

Thematic Review of Ordering and Supply Arrangements for Home Enteral Tube Feeds and Equipment - Executive Summary

People who are unable to meet their nutritional requirements through oral diet but have a normally functioning and accessible digestive system may be fed “enterally”. This means specialised dietary products known as enteral feeds are fed directly into the stomach (or on occasions the bowel) using a tube. The safest and most appropriate administration method is selected following an individual assessment by a dietitian. Enteral feed may be administered either via an electronic feeding pump, using a gravity technique or using an enteral syringe, and for the majority of patients it is their sole source of nutrition. In April 2021, 961 people required home enteral tube feeding in Northern Ireland.

A multidisciplinary workshop led by the Department of Health (DoH) in 2018, scoped the current arrangements for ordering and supply of enteral tube feeds, pumps and the consumables required for their administration. It concluded that there was potential for improvement to the current systems available for service users in primary care. HSCB¹, as commissioner of services, sought additional opinions from service users, their representatives and healthcare professionals in 2020 via a survey hosted at the NI Direct website. A multiagency working group, including representatives from HSCB¹, PHA, BSOPaLS and HSCTs analysed the 249 responses (service users 49.4%; healthcare professional 50.6%). This review identified key themes and recommendations for service improvement which are outlined in this summary.

Ordering and Supply of Equipment

The facility for a single supply mechanism including direct delivery of equipment (consumables) to service users is included in the “Homecare” arrangements within the Regional Framework for Nutrition Products (March 2017)² which HSC Trusts are working towards fully implementing. Service users and healthcare professionals have provided positive feedback where the arrangements are in place; though some practical recommendations to enhance the flexibility of current arrangements were suggested by service users.

Where arrangements have not been fully implemented, survey feedback indicates that this creates problems for healthcare professionals (46% indicated the current arrangements for supply of consumables were inadequate or they were unsure of the adequacy). Problems were highlighted from primary care, district nursing and care homes. Service users also outlined problems particularly in relation to managing supplies from multiple sources with no centralised coordination.

¹ Now Strategic Planning and Performance Group, Department of Health

² Update in 2022

Full implementation of Homecare arrangements for all consumable products across all HSC Trust areas would:

- Reduce confusion for service users;
- Ensure timely access to consumables
- Reduce unnecessary follow-up by primary care health professionals.
- Facilitate redirection of community nursing time to clinical care
- Provide arrangements for access during out-of-hours scenarios and when the service user is away from their usual residence.

Ordering and Supply of Enteral Feeds

Enteral feeds are not licensed medicines but can be ordered in primary care on HS21 prescription for specified conditions as detailed in the Northern Ireland Drug Tariff's "borderline substance" arrangements³. The GP or other independent prescriber assumes clinical responsibility for prescribing following a prescribing recommendation from the dietitian managing the patient's clinical nutritional care.

Supply in primary care is governed by Pharmaceutical Services (NI) Regulations 1997 which authorises dispensing against a HS21 prescription in any of the 525 registered pharmacies included in the Pharmaceutical List. The Regulations require the community pharmacist to supply products "with reasonable promptness"⁴. It would be unusual for a community pharmacy to stock any enteral feed as normal practice and there would be no expectation that this should be the case. These products have a short shelf life and are expensive; community pharmacists would generally have arrangements in place with service users to ensure their specific products are ordered in, for supply on receipt of a prescription.

Service users or their carers collect the feeds from the community pharmacy; some pharmacies provide a delivery service although there is no legislative or service level agreement requirement to do so.

Survey feedback indicated that while 84% of service users reported that the current arrangements were good or excellent this was considerably less in feedback from HCPs; 65% of healthcare professionals reported that current arrangements were adequate in that supply can be organised via prescription if appropriate information is communicated to the GP; 35% did not consider the arrangements were adequate. Both service users and HCPs highlighted problems and provided suggestions to support improvement in governance arrangements as well as access to feeds.

³ Borderline Substances http://www.hscbusiness.hscni.net/pdf/DT_PART_10a-1906.pdf

⁴ Schedule 2 Part II, Terms of Service for Chemists.
http://www.legislation.gov.uk/nisr/1997/381/pdfs/nisr_19970381_en.pdf

Key points highlighted by both service users and HCPs included:

- A lack of knowledge and expertise by healthcare professionals outside of the specialist teams; potential risks in transfer of prescribing information, or in management of product changes or where there are supply issues.
- The need for more streamlined systems for ordering and supply and suggestion of a direct role for dietitians in prescribing/ordering.

Healthcare professionals identified inadequacies in relation to clinical responsibility for prescribing enteral feeds and GPs have clearly indicated they are an additional step in the ordering process as they do not have expert knowledge of these products. Models of dietetic led ordering of nutritional products have been established in other areas of the UK and have demonstrated benefits for patients and healthcare professionals as well as efficiencies for the health service. Dietetic led ordering would:

- Support the principles of the NI Medicines Optimisation Policy which recommends that “*Clinical responsibility for prescribing should sit with those professionals who are in the best position and appropriately skilled to deliver care which meets the needs of the patient*”.⁵
- Support the dietetic profession - the British Dietetic Association considers it reasonable to propose that the clinical responsibility for ordering nutritional products should sit with dietitians.

It is acknowledged that arrangements to support a non HS21 prescription route would require legislative changes and supporting policy arrangements.

Survey feedback has suggested that a direct supply mechanism for enteral feeds would improve access for service users and ensure arrangements were in place for emergency situations out-of-hours and for travel away from home. In other regions of the UK, direct supply via “Homecare” arrangements is a frequently used mechanism for service users to obtain their enteral feeds as well as their consumables and arrangements are outlined for service users on the *Patients on Intravenous and Naso-gastric Nutrition Treatment* website.⁶

In other regions of the UK, this direct supply is facilitated by issue of GP prescriptions which are dispensed in a small number of specialist nutrition product only registered pharmacies based in England. Reciprocal dispensing and budgetary implications may need to be considered, or alternative arrangements developed to support dietetic led ordering on an off-prescription model. Consideration must be given to the impact on community pharmacy remuneration if there are changes to current supply arrangements.

⁵ <https://www.health-ni.gov.uk/articles/medicines-optimisation>

⁶ <https://pinnt.com/Support/Frequently-Asked-Questions/Enteral-Nutrition-FAQ-s/Feeding.aspx>

Feedback suggested supplies at discharge from hospital are insufficient to ensure continuity of care and it was suggested that a direct “Hospital to Home” supply mechanism would overcome these issues.

Specialist Support for Service Users in Managing Their Condition

The need for specialist support for both service users and health care professionals who may lack the knowledge and skills required for the management of enteral tube feeding was recommended in 2004 by the Clinical Resource Efficiency Support Team (CREST) for Northern Ireland and in 2006 by the National Institute for Health and Care Excellence. The roles (Home Enteral Tube Feeding (HETF) Coordinator and specialist nutrition support nurse respectively) were recommended to minimise complications related to enteral tube feeding and support coordination of care between the hospital and community. However currently posts are not in place in all Trust areas and where specialist services have not been established, the Trusts’ core dietetic teams and community nursing services provide support to service users in their own homes.

36% of healthcare professionals consider the current arrangements for specialist support adequately meet the needs of service users. There was positive feedback on the support provided in Trusts where these roles were filled. The most widely reported issue was the current inequity across the region and challenges in provision of optimum support for service users in Trusts currently without this support. Service users indicated there was a need for additional support post discharge.

Current arrangements do not comply with best practice to ensure optimal care is provided for service users as indicated in NICE and local CREST guidelines

Peer Support for Service Users

Patients on Intravenous and Naso-gastric Nutrition Treatment (PINNT), is a national, independent, not for profit membership charity established for over 30 years. It provides mutual support and understanding to hundreds of adults and children and their families adapting to life on home artificial nutrition. PINNT provides this support direct via local and regional groups, online forums, written information and a national telephone and email helpline.

PINNT offers access to 'Get-Togethers' via local PINNT Ambassadors and feedback indicates that many people benefit from the meeting experience where they can share experiences, gain support and offer advice to others in similar positions. Northern Ireland currently does not have a local PINNT group.

Conclusion

It is clear from the survey feedback that there is considerable scope for improvement to the current arrangements for ordering and supply of enteral feeds and the equipment required for their administration. Using information from the survey to shape services in a “whole system” approach would improve outcomes for service users and healthcare professionals involved in their care; it would support the principles for change outlined in *Transforming Your Care* by:

- placing the individual at the centre of the model
- integrating care – working together
- providing the right care in the right place at the right time
- promoting independence and personalisation of care
- ensuring sustainability of service provision
- realising value for money⁷

The four key themes for improvement identified from survey feedback were:

1. Ordering of enteral feeds in a dietetic-led approach
2. Supply of pumps and consumables via fully implemented updated Homecare arrangements
3. Direct supply of enteral feeds to service users
4. Equitable specialist support for service users and healthcare professionals across Northern Ireland

The specialist support roles along with additional, appropriately identified roles e.g. dietitians, dietetic support workers and administrative support would be key to facilitate implementation of direct supply arrangements and dietetic led ordering. Peer support would further enhance the service user experience.

The Working Group recommends that HSCB¹ should share the outcomes of the survey with DoH and work together with supporting organisations including PHA and HSCTs to progress the recommendations for improvement. Consideration should be given to the policy changes and resources that may be required to support their implementation.

⁷ <https://www.health-ni.gov.uk/topics/health-policy/transforming-your-care>