**THRIVE Privacy Notice - Data Protection and Confidentiality**

**Final Version 2.0 14/12/2021**

**What is the THRIVE registry?**

The THRIVE registry is The Right Infusion of Vitamin Evaluation registry. It is currently run in the UK and Ireland for Cystic Fibrosis patients of all ages who need vitamin supplementation as a result of their disease. The information in the registry will be used to assess and improve the quality of services and the outcomes achieved by vitamin treatments across the NHS. It will also provide comparative information to patients, commissioners and regulators of healthcare professionals.

**What information does it contain?**

The registry includes some details about their treatment with vitamins, their medical history and the patient, the investigations performed and outcomes achieved. The information importantly also contains the NHS number in order to check the patient’s ongoing vitamin levels etc. These are vital pieces of information that will help to establish how well the vitamins are being absorbed and how the patient feels about their treatment and management.

**What is the legal basis for the THRIVE registry?**

THRIVE data are collected for a “medical purpose”, as defined in the 2006 National Health Service Act Section 251, for the provision of care and treatment and the management of health and social care services.

The data are collected on ALL patients who are using Paravit-CF multivitamins as part of their disease management,

**Who manages the THRIVE registry?**

The THRIVE registry is managed by Manchester University NHS Foundation Trust in partnership with other clinicians at centres around the UK. Our technology partner is Dendrite Clinical Systems limited, who develop and support the registry and provide sub-contracted server hosting services

**What happens to the data and who can see it?**

The data are collected by the doctors, nurses, and hospital staff treating and managing the patient. Hospital computers are used to collect the information, which is collated, checked and approved before being sent to a single secure registry server on the NHS network. During the data transfer from the hospital to the NHS server the information is encrypted (locked) to ensure it cannot be interfered with. Only an approved member of staff at the hospital can enter data into the THRIVE registry. Once the records have been entered they can be reviewed by authorised staff at the hospital using an approved user account with a secure password.

Hospitals enter data directly into a secure Web-based THRIVE registry.

They will produce an annual report under the guidance of the clinicians at Manchester University NHS Foundation Trust. Some essential data will be shared with Manchester University NHS Foundation Trust and ParaPharm Development Ltd. in order to improve the treatment for future patients with CF.

The information collected is valuable as it allows clinicians to understand the uptake of multivitamins, the profile of patients and the results that are being achieved by hospitals around the country. The data will be analysed by Dendrite Clinical Systems to produce THRIVE annual reports. The reports do not contain the details of individual patients or their disease. They report results for groups of patients. These are broken down by region or hospital, and by other important information that may be related to outcomes such as age, general health status and disease burden.

The reports are used to help commissioners, providers and doctors understand how their practice and outcomes compare to performance in other centres. Non-technical versions of the reports are available for patients and members of the public. THRIVE information may also be presented at CF congresses in an anonymised form. This aims to help the CF-patients, their families and carers to understand the impact of vitamin supplements on the overall care of the patients across the UK.

The data will not be shared with anyone, or used for purposes other than those agreed with Dendrite to perform the audit.

**THRIVE Registry Server**

The server is hosted on the NHS network (N3) within a data centre in London, by Piksel. This is a tier four data centre which meets the highest levels of building security.

The service delivery and information governance provided complies with ISO 20000 & ISO 9001 accreditation and the security structure is aligned alongside ISO27001. The security arrangements are internally audited approximately every three months and externally audited every six months.

All servers have firewall and anti-virus software installed which is configured to use real-time scanning.

## Backup Resilience

The data is securely stored and backed-up each day on the NHS computer system. All backed up data stored is compressed, de-duplicated and encrypted within a secure off-site vault.

There are two backup vaults, the primary one is hosted locally and is then backed up to a secure secondary off-site vault hosted within a separate datacentre located at Heathrow.

**Dendrite Security**

Dendrite Clinical Systems is assessed against NHS Information Governance standards, which includes both physical and organisational security measures. Dendrite’s toolkit assessment score is available on the IG Toolkit website (<https://www.igt.hscic.gov.uk/Home.aspx>).

The computer software program created by Dendrite that holds the THRIVE data has been independently tested to ensure that it is not vulnerable to unauthorised access, or internal breaches of security.

**Can I ask to see the data that the THRIVE registry holds about me?**

Requests to see what data is held on the THRIVE registry about you may be made through the [THRIVE website](http://headandneckaudit.com/freedom-of-information/).

**Further information**

Queries should be directed to the THRIVE Project team - [team-THRIVE@Dendrite.co](mailto:team-THRIVE@Dendrite.co)m