

NHS BLOOD AND TRANSPLANT MULTI-VISCERAL AND COMPOSITE TISSUE ADVISORY GROUP

Referral criteria strategy for intestinal transplantation

This document aims to outline a strategy to raise awareness of intestinal transplantation in the professional and patient communities as well as within the general public. The goal is for patients to be referred at an appropriate timepoint along their illness. Over the years this has been addressed by publishing the referral criteria, publishing articles and editorials and talks given at National conferences. However, the feeling is that there continues to be a knowledge gap in this area. The approaches that can be utilised include:

A. Traditional approaches

1. Publications: professional articles and editorials

It will always be important for transplant and intestinal failure centres to publish original data relating to intestinal transplantation. Centres should be encouraged to publish and an approach to incentivise centres could be considered. It could also be helpful to utilise the statistical expertise of NHSBT where data between centres need to be considered together. This could help to facilitate multicentred analysis and raise the profile more by allowing publications in journals with a higher citation index.

Editorials in peer reviewed journals are important. Generally, these go alongside articles that may have some impact but invited editorials are also possible. This would require NHS BT/MCTAG to approach the journal editors directly. Generally, the opportunities are infrequent and the audience is clearly for the professional groups.

Over time the focus has been the medical scientific journals rather than the nursing, dietetic and pharmacy journals. There should be a drive to publish in a wider array of journals in this respect.

2. Conferences

Invited lectures at national conferences is an important way of dissemination of information. Many of the members of MCTAG are involved in the organisations running the conferences but it is hard to have a high profile for intestinal transplantation as there are always many competing issues. Again, over time the focus has been the medical conferences rather than the nursing, dietetic and pharmacy conferences. There should be a drive to present at a wider array of conferences.

With the development of virtual conferences over the past year it would be possible to hold a virtual conference specifically on the topic of intestinal transplantation aimed at referrers (intestinal failure centres).

B. Additional approaches

1. Patient support groups

The patient support groups are important as they do have influence on patients with intestinal failure. It is important that any information presented is understandable for patients and balanced. The most important group to involve in the UK is PINNT (Patients on Intravenous & Nasogastric Nutrition Therapy) but also MOTS (Multi-Organ Transplant Support) can have a role. This approach can be combined with the social media approach described below.

2. Social media

It is increasingly possible and important to raise awareness in the general public and patient groups directly. Balanced and targeted social media approaches would allow patients with intestinal failure to ask their medical teams about the possibility of intestinal transplantation for themselves.

M&F Health are a communications agency that work with BAPEN (they are commissioned by BAPEN). As an organisation they have been very effective for BAPEN in raising awareness of malnutrition and nutrition support. They initiated that Malnutrition Awareness Week in the UK and this has developed significant traction over the past 3 years, now becoming a more global event. They have the skills to portray sometimes complex information in a simple way.

BAPEN exec have agreed for us to be able to talk to M&F Health to see how they would develop a campaign to raise awareness of intestinal transplantation in the community. The starting point will be to see if this is possible within the remit that they are employed by BAPEN or if this will take additional time and therefore additional funding would be required. A cost exercise will therefore be important.

This exercise was going to go ahead in early 2020 but with Covid there have been delays due to different priorities.

3. NHS England

Development of educational and informative material by NHS England can be considered, especially around the time of HIFNET launch.

C. Initial suggested strategy

| | |
|---|---|
| Publications: professional articles and editorials | <ol style="list-style-type: none"> 1. Continue to encourage scientific publications 2. Actively encourage publications relating to intestinal transplantation in paramedical journals 3. Consider involvement of NHS BT statistics expertise if required |
| Conferences | <ol style="list-style-type: none"> 1. Continue to try to present at conferences 2. Consider holding a virtual conference aimed at intestinal failure centres at a multidisciplinary level |
| Patient support groups | <p>Approach PINNT and MOTS:</p> <ul style="list-style-type: none"> - If they would like information or articles/viewpoints that they can send out via their newsletters - Involve the organisations with any social media approaches |
| Social media | <ol style="list-style-type: none"> 1. Check that BAPEN remain in agreement for us to approach M&F Health 2. Discussions with M&F Health to see how they would develop a campaign to raise awareness of intestinal transplantation in the community 3. Develop a campaign with M&F Health, with costing. Multidisciplinary involvement very important as well as patient involvement. |
| NHS England | Liaise with Sarah Watson regarding for opportunities of involving NHS England from an educational and/or informative way. |