

# Strengthening parental knowledge to aid valid consent, a prenatal genomic videography series

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The North East and Yorkshire (NEY) Fetal Genomics Transformation Project commenced in late 2021 under the direction of the NEY Genomic Medicine Services Alliance (GMSA). The purpose was to reduce the inequity of access to genomic testing for women and families in the prenatal and postnatal period. The project identified a paucity of educational digital resources for pregnant people accessing genomic testing in pregnancy.

### Objectives

- To design a series of three bespoke, educational, and accessible videos for the pregnant person and their families within the North-East and Yorkshire (NEY) who have been referred to a regional fetal medicine unit (FMU) for consideration of a prenatal invasive test.
- To create the **first digital innovation videography package in the United Kingdom** relating to antenatal invasive testing and subsequent genomic results.
- To strengthen parental knowledge to aid meaningful and valid informed consent for prenatal genomic testing.

### Scoping

A scoping exercise found only two patient videos (American and Canadian produced) on the common streaming channels which cumulatively have over 200,000 views. The information obtained within is outdated, and in some instances factually incorrect when comparing to practise within the NHS UK healthcare setting.

Recent studies suggest that a targeted video-based intervention can improve patient experience and outcomes. Common themes emerged, notably the reduction of anxiety, better retention of information and increase in patient satisfaction (Chatterjee 2021).

(Chatterjee A, Strong G, Meinert E, Milne-Ives M, Halkes M, Wyatt-Haines E (2021) The use of video for patient information and education. Patient Education and Counselling. 104 (2189-2199))

### Design

Parental distress and anxiety levels are understandably high following referral to a FMU during pregnancy. Many seek to find information whilst awaiting an appointment. The videos and corresponding patient information leaflets were designed to increase understanding of the genomic tests being offered, an explanation of the potential results, their implications and care moving forward in the pregnancy.

### The NEY GMS Prenatal genomic videography series

- Prenatal invasive testing following a higher chance antenatal screening result**
- Prenatal invasive testing following an unexpected finding on ultrasound scan**
- Prenatal invasive testing where there is a family history of a genetic condition**



Scan the QR code to view the videos and information leaflets



### Methods

A patient and staff two-way focus group was created. Opinion was sought from the director of Antenatal Results and Choices (ARC). Small test cycles were used to develop the videos and make any necessary incremental changes. Collation of feedback allowed for the video content to be developed, moderated and condensed into three digital media tools, relevant to the reason for referral. Each with its own corresponding detailed patient information leaflet.

### Equity and Equality

Based on spoken language per percentage of the NEY population, we were able to make specific regional recommendations for translations of the resources Into Polish, Urdu, Romanian, Punjabi and Arabic, based on NEY GMS ethnicity and language data. Animated characters are non-specific and inclusive to all ethnic groups.

### Results

Qualitative analysis of staff and service user feedback has demonstrated unanimous agreement that the resources are easily understandable, pitched at the correct level of understanding and delivered both sensitively and compassionately. 100% of of respondents have recommended their use in clinical practice. Early quantitative data reflects a reduction in clinician time when counselling and consenting for invasive prenatal genomic testing within the fetal medicine clinic consultation.

### Conclusion

Following a rigorous local governance approval process and successful staff pilot, the resources were formally launched across the North East, Cumbria and Yorkshire in April 2023. We plan a further 6-months of collation of user feedback and thereby completion of the service improvement evaluation process.

The internet is a well recognised source of information for parents during pregnancy. Video resources created with service users, produced by experienced clinicians, can result in a valuable resource that reinforces and compliments the discussions between healthcare providers and parents.

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