## A NOVEL VIRTUAL ADVICE MEETING

## IMPROVES ACCESS TO TIMELY GENETICS

# ADVICE FOR PAEDIATRICIANS AND

NEONATOLOGISTS

**Authors** 

Rachel Coles, Rare disease consultants, Agnes Kiraly, Duncan Shepherd, Munaza Ahmed.

#### 1.INTRODUCTION

UK government policy has led to increased availability of genetic testing, with an emphasis on Paediatricians and Neonatologists requesting a broad range of genetic tests (1). This has increased access to genetic diagnosis in children, however there is a need for support and guidance for clinicians to navigate new and complex pathways. Additionally, there are currently long waiting lists for outpatient genetics clinics and genetic test results in many regions. Such delays can negatively impact patients and their families.

#### 2. AIM & METHODS

A novel weekly virtual Genetics Advice Meeting for

Paediatricians and Neonatologists was designed and piloted as a service improvement project. The meeting created a forum for clinicians to discuss cases with consultant geneticists and was piloted for 6 months.

The meeting aimed to:

- ·Provide helpful advice in a timely manner.
- ·Generate a collaborative approach to patient care.
- Share knowledge.
- ·Alter management in the patients discussed.

The meeting addressed:

- 1) whether referral was indicated
- 2) urgency
- 3) genetic testing to initiate at the point of referral
- 4) any non-genetic tests to initiate
- 5) key information to provide with the referral.

The meeting was evaluated using anonymous surveys of attendees who were asked to rate the effectiveness of the meeting using Likert rating scales. Data was gathered about the advice given and the aspects of management altered.

"Being able to discuss a case with a geneticist and get useful advice early on, rather than submitting a referral and waiting, is just gold dust!"

"A fantastic service, very accessible and relaxed - will save a lot of time with regards to referrals and cut out delays in management"

**Affiliation** 



#### 3.FINDINGS: DATA

- 24 Paediatric cases, 14 Neonatal cases and 6 Community Paedaitric cases were discussed (n=44), from 10 different hospitals.
- 11 cases were urgent, 24 routine and in 6 cases genetics referral was not indicated.
- The meeting discussion altered management in all cases.
- In 59% (n=26) the genetic testing planned was altered by the meeting.
- Non-genetic tests were advised in 8 cases and non-genetic referral in 7 cases.
- Key additional information was attained in 24 cases.

### 4.FINDINGS: CLINICIAN VIEWS



Figure 1. Word cloud of free text comments

#### <u>Paediaitricians + neonatologists:</u>

- 77% strongly agreed the meeting discussion was helpful
- 88% strongly agreed they would attend again
- 73% strongly agreed they **felt more confident in the management plan** after the meeting

#### **Genetics consultants:**

- Found the meeting helpful for networking with referrers
- Found it helpful to **educate** around clinical cases

Would you like to attend? Email rachel.coles3@nhs.net

(Clinicians in North East London only)