Developing a Nurse-Led Genomic Service to support patients affected by Inherited Cardiac Conditions

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Over the past decade, transformative advances in genomic technologies have enabled the development of precision medicine and improved diagnostics for individuals affected by Inherited Cardiac Conditions (ICC) and Sudden Cardiac Death (SCD).

The NHS Genomic Medicine Service Alliance believes nurses are strategically placed to facilitate the embedding of genomics into patient care pathways.

Despite this, a large proportion of genomic testing remains restricted to clinical genetics clinicians thus limiting the number of patients able to access this aspect of care.

OBJECTIVES

- Set up a Nurse-Led Genomic Service for individuals and families impacted by ICCs and SCD and increase equity of care.
- Increase competencies and job satisfaction amongst ICC nurses.

METHODS

- The electronic patient record (EPR) was reviewed in retrospect to cover genetic testing undertaken in the ICC service between 1st January 2022 - 1st January 2023.
- Structured interviews were conducted with key stakeholders to assess feasibility, benefits, and challenges.
- A Nurse-Led Genomic Service was trialed between 1st January 2023 – 1st May 2023 focusing on the counselling process, test initiation and dissemination of results.
- Key performance indicators (KPI) assessed: quality & equity of care and nursing competencies & training needs.

RESULTS

- Over the 12m review period, 79 patients underwent genetic testing, 12 of which involved deceased patients.
- Most stakeholders favour a Nurse-Led Genomic Service, with a small minority keen to keep current practice unchanged.
- The ICC nurse counselled, activated testing and disseminated results on 12 cases between 1st January 2023 – 1st May 2023.

Equity and quality of care KPIs:

- Patients receiving genomic care form nurses waited on average 12 weeks from referral to dissemination of results. By contrast, the waiting time using current practice exceeded 28 weeks.
- Feedback was positive, demonstrating patients found the nurse-led service to be particularly of value in inherited, lifelong disorders such as ICCs. Patients felt confident in the nurses' ability to counsel, disseminate results, and ensure continuity of care.

Competencies and training needs KPIs:

- The trial run identified that minimum training requirement is at level 7 and should include fundamentals of human genomics and genomic counselling skills, followed by supervised practice. Level 7 genomic courses are currently funded by Health Education England.
- Nurses expressed increase job satisfaction achieved by developing new skills and competencies.
- The ongoing NHS workforce pressures, lack of protected learning time, role ambiguity, and discrepancies between educational pathways are some of the main challenges identified.

CONCLUSIONS

- Nurse-Led Genomic Services are increasingly suitable to the fast-paced genomic landscape , nurses being strategically placed to inform, educate, raise awareness, counsel, and provide genomic care to patients.
- This approach ensures ICC patients have timely access to the benefits brought forward by genomic testing, improving patients' equity of care and quality of life by reducing unnecessary wait times, enabling early disease recognition, initiation of treatment and tailoring lifestyle advice.
- Furthermore, this approach will afford nurses the opportunity to expand their competencies, autonomy, and clinical judgment skills.

REFERENCES

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