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Patient Empowerment and Autonomy in Cancer Care: Oakland Lodge and a Dedicated Transport Service, St Luke's Hospital, Dublin

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Key Points - Oakland Lodge

The lodge is a positive, largely self-supporting community of similar patients. It is not simply accommodation, but engenders feelings of belonging and ownership. It provides an easily accessible space where patients can both spend time on their own or with their family when they want to, and gain support from other; and also have good access to services and activities.

- The lodge is more than just a building, but the building plays an important role through its:
 - a) Design:
 - Scope for communal activities but also for privacy when wanted
 - Room for a relative to stay
 - Rooms for therapy and meals (forthcoming)
 - b) Situation:
 - In a calm, green environment (this is enhanced by St Luke's being a dedicated cancer centre with no A&E)
 - Close to, but not part of, the main hospital building
- The lodge, in conjunction with other activities and support provided by St Luke's, not only reduces isolation, but enables a positive sense of community that empowers patients to help each other and makes full use of their skills and experience.
- The lodge requires careful admission criteria, carefully administered, in order to maintain the sense of community, while minimising the exclusion of patients who could benefit individually. This is not an easy concept, and greater explanation of this to staff and patients may help to maintain their support for the system. It may also be worth St Luke's carrying out some small scale pilot experiments to see whether the admission criteria can be relaxed without detriment to the character of the lodge.
- The design of facilities such as the lodge needs to be sensitive to the cultures of patients and relatives in its community, and in particular the balance

between individual/family privacy and communal sharing. The development of the lodge has been based on regular feedback from patients, and good input from patients seems likely to be helpful in developing other such facilities.

- The lodge concept was based on some background research, including visits to other hospitals. Such networking with other organisations seems to have been useful.
- The lodge appears to have been driven primarily by nurses and by nursing values. This may reflect the caring ethos of St Luke's. Even so, there may be some tensions regarding the lodge because of different views within and outside the nursing profession, about what nursing is and should be. Such differences might affect the level of support for such a development from an organisation, and also whether it is staffed by nurses.
- It is not possible to tell from this study what the impact of accommodation charges might be on facilities such as the lodge. This seems likely, however to be sensitive to past practice and expectations regarding charging.

Key Points – Dedicated Transport Service

- A transport service like this is likely to be valued by patients where there is a poor transport infrastructure.
- Positive aspects of the service include its simplicity (fixed travel times) and reliability, the possibility for a relative to travel, and integration with treatment appointment times
- The commitment of the bus company and its drivers has enhanced the quality of the service. It is important to take time to establish a good relationship with the service provider, and to select drivers carefully with regard to their personal qualities and interest in patient wellbeing.
- It is not clear how easy it may be to make a case for establishing such a service, as the full costs and benefits of the service have not yet been calculated and compared with other options, such as various types of patient accommodation. The impact on utilisation of patient accommodation is also not known. While St Luke's has decided not to charge for the service, in other situations this may be possible, as may sponsorship – although this may be difficult to manage if cancer carries a stigma in society (patients do not want to publicise that they have cancer).
- The service has not been actively publicised, but has relied largely on word of mouth. More active publicity to patients might be considered, as the costs of the service are largely fixed, while benefits will increase with more passengers.

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- Bill Corkery, Director of Operational Services, St Luke's Hospital
- Eileen Maher, Director of Nursing, St Luke's Hospital

1. Background

St Luke's Hospital (SLH) is a specialist cancer hospital, located in the south of the city of Dublin, Ireland. SLH has 160 beds, including four inpatient wards, a day unit and a five-day unit (Oakland Lodge). There are 6 linear accelerators. The hospital treats over 4,000 new patients per year, equating to 70,000 treatments. SLH currently provides a national service in conjunction with sixteen regional clinics where outpatient and other services are provided. The hospital aims not just to be about medical treatment, but also about wellbeing and healing for a person's whole being, and is noted for providing a friendly and caring environment for both patients and staff.

In 1994 a major investment programme commenced at St Luke's site, with the closure and transfer of services available at another site being completed in 1997. Since then there has been an extensive building and refurbishment programme, with additional financial support from the Friends of St Luke's.

SLH is one of four centres in the country that provide radiotherapy treatment. Three of these centres are in Dublin (in the East of the country) and one in Cork (in the South), where the service is relatively small, so services are concentrated in the capital. In late 2003, an Expert Working Group on The Development of Radiation Oncology Services in Ireland (EWG) identified a profound deficit in radiation oncology services compared with some other EU countries, and instigated the development of a clinical network of large centres in Dublin, Cork and Galway (in the West).

A key objective is equal access to treatment regardless of location. This does not necessarily mean that radiotherapy services must be located in many centres throughout the country, however, but rather that there should be access arrangements for patients to get such services. The EWG recommended that there should be two treatment centres in the Eastern region, which has the largest population, and six hospitals in Dublin, including St Luke's submitted proposals in October 2004. An International Panel was due to advise on the proposals by the end of the year.

The EWG commissioned an independent study of the priorities of Irish patients and their experiences of existing radiation oncology services. While geographical closeness of services only ranked thirteenth of the examined parameters, local roads and transport infrastructure are often poor, even in areas such as Wicklow, which are close to Dublin. Dublin suffers from traffic congestion and there is a lack of car parking. There is no direct public transport to SLH, though buses from the city centre run to within a few hundred yards of the hospital.

The group determined that the potential development of a more restricted number of sites would require the development of innovative transport solutions and additional new inpatient and hotel/hostel/bed and breakfast (B&B) accommodation for a greater percentage of patients and relatives. Initiatives like these might be expected to make radiotherapy treatment easier for a substantial proportion of the patients who experience some difficulties (Table 1).

Table 1: Responses to the question “What might help make the experience of radiotherapy treatment easier for you?” in the EWG patient survey

Experience	Number
I typically had no difficulties travelling for radiotherapy treatment	72
Availability of hostel facilities	12
Assistance with transport	12
More control over the timing of radiotherapy treatment	7
Other	6

2. Oakland Lodge

2.1. Overview

Oakland Lodge provides accommodation while patients are receiving courses of radiotherapy treatment at St Luke’s Hospital, typically lasting 5 weeks or more. The lodge is located in the hospital’s landscaped grounds, about 100 yards from the main building. It currently has 30 rooms, all with ensuite bathrooms. 8 of the rooms are for private patients, and 20 have a second bed, so that a relative can stay too. The lodge is being extended by a further 19 rooms, most of them with a second bed. There is also a kitchen area with extra cooking facilities for patients and a sitting room where patient support groups meet. There are security cameras so that patients feel secure.

The lodge is open from Monday morning until Friday lunchtime and patients staying there return home at weekends. There is 24 hour nurse cover. During the day there are 2 full time nurses on duty, plus a 3rd nurse in the afternoon. There is one nurse on duty during the night. Initially there was also a care assistant, but it was later decided that this assistant was not needed.

Patients are encouraged to regard the lodge as a “home from home” facility and can come and go as they please while receiving treatment. This allows for complete patient privacy and independence, while receiving cancer treatment with the support of the full range of hospital and medical services. The lodge has been widely acclaimed by patients and relatives since it opened in 1996.

The main groups of patients who use the lodge are those with breast or prostate cancer who are self caring. The lodge is intended for people aged 16-85, but there is some flexibility in special circumstances Eg once a 10 year old child was accommodated with a parent staying in the room next door. There some young patients with early diagnosis of hodgkins disease – about 20 each year. These patients tend to have different problems. They may suffer from fatigue, loss of appetite and loss of interest, and find it difficult to get up and wash. They worry about getting back on track with their education. Staff can organise things like a playstation, but it is better if a parent is able to stay and support them. Generally, it is good that a relative can stay, because many relatives also need support, and this can be provided better face-to-face than over the phone. Patients are also encouraged to bring their children to the hospital for the day to see what goes on.

Patients are seen by a doctor in the hospital once a week. If a patient falls ill suddenly, then a doctor can come to the lodge, and patients can be transferred back to the hospital if necessary. Lodge patients are regarded as inpatients by the radiotherapy department, which means they are slotted in whenever there is a space, whereas outpatients are given specific times in advance. If outpatients are delayed, then a patient may be brought down from the ward or the lodge, so lodge patients need to be flexible. 2 radiotherapy machines run late into the evening, and most male lodge patients are treated then, but their first treatment is always given during the day, when they get to see staff and receive information.

Patients are referred initially following assessment by a doctor in the outpatient clinic. The admission criteria are nursing led, but also include the patient's Karnovsky status (see Appendix 1). A nurse from the lodge then phones the patient at home to do a second assessment and decides whether admission should be to the lodge or to a ward as an inpatient. The ward patients might have other conditions such as epilepsy, even though they may not have had a seizure for years. They tend to be older. Waiting times for admission can be more than 3 months, with longer waits if the patient requires hormone treatment or has prostate cancer. The extension of the lodge should help to address this problem to some extent.

Patients are asked to come in for a "simulation" day before admission, when a further assessment may be made. It is difficult to cover everything over the phone. The cancer often takes precedence over everything else for the patient and they cannot remember other things that may be relevant to the admission criteria. The lodge is not formally part of the simulation day, so sometimes patients are not seen at the lodge and are assessed instead by the nurses in the radiotherapy department. Patients may phone the lodge later with various questions, and this provides an opportunity for them to "unload" any concerns they may have, and for the nurse to provide information about the lodge.

2.2. Development of the Lodge

The hospital used to have a hostel upstairs in the old main building, but the building was not well suited to this (Eg it had staircases, not lifts) and there was no nursing support. Today, we do not like the word "hostel" and the concept it expresses – "our patients are not homeless!" – they are lodging with us.

Before establishing the lodge, other centres in the UK were visited (Eg Clatterbridge, Mount Vernon, Royal Marsden), and contact was made with aparthotels in Denmark and Sweden. Patients were also asked what they wanted, and it was decided that SLH should develop a facility the equal of any in the private sector, because patients do not want to be in a hospital environment. Some managers wanted patients to pay to stay in the lodge, but many patients have limited funds, if any, and SLH has a number of benefactors, and the Department of Health also provided some funding, so it was decided not to charge.

To start with there was a pilot with 6 refurbished B&B rooms, some with a kitchenette. But patients didn't like this: some were too unwell, there was no nursing support or company, and they couldn't manage. The only people who could really

use the rooms were people who were just attending for a test. At Mount Vernon although there was a housekeeper present in the mornings, the patients seemed a bit isolated during the rest of the time. It may simply be a difference of culture between Ireland and England, but patients being on their own so much didn't seem to work in an Irish setting. So the concept of the lodge was developed by the Medical Director and the Director of Nursing.

Initially, although the lodge provided accommodation, there was little else happening for patients other than their treatment. Following a patient survey in 1997, aromatherapy and activities such as arts and crafts, flower arranging and tending a patio garden were introduced. These were modelled on Memorial Sloan-Kettering and some elements of Clatterbridge and Mount Vernon. The patients love to make something and take it home to their family. They are sad at being away from home, and this helps to maintain the family bond. The hospital activity centre is open from Tuesday to Thursday on a "drop in" basis. There is a digital camera and computer so that patients can take photos of the crafts they have made and print them out, and from January 2005 a newsletter will be produced. There is also pottery, art, glass painting and a floristry course. The centre, although it is in the hospital building, enables patients to "get away from the hospital". There is also a pitch and putt golf course which is well used in summer.

2.3. Activities that take place in the lodge

2.3.1. Complementary Therapies

Complementary therapy started as a pilot in the lodge in 1996, one day per fortnight. Many patients wanted to take receive therapy, and the service "took off", so that a full time complementary therapist was employed in 2001.

About 80% of the lodge patients are referred for massage and aromatherapy, mostly by nursing staff, for reasons such as anxiety, tension, panic attacks or insomnia. Younger patients in particular may need extra support: it is difficult be staying away from home if you have small children, for example. The aromatherapists create a safe space where patients can slow down and reveal their anxieties and ask any "silly questions" they have been reluctant to ask previously. The staff are trained oncology nurses so can answer any questions about treatment, and are also well respected by the consultants.

Patients are seen every week, or as and when they need support. There is only one room in the hospital for aromatherapy, so female patients are seen in their room in the lodge, while male patients come to the room in the hospital (the aromatherapists are female). When the lodge is extended there will be a room for aromatherapy. Currently there can be interruptions from the cleaner, even though there is a notice on the door. It will also be easier to treat patients because they will lie on a comfortable massage couch rather than on their bed, and the room will have more space and be more airy. It will also be easier to see the patient on their own. At the moment, if a relative is sharing the same the room in the lodge, then they may not be willing to leave the room while the treatment is given, and this reduces its value, because the patient is less able to relax and talk about their anxieties.

2.3.2. Formal and informal Patient Support Groups

The breast cancer nurse specialist visits the lodge every Tuesday for a 1.5 hour group session. There is also a prostate cancer patients support group which meets fortnightly in the lodge, and a medical social worker has a one hour session at the lodge once a week. The sessions are very good for providing support. The nurse gives information what will happen with treatment and side effect, and about support services. She can also see how patients are coping and assess their needs. Patients, particularly the men, also find it easier to open up and talk in a group situation without their partners. It is also a good opportunity to get feedback on services

One of the best aspects of the lodge is how patients in the lodge support each other, in effect forming their own informal 24 hour support groups. They do this to a huge degree and make good friends. Relatives don't understand how patients feel, but other patients do, particularly if they have the same type of cancer. Those patients who have been staying in the lodge for a while tell newer arrivals about what goes on and show them the activity centre and other facilities. Men in particular seem to benefit, they get fussed over by the women and also bond with each other. Younger women in the lodge tend to bond and to go shopping together. Those patients who are religious go to mass, and chat there as a group.

Patients currently take their meals in the hospital restaurant. Meals are free on presentation of their room key, but they can be a bit rushed because staff also need to be served, and patients would like to be able to relax and talk more. A new room is being built at the lodge where patients staying there will eat their meals, and it will also be used for other activities. This will further improve their quality of life, and help to build coping mechanisms and empowerment.

The nature of the community in the lodge changes as the patients change, because what goes on depends on who is staying there. A few weeks ago they were fundraising, for example. Whether patients have their partners with them also makes some difference – they may then be slightly less likely to mix with the other patients staying in the lodge.

Patients have fun: “It was the best holiday I ever had”. There is a farewell party every Thursday because some people will be leaving the next day after finishing their treatment. People have built up relationships during their stay, and often exchange phone numbers when they leave. People have made friends for life in the lodge. Although there are support groups around the country, it can be hard for patients when they go home because they have had so much support in the lodge: “Patients cry when they come and cry when they leave”

2.4. Evaluation

A survey of lodge patients was conducted in 2004. 28 responses were received, and were overwhelmingly positive about almost all aspects of the service. Patients were positive about nutritional facilities, but less strongly than for other service areas. A quarter of the patients were not happy about the set menu times, with 9 people wanting a longer gap between meals. There should be more scope for addressing

these concerns when the lodge's own dining room opens. Appendix 2 contains a patient's poem about their stay in the lodge.

Staff think that the lodge is a tremendous success. Unsolicited, patients tell staff that they love it, and they express genuine thanks E.g. phoning up staff to wish them a happy Christmas. And staff find the patients inspirational. They suspect that lodge patients may have a better tolerance to treatment than similar patients staying on the ward, where they are mixed with patients with a variety of other conditions. In addition, many of the lodge patients are recruited to ongoing research studies.

2.4.1. Comparing the lodge with Bed & Breakfast (B&B) or hotel accommodation and with staying at home

SLH does place people in Bed & Breakfast (B&B) accommodation, but this is not designed for people to be in during the day, and patients may have a sense of isolation – they are identified as “cancer patients” when they are in a hotel, rather than as “people”, and this can still have a stigma. They are neither at home, nor in the hospital, but a netherworld in between. SLH has developed relationships with a number of small B&B proprietors (smallness helps with continuity of patients and for the staff to become more familiar with patients' needs), and only use accommodation where patients have reported a positive experience. The distance between their accommodation and the hospital can be a problem E.g. if the weather is wet. Also, they cannot just go back to their room if they want to like the lodge patients can. Some patients have phoned up in tears about this situation. After they have talked with lodge patients, B&B patients want to get into the lodge!

Hospital staff are aware of the difficulties for patients staying in B&B and try to provide them with extra support. Such patients are prioritised by the complementary therapists, and are invited to the hospital activity centre and to the various support groups. The specialist nurse meets them individually when they come in to the hospital. The patient and a partner are funded by SLH, including meals, and there is a comfortable room in the hospital with couches where they can rest if they feel tired.

Research in Canada on travel issues has suggested that it is generally better for patients (psychologically and cost-wise) if they can stay at home during treatment. But for some patients it can be a relief to stay in the lodge because they don't have to deal with some of the issues that there may be at home, and they find comradeship and support. Patients who do travel to SLH each day for treatment are seen by the specialist nurse at the time when they have their treatment, but it is hard to have a private conversation, and the patients are often rushing and not able to come to a support group.

2.4.2. Admission Criteria

The initial assessments for admission to the lodge are usually accurate, but sometimes patients referred to the lodge may subsequently be admitted to a ward instead. The initial referral to the lodge builds up expectations among the patients, and the “rejects” are very disappointed, although the wards do provide a very good environment, within the constraints of being a ward. Some staff believe that a suitably trained nurse might perhaps be better placed to do the initial assessment than a doctor.

Some staff believe that the criteria for admission to the lodge are too strict (“you have to be an Olympic athlete to get in!”) and broad brush, so that patients who could benefit from it miss out. There might, for example, be greater access for patients with mild head and neck disease and some with colorectal cancer. It appears inconsistent to these staff that some patients who are permitted to stay at home (E.g. those on morphine) are not eligible for admission to the lodge. Care would need to be taken, however, if widening the admission criteria, that the positive atmosphere of the lodge is not lost, and that acceptable patient safety levels are maintained.

2.4.3. Staffed by Nurses

The nursing cover of the lodge means that the patients feel more secure, knowing that they can talk to a nurse if they need to, and that the nurses can respond to their needs straight away. A lot of the work is psychological support and education (E.g. about skincare), and helping with everyday problems, but patient safety must also be borne in mind, as must patient expectations. Some staff believe that having a qualified nurse on duty is not the best use of manpower.

2.5. Plans for the Future

The lodge may act as a model for other developments. The new radiotherapy centre in Galway is already planning to set up a lodge similar to Oakland Lodge, but it will be run by the charity that has raised the money to build it. There have been objections from local residents who are concerned about increased traffic, so the planning process may take some time. St Luke’s Hospital owns and controls Oakland Lodge, so the situation is simpler. On the other hand, the Galway hospital has an Accident and Emergency department, which should make it easier for it to meet its legal and medical responsibilities. A decision has not yet been made about whether the lodge will be staffed by nurses or not. SLH is trying to support Galway with regard to this and other issues, because it is a steep learning curve.

Because of the national reorganisation of radiotherapy services there may in future be fewer patients coming to SLH from the west of Ireland and from the north side of Dublin. If the radiotherapy centre in north Dublin does not have a lodge, however, then a number of patients will probably travel the extra distance to SLH for treatment. Also, given the relatively low proportion of people that are currently receiving radiotherapy, it would seem likely that referral rates will increase as radiotherapy capacity increases, so there will continue to be a demand for places at Oakland Lodge.

3. Dedicated Transport Service

3.1. Overview

The dedicated transport service consists of 2 free bus services for SLH patients and relatives living in the MHB (MHB) area:

1. From Longford County Hospital via Mullinagar Hospital
2. From Tullamore Hospital via PortLaoise General Hospital

Up to one relative can travel with each patient, provided that there is space on the bus – patients have priority. The pick up and drop off points are hospitals where consultants from St Luke’s hold outpatient clinics. These are about 170km from SLH. Patients make their own way to and from the pick up points, generally a distance of up to 30km.

The services aim to get people to SLH in a timely manner, to avoid the pressure that some patients feel when they are travelling (Eg feeling dependent on relatives to transport them), to reduce the number of patients needing to stay in the hospital during their treatment, and to improve utilisation of radiotherapy machines. The National Cancer Strategy (1996) noted that: existing hospital transport services were neither punctual nor reliable; many patients waited long periods of time to be picked up from healthcare facilities; too many patients spent too long travelling in multi-occupancy vehicles on extended itineraries [i.e. stopping at various hospitals en route] ; many patients travelled in vehicles unsuited to their needs; and some patients were delivered late for healthcare appointments, with disruptive knock-on affects both for other patients attending clinics and for hospital systems of work.

Each service operates every weekday, departing at 7.45am and arriving at SLH by 10.25am. There is a “comfort break” of 10 minutes en route, which is particularly important for patients with prostate cancer. The bus leaves SLH at 3.30pm. Appointments for treatment (radiotherapy or chemotherapy) are scheduled to fit in with the arrival and departure times of the bus, which have partly been chosen so as to avoid rush hour traffic. If a patient’s treatment at SLH is delayed (Eg because of machine down time), then a taxi is arranged if necessary.

When a patient attends the local outpatient clinic of a consultant from St Luke’s, following GP referral, the clinic nurse explains about the transport service. If the patient wants to use the service, or has any queries, then they phone the ward clerk on the day ward at SLH, who can be phoned direct, rather than going via the switchboard. Bookings should be made at least 24 hours in advance. The ward clerk compiles a list of patients who will be using the service on a particular day and sends it to the transport provider. She also arranges food vouchers etc for the patients so that the visit to SLH is as stress free as possible.

3.2. Development

In June 2001 a random selection of 12 patients (6 male and 6 female) attending SLH for radiotherapy treatment from the MHB area were surveyed about travel to and from the hospital. Patients were asked about their current travel arrangements and about their views on the possible development of a minibus service between St. Luke's Hospital and Tullamore/Portlaoise.

Patients travelled from six different counties and used a variety of transport services i.e. Bus Eireann, Train, Taxi, Health Board Transport and Private Cars. The time taken to arrive at the hospital was 2- 3 hours. The expectations from patients in respect of the service were: that it is available at short notice, meets the appointment time, is a direct route, is comfortable, has wheelchair access, comfort stop on route and runs on time. All respondents believed that such a service would enhance patient support.

To assess the likely demand for the service, a survey was undertaken of patients who attended the outpatient clinic of a supportive consultant in the MHB area during a single week (11th June 2001). 18 patients attended from 11 different counties. On the basis of this information it was decided that the MHB was a suitable area for the pilot of a non-emergency transport service.

Following agreement between the Chief Executives of SLH and MHB, senior managers from SLH met with MHB's Acute Services Manager. He was able to advise on the internal arrangements that existed for transport within MHB, the likely level of interest from his personal experience, and the identification of and approval to use designated MHB locations as pick up points for patients. He also supplied contact names for nursing management, community welfare staff, administrative staff and established transport contractors used by MHB for patient transport.

The next step was to convene a multidisciplinary team, consisting of representatives from:

- Nursing - who interact with all patients within the hospital, and who liaise with staff at local clinics before patients arrive at SLH for treatment.
- Medical Social Workers
- Medical Records - who provide clerical support for local clinics and the patient records system (wherein patient information is recorded longitudinally throughout the duration of the treatment)
- Radiographers - who schedule the patient flow on the treatment machines and administer the radiation dose.

In view of the availability of funds from public donations to SLH, and the poor financial circumstances of many patients, it was decided that the service should be free to patients and funded from these donations. The team reviewed the flow of patients through the existing processes, and planned and implemented the necessary changes.

Tenders were invited from a number of the transport contractors suggested by MHB. The tender specification included safety, easy access for getting on and off, adequate lighting, appropriate seating, internal climate control, acceptable noise and vibration

levels, and adequate space. Drivers needed to be able to communicate effectively, to function as part of a team and to know about emergency procedures such as vehicle evacuation. Common sense is also important – knowing their limitations and ringing for assistance if necessary – as is being able to establish a good rapport with patients and being sensitive to their issues and feelings. When the successful contractor was awarded the tender, both he and his staff were interviewed and all aspects of the arrangement were clarified, including referring, transporting and administrative guidelines (insurance, budgeting, communication etc).

3.3. Evaluation

The services began operating in February 2002. Three months later, review meetings were held with the transport contractor and staff, and with the multidisciplinary team. In October 2002, a 15 patients (out of a random sample of 18) completed questionnaires about the service. The responses indicated a high level of satisfaction with the service in all areas i.e. punctuality, appointment times, personnel, vehicle comfort, comfort stops, communication and co-ordination. Senior management of MHB also said they were happy with the service.

Numbers of patients using the service fluctuate widely from month to month (Figure 1), with some seasonal effects, which are probably due to staff holidays. The level of usage appears to be broadly static on the Longford/Mullingar route, but is increasing on the Tullamore/Portlaoise route (Figure 2). On a typical (average) day, 3 or 4 patients use each bus. The total contract is worth about €150,000 to the bus company. This equates to an average cost per return patient journey of about €80. Because the service is dedicated to cancer patients at SLH, it is more expensive to run than other services which serve a variety of hospitals.

Figure 1

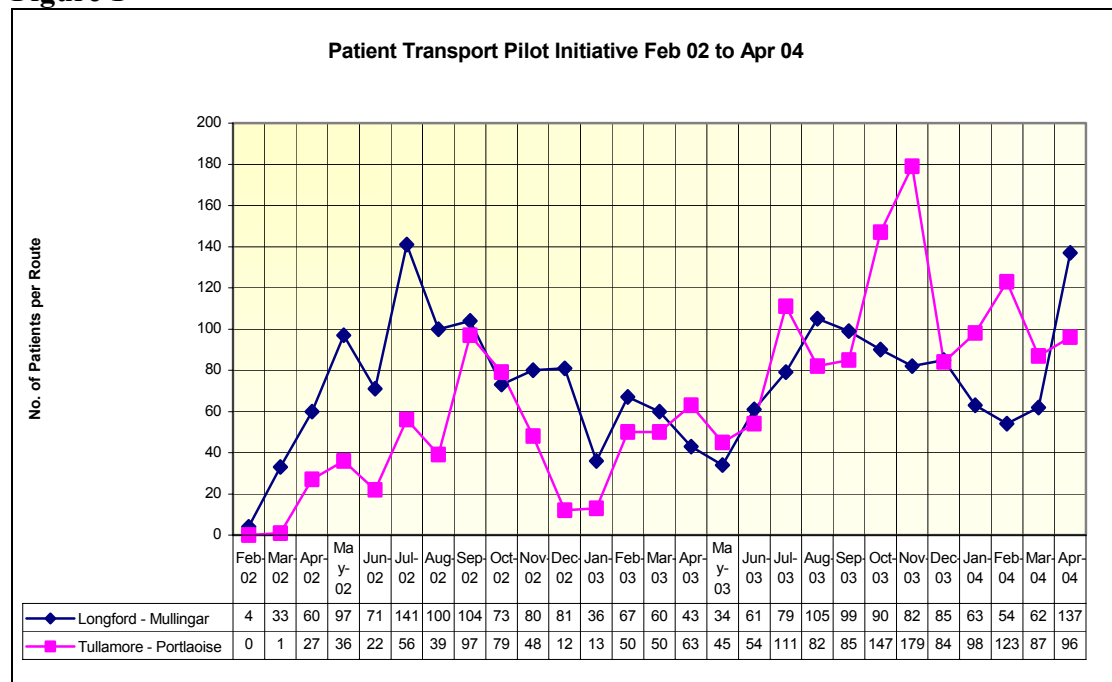
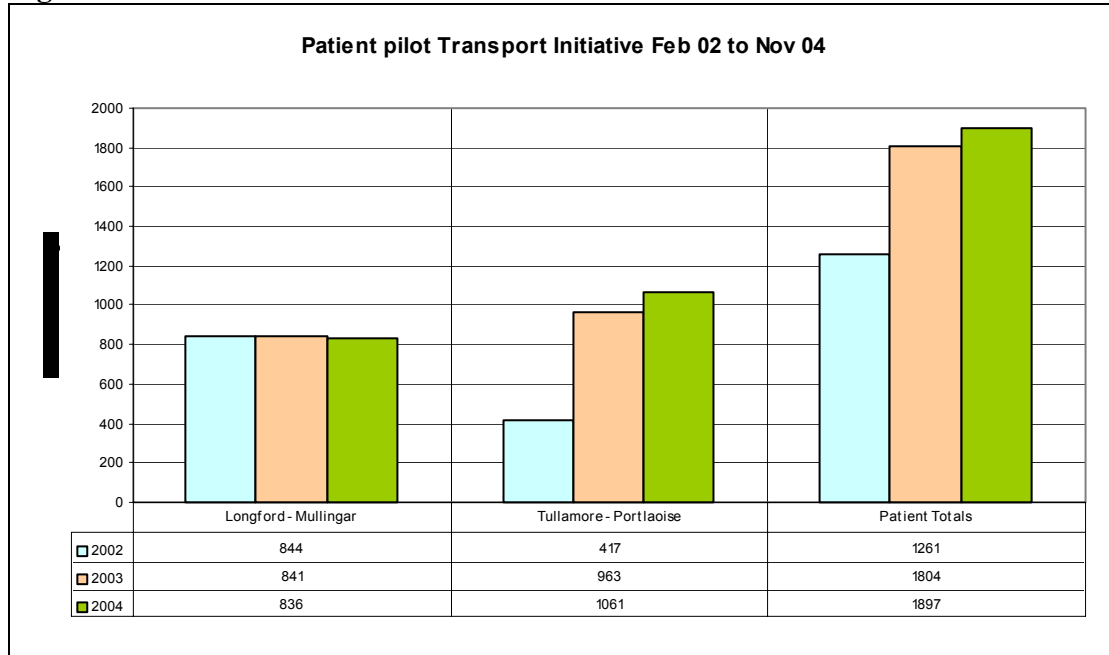


Figure 2



Not all patients are able to continue travelling every day, and may need to be admitted to the hospital because of exhaustion. As their treatment progresses, some patients also become more concerned about having to wait until 3.30pm to travel home, even though their treatment may have taken place sometime earlier.

Both the bus company and the drivers have been excellent. The company is flexible, and will “fit in” when there is less than 24 hours notice about passengers travelling, which can quite often be the case. The drivers are committed, and may wait if a patient’s treatment is delayed, or they forget the return time for the bus and have to be looked for – it is helpful if they have a mobile phone. If waiting would take too long then a taxi is arranged (but this has been necessary only rarely). Sometimes drivers will go a little out of their way on the journey to people’s homes, so long as it doesn’t interfere with the schedule of pick ups and drop offs.

The drivers may advocate on behalf of the patients, via the ward clerk, who the drivers find helpful. Driver feedback has played a role in making sure that patients are clear that they are entitled to a free meal at SLH, and that a relative can travel, provided there is space – when this was not the case, this caused some negativity among patients. If there has been one complaint, it was that one driver over-extended herself and became too much of a patient advocate. This was dealt with via the bus company.

One driver reports that he has been touched by the people he has met, and now has a greater appreciation of life. There have been problems with some people who are very agitated – they need to be handled gently while they let off steam. The driver needs to be caring and to be able to handle people.

The comfort breaks are very important, particularly for men with prostate problems – sometimes the men sit on the back seat with a bottle!

Administering the service takes up about an hour of the ward clerk's time each day, with Friday being particularly busy. It can be difficult to keep the phoneline dedicated to the service because it is easily accessible to other staff, and they make use of it.

3.4. Plans for the future

The transport service is unlikely to be directly affected by the national reorganisation of radiotherapy services, as it only covers areas probably continue to be served by SLH in the future.

The service might however act as a model for services in other parts of the country, but funding requirements might be a limitation. Although it was discussed with them, MHB were reluctant to take on the service. SLH runs the service because it can see the benefits for patients and has the funds, but transport is not SLH's core business, and the organisation lacks some of the experience and infrastructure (E.g. I.T.) that would be useful. Various small groups run minibuses, and SLH doesn't want to compete with them, just to provide a more patient-centred service.

The bus company is keen to continue the service, and plans to introduce 2 new vehicles soon.

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