

Improving care for asymptomatic patients with congenital long QT syndrome through remote monitoring

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Introduction

Congenital long QT syndrome (LQTS) is an inherited cardiac condition (ICC) associated with a risk of sudden cardiac death. This can be mitigated through lifestyle measures, medication and implantable cardioverter-defibrillators (ICD) for those at the highest risk. Most patients are low-risk and asymptomatic.

This project presents a proof of concept pilot aimed at managing low-risk patients with LQTS remotely. It addresses current challenges in patient care, including inconvenience of annual face-to-face (F2F) clinic visits exacerbated by long travel distances, and pandemic-related service backlogs for an increasing ICC patient population.

Methods and Objectives

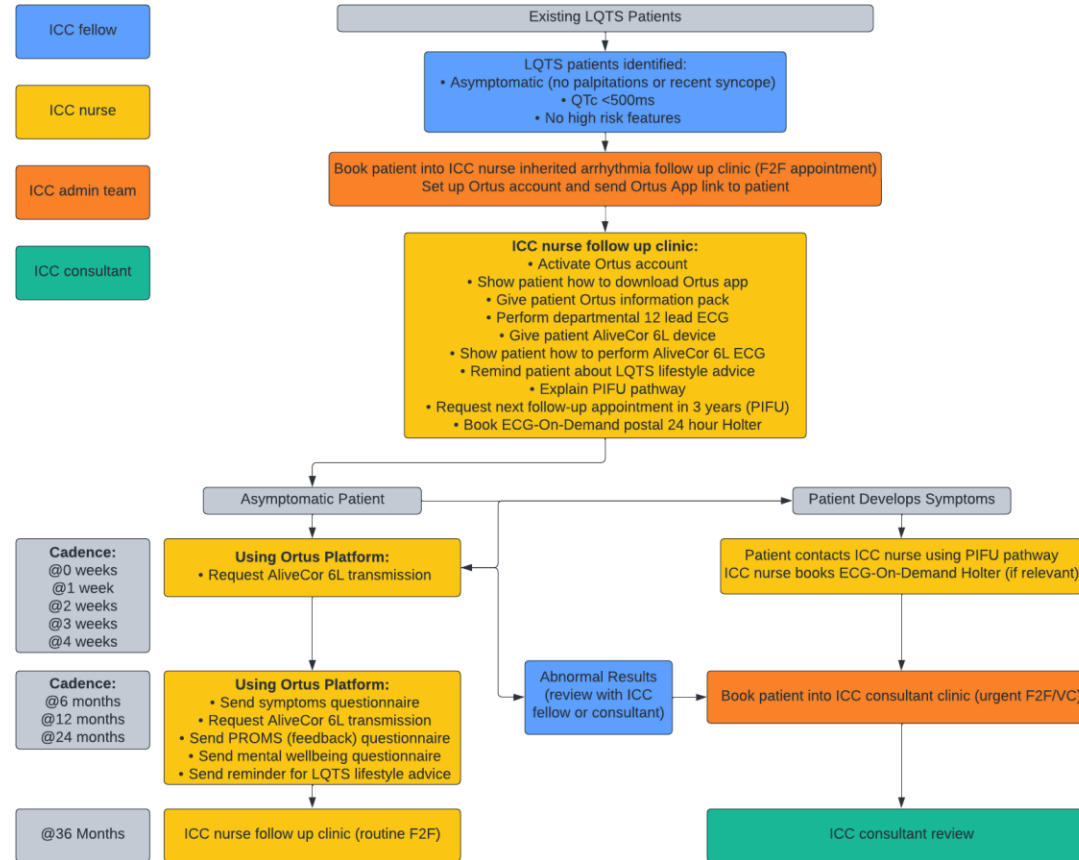
We have designed and implemented a novel solution utilising remote monitoring technologies integrated with the Ortus platform, commissioned by NHS England for digital cardiovascular care across London. The new pathway reduces F2F appointments to once every 3-5 years while ensuring continuous monitoring and rapid intervention if symptoms develop. It implements patient-initiated follow-up (PIFU) supported by home monitoring of symptoms and ECG data.

Key technologies include AliveCor's KardiaMobile 6L for patient-recorded ECG enabling QTc measurement integrated with Ortus for remote patient management, and ECG-On-Demand postal Holters for ambulatory ECG monitoring. The project aims to streamline care, improve patient experience, enhance education, maintain high care standards, and introduce mental health screening.

The project's implementation involves intensive training for staff members, including the ICC specialist nurse, who plays a pivotal role in coordinating patient care and overseeing the Ortus clinical dashboard. Patient pathway redesign is another critical aspect, ensuring smooth transition to the new remote monitoring system. Additionally, the project establishes robust feedback mechanisms, including patient satisfaction surveys and safety monitoring, to continuously refine and optimise the pathway.



Pathway Redesign



KardiaMobile 6L

Ortus Platform

ECG-On-Demand

Anticipated Benefits

- Increased patient satisfaction
- Comparable or improved patient safety
 - Prompt availability of symptom and ECG data
 - Lifestyle advice reminders
 - Easy access to patient education resources
- Enhanced ICC service efficiency with cost savings
 - Reduced number of F2F appointments
 - Reduced number of unattended appointments
 - Fewer Holter and ECG appointments
- Scalability to extend similar remote monitoring pathways to other patient cohorts and healthcare settings

Progress and Future Plans

1. Project steering group established to refine the patient pathway, set outcome measures, and targets.
2. Recruitment and training of an ICC specialist nurse completed.
3. Patient resources identified and linked to the Ortus platform.
4. LQTS patient cohort identified using the Trust's ICC database and the Cogstack data mining tool developed at King's College London.
5. To date, 12 of 13 patients educated regarding the new pathway have been enrolled, with one declining remote monitoring. Aim to enrol 50 patients within the first year.
6. Audit of LQTS patient care pre-COVID-19 and pre-pathway implementation ongoing. Plan to re-audit 12 months after the first enrolment.
7. The project's scalability will be evaluated, focusing on appointment frequency, patient satisfaction, and safety outcomes.

Conclusions

Overall, this project pioneers a patient-centric, technology-driven approach to managing LQTS, designed to transform care delivery for low-risk patients and serving as a model for similar initiatives in the future.

Declarations and Acknowledgements

- No conflicts of interest.
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