was formed incorporating key areas of care and information. Draft copies were then disseminated to a selection of patients and the entire ECP team. Feedback was obtained at the monthly governance meeting prior to final approval and printing of the document.

REQUIRED INFORMATION	NOT DOCUMENTED
Anatomical Location	91.6% *(n=33)*
Line Type	83.3% *(n=30)*
Line Side (Left/Right)	97.2% *(n=35)*
Brand of Line inserted	100% *(n=36)*
Line size	97.2% *(n=35)*
Insertion Location	97.2% *(n=35)*

Table 2: Central Venous Access Device Insertion information - Data missing from the patients notes

Conclusion

The initial aim of the passport was to ensure that line insertion and care was appropriately and reliably documented. In addition we aimed to improve communication between ourselves and the referring Trust with regards to line care. This idea was further developed providing a finished product that we feel will be a valuable reference tool for healthcare professionals. The accessible patient held record will also provide each patient with an individual guide to their personal ECP schedule, ensuring optimal treatment and patient satisfaction.

Figure 1: Cellex device

Patient comments

'A really good idea, very handy for the nurses and myself.'

ECP patient

'A good way of keeping check on my appointments – it helps me keep track of my care as everything is together in one place.'

ECP patient

'An innovative idea – the document is both clinically relevant and patient friendly'

Haematology Consultant – Rotherham

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