National Specialist & Screening Services

Gyle Square
1 South Gyle Crescent
Edinburgh EH12 9EB
Telephone [redacted]
Fax [redacted]
www.nsd.scot.nhs.uk/

Draft Minute

Subject: **Ehlers-Danlos Syndrome (EDS) Pathway Discussion**
File ref: **K:\07 Health Support Ser\Specialist & Screening\Cttees & Grps\Rare Diseases Implementation Oversight Grp (RDIOG)\Patient pathways\EDS**
Author: **Miss Laura McDonnell**
Date: **7th July 2017**

In Attendance:
Dr Craig Wheelans, National Medical Advisor, NSD, NSS
Ms Jill Carnevale, Clinical Specialist- Occupational Therapy, NHS Lothian
Dr Joyce Davidson, Consultant Paediatric Rheumatologist, NHS Greater Glasgow and Clyde
Ms Lorraine Friel, Rheumatology Physiotherapist, NHS Greater Glasgow and Clyde
Dr Alan Hakim, Consultant Rheumatologist, The Hypermobility Unit, London *(via teleconference)*
[redacted] Patient Representative
[redacted] Programme Support Officer, NSD, NSS
Ms Patricia McLaughlin, Senior Specialist Nurse, The Single Gene Complex Needs Service
Professor Mary Porteous, Consultant Geneticist/Head of Service, NHS Lothian
Professor Stuart Ralston, Consultant Rheumatologist, NHS Lothian
[redacted] Patient Representative
Mrs Louise Wilson, Senior Programme Manager, NSD, NSS

Apologies:
Dr Rachel Atherton, Clinical Lead, Scottish National Residential Pain Management Programme
Dr Anke Roexe, Programme Manager, NSD, NSS
Mr Alan Seddon, Senior Physiotherapist, NHS Lothian
Dr Lars Williams, Consultant, Scottish National Residential Pain Management Programme

1. Welcome and Introductions

Dr Craig Wheelans welcomed everyone to the meeting and introductions were provided. Apologies were noted as above.

2. Background and Context

Dr Wheelans set out the context for the meeting. He explained that at present there was no clearly defined patient pathway for patients with Ehlers-Danlos Syndrome (EDS) in Scotland. The complex and varying needs of those affected and their families required the input of various different clinical specialities but at present there did not appear to be any structured mechanism as to how this care was co-ordinated, nor did there appear to be specific structured mechanisms in place for complex patients to be discussed. NSD was often asked to provide funding to allow access to the designated NHS England commissioned EDS service in London or Sheffield but such services were designed to identify specific genetic variants in a very small subset of patients. The services were not designed to provide specific rehabilitative services nor deal with specific symptoms related to the various body systems affected by EDS.

The aim of discussion was to fully understand the provision available for these patients in Scotland and the best approach moving forward, to allow a clearer more defined patient care pathway and improved patient experience.

2. Patient Experience

Patients with EDS varied in severity and presentation of condition. The complexity of the disorder often resulted in missed or delayed diagnosis for patients and as a consequence, patients felt confused, frustrated and misunderstood by healthcare professionals, which was damaging to the overall patient experience. There was therefore a need to educate primary and secondary care clinicians to improve early identification and reduce this barrier.

Due to the nature of the condition, treatment and care required a multi-disciplinary intervention, integrating services such as pain management, clinical genetics, gastroenterology and rheumatology amongst others. Within Scotland, these resources were often oversubscribed and in the instance of pain management, were not tailored to the needs of EDS patients specifically. Attending group therapy with other patients who had significant chronic pain relating to specific trauma or cancer often made EDS patients feel that their needs were insignificant by comparison and for some the perception of poor quality of life faced by suffers of these conditions was indeed de motivating.

Whilst the National Pain Management Service in Glasgow was to be applauded for the work that they had done in improving care for those with long term pain, it was no focussed on the specific needs of EDS patients eg related to acute pain when dislocation occurred. It was also commented that there appeared to be a lack of provision for adolescents in Scotland who required greater input than could be afforded by local pain services.

It was reported that the greatest benefit that any interaction within a specialised care setting , specific to EDS was the length of time clinicians spent with the patient to fully understand their needs and condition. Specific tailored information and knowledge of those with an interest was also valued. However, it was acknowledged in the current climate with pressures on resources, this extended time was often not achievable.

It was also commented that patients often felt dismissed in traditional care settings if nothing could be fixed by a drug or specific intervention. Clinicians were often hostile when patients presented accredited information resources during consultations.

Post meeting note: There is a wealth of very good public and professional information available from Two national charities serving the Hypermobility /EDS patient/family groups.http://www.hypermobility.org (HMSA) and http://www.ehlers-danlos.org .

3. Service provision

a. Scotland

Meeting members acknowledged that the majority of care for patients with EDS could be delivered locally; there was the right expertise but there needed to be a multidisciplinary structure to make this work. The pressure on current staff was also noted as one of main barriers to allow planning of a coordinated care approach.

Ms Friel gave an example whereby all EDS referrals for the West were referred to her clinic and it became unmanageable. She therefore visited the local regional clinics to give advice on how to cope with the less severe patients. Ms Carnevale advised that a visit to the Stanmore Clinic at Royal National Orthopaedic Hospital confirmed that treatment was not any different in Scotland but that the process and approach of planning and organising the care of these patients differed and in this helped support the patient experience. Ms McLaughlin added that there was a lot of willingness across the services to learn from other areas to increase knowledge.

Patient demand was difficult to quantify due to the nature of the condition, in addition to an unknown number who were not formally diagnosed.

b. England

NHS England offered a highly specialist service for the precise genetic diagnosis of EDS in Sheffield and London. Over the last two years, 16 patients had been referred to this service. It was felt that patients travelling simply for a diagnosis would not provide much clarity / support for

patient and only exceptional complex cases to diagnosis would derive of any benefit from attending the Sheffield service.

There were centres in Bath, Kent, and London with dedicated hypermobility units who treated patients with EDS. Specific provision was also available in the private sector in London.

Dr Hakim explained that the centre in Kent had recently developed a multi-disciplinary network of expertise to provide patient treatment care as locally as possible and the model for bringing together the stakeholders and establishing the network worked well.

4. Conclusions and Next Steps

All agreed a joined up multi-disciplinary approach was required in Scotland to reduce barriers to care. There was however a real issue in secondary care of who was responsible for managing this group of patients and being able to triage and provide support based on the severity of the patient.

Dr Davidson advised that planning for paediatrics would be seen as a separate pathway rather than an 'add on' to an adult service. All agreed, with it being noted misdiagnosis was a huge risk and diagnosis and management at early stage in life could help reduce long terms complications.

A multi-disciplinary network was proposed with a small service component, in essence a hub and spoke model. The proposed networked service would include a core of expertise and the requirement to improve education and training for those in primary and secondary care settings, to encompass the entirety of the patient pathway.

There was a need to fully understand the patient demand within Scotland to ensure the service delivery model proposed was appropriate. Meeting members advised that this could be could be difficult to quantify as not all patients are known.

Dr Wheelans suggested that there could be the possibility of the new NSD attached Clinical Leadership Fellow may be able to look at ISD data and Professor Porteous suggested that a trainee genetics councillor could review the NHS Lothian data. Ms Holmes also suggested that Dr Emma Rhinold, GP from NHS England, was also working on a project to identify patient demand which could be beneficial to collating an estimation of patient need for Scotland.

The costs attached to the proposed network would need to be calculated. The current patient experience which was on many occasions inconsistent and uncoordinated should be used to demonstrate the need and the benefits that a networked approach to care would bring. Meeting members agreed that a coordinated approach would reduce demand on multiple services and therefore provide cost savings rather than incurring additional costs.

Dr Wheelans agreed to share the minutes of this discussion with the National Services Division Senior Management Team (NSD SMT) to agree the best way forward and update meeting members of the outcome as soon as possible.

Action: Dr Wheelans

5. A.O.B

Based on the conclusion of Dr Wheelans discussion with NSD SMT, the group agreed to meet again to discuss next steps. [redacted] agreed to organise following the update.

Action: [redacted]