

Jazz Collaborative Working Executive Summary

A personalised model of care for developmental epileptic syndromes using Tuberous Sclerosis as an initial model of a service design in Republic of Ireland

This summary has been written and approved by Jazz Pharmaceuticals.

St James's Hospital Dublin, The St.James's Hospital Foundation and Jazz Pharmaceuticals are undertaking a Collaborative Working project. This involves contributions from all three parties with the pooling of skills, experience and resources between the parties, to improve the provision and quality of patient care. The project will run from March 2025 to March 2028.

This is a non-promotional project and Jazz Pharmaceuticals will have no involvement in any clinical or prescribing decisions.

Jazz is committed to increasing the provision and improvement in the standard of care of people with developmental epileptic syndromes (DEEs), appreciating that they are rare and often complex syndromes to manage.

The aim of the project is to achieve optimal patient outcomes at a population level with particular emphasis on the safety, quality and sustainability of the services that patients with a diagnosis of Tuberous Sclerosis Complex (TSC) receive, while creating a model of care for other developmental and epileptic encephalopathies.

The establishment of a dedicated Project Manager (PM) will lead the co-ordination of the TSC service at St James's Hospital. They will oversee and manage the delivery and implementation of the identified solutions and evaluate the impact.

This will be achieved through a robust data analysis of existing global service provision, examination of relevant international best practice, and public and stakeholder consultation. As well as national and international consultation with experts and clinicians in TSC management and patients and families affected by TSC.

This should allow the creation of a multidisciplinary, coordinated care service for patients with TSC of all ages in the Republic of Ireland.

The primary aims of this project are to:

- Conduct a robust data analysis of existing service provision, examination of relevant international good practice, and public and stakeholder consultation.
- Conduct national and international consultation with experts and clinicians in TSC management as well as patients and families affected by TSC to determine requirements for a multidisciplinary, coordinated national care service for patients with TSC of all ages.

- Establish an internationally renowned national model of care for rare epileptic syndromes using TSC as an initial model of a service design in Republic of Ireland.
- In parallel develop a TSC patient registry and national TSC Guidelines and clinic Protocols for the ROI.
- Develop a business case proposal for HSE to continue to fund the project beyond the project end date (December 2027).

In achieving these goals, the project should:

- Create a sustaining legacy of a national model of care for the treatment of TSC which can act as a blueprint for the care of developmental epileptic syndromes internationally.
- Reduce health inequalities for patients suffering with a rare syndrome in the ROI by offering a dedicated national clinic, with a clear patient pathway and clinical protocol.
- Establish the first national TSC guidelines and TSC patient registry in ROI.
- Establish a business case for the long term HSE support for this national model of care of TSC.
- Support broader HSE uptake of the model of care for similar rare epileptic syndromes through documentation, publication and distribution of project methodology and outcomes.

Intended Benefits:**Expected benefits for patients:**

- The project should enable an increase in the quality of care for patients with TSC in Ireland.
- Increased speed of access to specialist TSC care nationally.
- Better management of their syndrome leading to a reduction in complications and hospitalisations.
- Access to a dedicated MDT that can also look at improvements in common patient co-morbidities.
- Improved patient and carer satisfaction with the healthcare system.

Expected benefits to the Health Service:

- The project will enable the establishment of the first national specialist TSC clinic in the ROI.
- Improved TSC patient satisfaction through the provision of a dedicated specialised national clinic.
- The project will look to highlight the reduction in unexpected healthcare utilisation costs of these patients to the health service through the creation of a specialist clinic for these patients.
- Opportunity to create a blueprint model of care that can be adopted for similar rare epileptic syndromes resulting in similar improvements in patient satisfaction and reductions in unexpected healthcare utilisation costs.

Expected benefits to St James's Hospital & St. James's Hospital Foundation:

- Establishing a specialist TSC clinic will enhance the hospital's reputation as a centre of excellence for rare disease management.

- By streamlining care within a dedicated service, the clinic will improve patient outcomes, optimise resources in providing evidence-based care to people with TSC, and reduce the burden on emergency and general neurology services.
- Additionally, the project will support staff training and multidisciplinary collaboration, fostering expertise in TSC and rare epileptic syndromes within the hospital.

Expected benefits to Jazz Pharmaceuticals:

- This project will enable the company to partner with leading HCPs to ensure this rare patient population receive access to a well thought out *gold standard* of care in ROI, which helps Jazz live its values of being a collaborative, patient-focussed company.
- The project will create a legacy for patients of rare epileptic syndromes enabling the establishment of the first national TSC clinic in the ROI, allowing Jazz to live its values of being an innovative company that pursues excellence.
- It will create a blueprint model of care for other rare epileptic syndromes in ROI while also establishing a “best practice” of care that, as part of the project, will be published and shared further afield, thus potentially improving the care of these patients globally.
- Increased utilisation of Jazz’s epilepsy medicines, as well as other pharmaceutical companies, in appropriate patients, in line with national guidelines and clinical protocols.

Jazz Pharmaceuticals will have no involvement, influence or visibility in any clinical or prescribing decisions.



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