



# MORE THAN JUST A PLACE TO STAY

Inis Aoibhinn Residents' experience  
of services at Cancer Care West

Report on Qualitative Research  
conducted for Service Improvement

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# 1 INTRODUCTION

**CANCER CARE WEST** is a registered charity, dedicated to supporting cancer patients and their families in the west and northwest of Ireland. In the late 1990's Cancer Care West recognised the need for residential and cancer support services and began planning and fundraising to provide these services. In 2002, University Hospital Galway (UHG) was designated as the supra regional cancer centre for the west of Ireland, and in 2005 the Radiotherapy Department opened at the hospital, delivering Radiotherapy treatments to patients from the west and northwest of Ireland.

In response to this development, Cancer Care West opened its residential facility, Inis Aoibhinn in 2007 to provide accommodation to cancer patients travelling to Galway for Radiotherapy treatment at UHG. Inis Aoibhinn has 33, twin bedded rooms where each patient can stay with a family member or friend, for the duration of their Radiotherapy treatment, usually 5-7 weeks. Radiotherapy treatment is given each day from Monday to Friday, and patients stay at Inis Aoibhinn during the week and return home each weekend. Patients come predominantly from counties Donegal, Sligo, Leitrim,





Roscommon, Mayo, Galway and Clare, and sometimes from counties further afield.

In 2009 Cancer Care West opened its dedicated Cancer Support Centre at Seamus Quirke Road in Galway city. The Cancer Support Centre complements the charity's residential services with a range of emotional, psychological and practical support services which are available to anyone whose life has been affected by a cancer diagnosis.

All of Cancer Care West's services are provided free of charge.

Between October 2014 and March 2015 Cancer Care West undertook a research study to better understand Inis Aoibhinn Residents' experience of Cancer Care West's services. Two groups of Residents were interviewed –

- 1 Residents currently staying at Inis Aoibhinn who were coming to the end of their stay were interviewed on a semi structured, one to one basis.
- 2 A series of focus groups were held with a sample of former Residents of Inis Aoibhinn who had stayed at the facility during the previous 7 years, 2007 – 2014.

Through these qualitative studies, the organisation gathered information to help evaluate current services and to identify some key themes which emerged from Residents' feedback. The research team devised some recommendations based on these findings. These recommendations are outlined in this document.







## 2 AIMS

**DISCUSSIONS** with participants were designed to gather information with regard to the following research objectives:

1. To understand what participants knew about Cancer Care West
2. To understand participants' preconceptions of Inis Aoibhinn
3. To understand how participants made the decision to stay, or not to stay, at Inis Aoibhinn
4. To understand the support that participants sought and received from Cancer Care West
5. To understand participants' experience of Inis Aoibhinn, and what helped or hindered their stay
6. To understand participants' perceptions of the atmosphere at the Cancer Support Centre
7. To understand what life was like for participants after they left Inis Aoibhinn

## 3 METHODOLOGY

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- ▶ The study protocol was approved by the Clinical Research Ethics Committee at University Hospital Galway.
- ▶ An interview guide was developed by key stakeholders working within Cancer Care West in line with the aims of the research. The team included Inis Aoibhinn's Operations Manager and Acting Operations Manager, Research Assistants, Nurses and Psychologists.
- ▶ The research was described as a general evaluation of Inis Aoibhinn with the objective of improving service for future Residents.

### 3.1 WHO TOOK PART?

See Appendix for further information on participants.

#### Individual Interviews with current Inis Aoibhinn Residents

(See Appendix Table 1.)

- ▶ Participants were randomly selected from the list of current Inis Aoibhinn residents who were coming to the end of their stay at the facility
- ▶ Contact was made via phone to potential participants explaining the purpose of the research. Those who expressed an interest in the project were then asked to attend an informal interview to discuss the topic and a suitable interview date and time was arranged.
- ▶ Twenty-eight interviews were held with current residents of Inis Aoibhinn between December 2014 and March 2015.

## Focus Groups with former Inis Aoibhinn Residents

(See Appendix Table 2.)

- ▶ Former Residents of Inis Aoibhinn were recruited between October and November 2014. A letter was sent to potential participants explaining the purpose of the research. Those who expressed an interest in the project received a second letter stating the date, time and location of the focus groups.
- ▶ Participants were eligible to take part if they had been a resident in Inis Aoibhinn at any stage in the seven year period prior to the commencement of the study.
- ▶ A total of twenty five people were randomly selected from three location clusters (Donegal, Mayo and Sligo). These people had stayed at Inis Aoibhinn between 2007 and 2014. Care was taken to ensure as many towns in each county as possible were included in the selection to ensure a proportional geographical spread.

## 3.2 HOW THE DATA WAS COLLECTED

### Individual Interviews

- ▶ The interviews were conducted by a research assistant with a background in Health Psychology. In total, 28 residents took part in the individual interviews.
- ▶ The sessions lasted approximately 20 minutes each and took place on the grounds of Inis Aoibhinn.
- ▶ Each participant granted permission for the session to be recorded. Data was audio recorded.

### Focus Groups

- ▶ Five focus group sessions were held in the counties of Donegal, Mayo and Sligo between October and November 2014. In total, 25 former residents participated in the group sessions.
- ▶ The focus groups were conducted by the CEO of Cancer Care West and a research assistant with a background in Health Psychology. The sessions lasted approximately 90 minutes each and took place in a hotel in each of the representative counties.
- ▶ Each participant granted permission for the session to be recorded. Data was audio recorded.



### 3.3 WHAT PARTICIPANTS WERE ASKED

Participants in each group were asked questions such as;

- (a) **Had you heard about Cancer Care West before your stay at Inis Aoibhinn?**
- (b) **What were your first impressions of the facility upon arrival?** *and*
- (c) **How was the service explained to you?**

Participants were also asked about their use of the other services provided by Cancer Care West and how they spent their stay in Inis Aoibhinn, with questions such as;

- (a) **How did you pass your time between appointments?** *and*
- (b) **Did you use the Cancer Support Centre?**

Additionally, participants were also questioned about life after Inis Aoibhinn

- (a) **How do you feel about leaving Inis Aoibhinn?**

and about their knowledge of Cancer Care West following their stay

- (b) **What had you learned about Cancer Care West by the time you left?**

### 3.4 HOW THE FINDINGS WERE ANALYSED

See Figure 1 overleaf.

- ▶ All interviews were transcribed verbatim from the audio recordings. The transcripts were then checked for accuracy by another researcher. Six individuals with expertise in cancer care identified and independently coded this information.
- ▶ The coding was discussed in a series of meetings led by a researcher with expertise in qualitative research. A methodology called 'Thematic Analysis' (Braun & Clarke, 2006) was used to ensure that the coding process was thorough and comprehensive. Groups of codes were organised into themes and sub-themes. Direct quotes from the interviews were used to illustrate these themes.

- ▶ Two transcripts were assigned to each member of the research team. Each transcript was read by at least two individuals to ensure triangulation of the data. Researchers engaged in a process of reading and rereading the interview transcripts in order to become more familiar with the information and to take note of initial ideas.
- ▶ Codes are shorthand labels used to cluster together key related ideas from the original transcripts. These codes are named using words, short phrases, or metaphors – based on the participants' accounts. Each code was supported with quotes from the transcript. A list of codes was compiled by each member of the research team. The list of codes was then discussed. Again, similar ideas were grouped together. These groups of codes formed the basis of repeated themes across the data set.

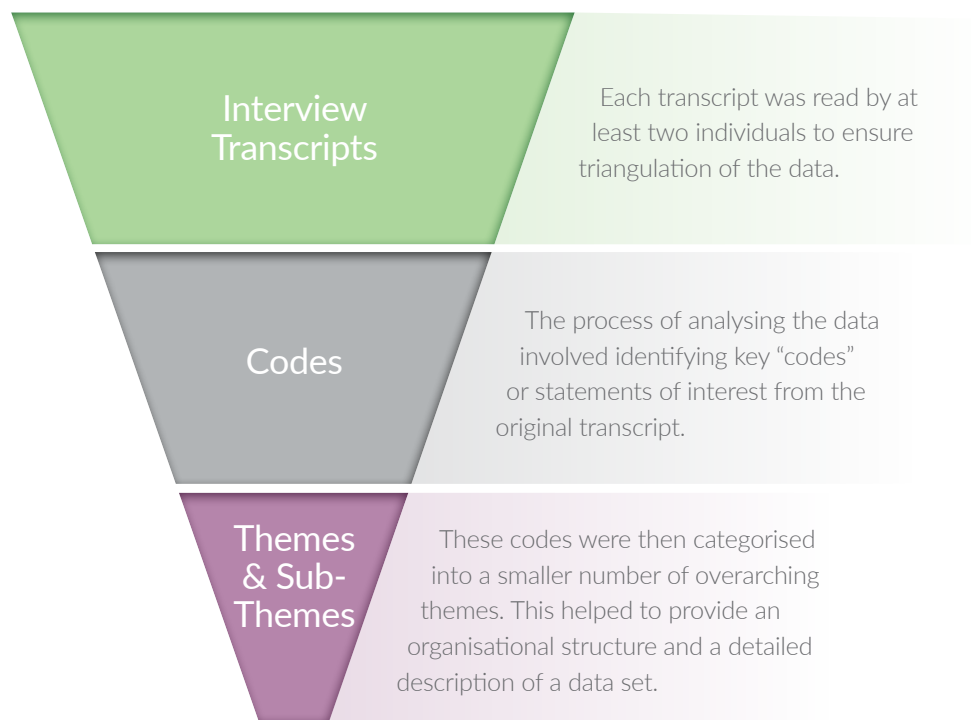


FIGURE 1: The data was analysed using Thematic Analysis which is a structured method that identifies a small number of overarching themes from a large data set, through a process of coding and grouping together of key ideas.

## 4 INDIVIDUAL INTERVIEW FINDINGS



FIGURE 2: Findings from the Individual Interviews fell within the major themes outlined above.

These themes are described in further detail below

### Theme 1: Awareness and Understanding

- In general, participants **had little awareness of Cancer Care West before their cancer diagnosis**. A small proportion of people had previous knowledge of the facility; however, this was usually as a result of having family members who had prior experience of the charity. The sources of information about Cancer Care West and its facilities included staff from the Radiotherapy department in the hospital and nurses in the BreastCheck clinic. The majority of participants sourced their information from previous residents who had stayed in Inis Aoibhinn. Some people had partners and family who had been resident at the facility in the past and almost all participants had spoken to local people in their area who had stayed there. One participant said “Well I just started hearing little bits of conversation – with people from my own area, people who had some experience of prostate cancer (same as myself). That was the first I heard of Inis Aoibhinn” (Male, age 65).



- ▶ For the most part, participants **felt that the explanation that they received in the hospital about Inis Aoibhinn was insufficient and lacking in detail**. One person stated that *"They didn't really explain much about it in the hospital, just that it was there and that it was on the grounds of the hospital – it wasn't attached to the hospital, it was on its own."* (Male, age 59).
- ▶ Participants spoke about a **lack of understanding at this stage of their experience, about what 'The Lodge' (Inis Aoibhinn) actually was**, or about the services it provided, other than knowing that it provided temporary accommodation. A few participants did recall being informed about the difficulty in acquiring a place at Inis Aoibhinn but not much else.

## Theme 2: Deciding to stay

- ▶ A number of participants talked about **feeling unsure about deciding to stay at Inis Aoibhinn**. This may have been due in part to confusion surrounding the explanation of the facility and a lack of understanding as to what to expect.
- ▶ Some participants had an understanding of the limited availability at Inis Aoibhinn and cited it as another **potential reason not to put their name down to stay**.
- ▶ A number of participants expressed **worries about a preconceived negative atmosphere** or a type of hospital-like setting. One woman said she *"was a bit worried about it being an I've got cancer doom and gloom kind of thing. I was very aware that I didn't want to walk into that because I try and stay as positive as I can but I found out it's not like that at Inis Aoibhinn at all."* (Female, age 48). **Several participants expected a hospital or youth hostel setting with communal bathroom facilities**. Others had **envisioned a set-up similar to that of a nursing home**.
- ▶ The **lack of understanding of what to expect from the service resulted in anxiety for some of the participants**. One man said *"I was shocked. I thought it would be more like a hospital. A lot of things went through my head. I didn't know what to expect. I don't think my mind was tuned into what it was. There was a part of me that was dreading the 5 weeks"* (Male, age 67).
- ▶ Ultimately, **not wanting to travel was one of the most significant factors in making the choice to stay in Inis Aoibhinn**. One man said he was *"delighted because I wouldn't have liked to travel up and down every day. I know there's a bus that comes up from Sligo everyday but it was too full, I couldn't face going up and down every day"* (Male, age 76). People spoke about **the comfort of being able to go to your room and relax after your radiotherapy treatment** rather than face an oftentimes long and gruelling car journey.

### Theme 3: Settling In

- ▶ For most participants, there was very little difficulty settling in to Inis Aoibhinn. Many commented on the **comprehensive explanation of the service that they received from the nurses upon arrival and talked about being made feel welcome almost immediately.**
- ▶ Participants frequently used words such as **'welcoming' and 'homely'** when describing their initial impressions of Inis Aoibhinn. People often **compared the standard of the building and its facilities to a hotel.**
- ▶ Participants described the importance of the **warm nature of the staff and residents in helping them to settle in.** One woman summarised this consensus by saying *"Everyone is so welcoming and so caring you know. It's a home away from home, that's the only way to describe it"* (Female, age 48).
- ▶ Individuals frequently spoke about the **new friendships they had formed and the role of these friendships in helping them to settle in.** Participants from Donegal in particular spoke about how **meeting others from Donegal made them feel more comfortable and less out of place.**
- ▶ Introductions and **interacting seemed to have evolved naturally.** Participants explained that they would either introduce themselves in the first few days or were approached by other residents and welcomed aboard. This friendliness seems to have created **a sense of camaraderie among residents which was conducive in helping people adjust to their new surroundings.** For many, this bonding developed as a result of **sharing their cancer experiences with each other.** One of the participants said *"it's great to talk to the other patients too. You talk about things and compare. You can talk to anybody, discuss your treatments. We're all going through the same treatments but we all react differently. You get a benefit knowing that you're all going through the same. It does help you"* (Female, age 69).

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the only way to describe it."*

## Theme 4: Passing the Time

- ▶ Participants spoke about engaging in **a range of activities and pursuits to pass the time during their stay at the facility**. Some of the most popular activities mentioned were: chatting with residents, watching television, reading the newspapers, playing scrabble and shopping.
- ▶ Participants had **little difficulty in passing the time; however, this was somewhat dependant on the weather**. People expressed the view that good weather was crucial in order to be able to access town or any other outside facilities. If it was too cold or raining, people tended to stay indoors. Walking and exploring Galway were commonly cited activities. However, these activities tended to be dependent on how people were handling treatment. One woman described this experience, saying *"We did days out. We went to see all the things we hadn't seen in Galway. My parents visited and we showed them around. We visited my niece in Connemara. A lot of it was down to how I felt on the day, if I was tired or not tired."* (Female, age 69).
- ▶ The use of the **Cancer Support Centre was also popular with people**. Participants mentioned attending art and exercise classes and receiving treatments such as massage and reflexology. More specifically, some participants commented on the Cancer Support Centre being **particularly useful when friends or family were unavailable**. Many of the participants mentioned **difficulty in accessing the Cancer Support Centre in bad weather** as it is in a separate building, causing them to cancel their appointments, with some missing out on using it altogether.
- ▶ Some participants commented on **how long they found the evenings to be**. After dinner, residents that had visitors staying seemed happy to retire to their rooms for the evening. Participants who found the evenings particularly long were those who did not have a friend or family member staying with them. One individual said *"In the day it was great. In the night or early evening people tended to disappear to their rooms. So in the evening there was a bit of a lull, you'd feel a bit lost"* (Female, age 58).
- ▶ Many residents expressed an interest in the possibility of including a **weekly social event in Inis Aoibhinn**. One woman explained *"If there was a social thing once a week in the evenings that would be great. I know there is card making – maybe something like that in the dining room or some other activity that wouldn't cost too much and that the majority of people would have an interest in. People mightn't know they had an interest until they tried it."* (Female, 58).



## Theme 5: Helps you to cope

- ▶ Participants emphasised the **instrumental role of Cancer Care West in helping them cope with their cancer treatment**. This was achieved through the positive atmosphere, the care of the staff, the support garnered from other residents and the independence given to residents.
- ▶ The welcoming and uplifting atmosphere was identified as a key feature of Inis Aoibhinn. One man said *"Everything about Inis Aoibhinn is so positive, and I have to agree that after 7 ½ weeks staying at Inis Aoibhinn I'm very positive"* (Male, age 59). There appears to be a **level of friendliness and camaraderie, not just among residents but also between staff and residents**. People mentioned that they often looked out for one another, especially the newer residents to ensure that they were coping well. As a result of such social support, **many people reported feeling optimistic at this particular stage of their cancer journey**. One man explained *"There was nobody going around down in themselves, and I think when you are in an environment like this, you're not down on yourself. If I had to rate Inis Aoibhinn out of 100, I'd give it 100"* (Male, age 67).
- ▶ The **support from staff and the compassion from fellow residents were also important factors**. The staff of Inis Aoibhinn were noted as promoting a climate of support and assistance. Participants frequently commended staff members on their friendly dispositions. One man said *"Anybody that you talk to, they're always wanting to know how you are and how you're doing. The support of the staff and people going through the same thing – they're great and so pleasant"* (Male, age 66). Other participants mentioned that the **kindness of staff helped them to feel more secure and safe during their stay**.
- ▶ Residents also found solace in **communicating with others who were experiencing cancer**. For many participants, they were the only member of their family or close network to have an experience of cancer. Being able to relate to fellow residents provided an additional layer of support. One woman identified this saying *"If you are upset and you're at home, they don't understand. Here, they understand how you feel, if you're a bit down you can just go and talk. It's the whole atmosphere, it just seems to calm you"* (Female, age 69). Sharing their cancer experience helped residents to build and develop relationships from that of acquaintances to friends. Another participant said *"We're all in the same boat here, we all have cancer and we compare notes with others and that's good. Each person tells you their experiences which helps"* (Male, age 67).

- ▶ Some participants alluded to a perceived gender divide, in terms of support between residents at Inis Aoibhinn, particularly with regard to **male support**. One woman explained *"The women stay together more than the men. The men seem to go in the tv room. They do speak, they do talk to you but I do notice a divide, we're here and they're there. I suppose they don't want to sit and watch us knit and listen to the chatter"* (Female).
- ▶ Some residents appreciated the **privacy offered at Inis Aoibhinn**. Having your own space and being able to come and go as you please were important aspects for individuals. Some residents often felt the need to be alone, which was possible and supported at Inis Aoibhinn.

## Theme 6: Going Home

- ▶ Participants asked about this topic were resident at Inis Aoibhinn and were coming to the end of their stay. **Many were unsure as to what to expect from the process of leaving Inis Aoibhinn and returning home.**
- ▶ Leaving Cancer Care West can often mean losing important outlets of social support which could prove difficult for some people. Some people **anticipated returning to their local area with few support outlets**. One of the female participants explained *"I'm going to feel sad. We live out in the middle of nowhere and I don't have any friends where I live so yes I feel really sad. During the night time I find it very hard to sleep. I'll go down and chat to the staff and have a cup of tea & we'd have great craic and then I'd feel tired and I'd go up and be able to sleep so I'll miss all that"* (Female, age 51).
- ▶ For others, leaving Inis Aoibhinn **not only signified the end of their radiotherapy treatment but also the beginning of leaving cancer behind and moving on to the next chapter**. A number of the residents spoke about **looking forward to returning to normal and having a routine once more**.
- ▶ Several of the **participants stated that they would like to stay in contact** with Inis Aoibhinn in some form and many more spoke about returning to the facility for a visit in the near future.
- ▶ A large number of people also talked about **plans to do some fundraising for the organisation** once they got settled back home.
- ▶ The majority of residents interviewed **were unaware of the availability of cancer support groups in their locality and what services were available to them moving forward**.

## 5 FOCUS GROUP INTERVIEW FINDINGS

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FIGURE 2: Findings from the Focus Groups fell within the major themes outlined above.

These themes are described in further detail below:

### Theme 1: Awareness and Understanding

- In general, participants said that they had not been **aware of Cancer Care West prior to diagnosis**. The majority of participants became familiar with the organisation following their diagnosis and remarked that people who had not had some experience of cancer were oblivious to it. One man said “If you asked your average Joe soap about Inis Aoibhinn, they wouldn’t know anything about it. We are so far away, people that haven’t been affected by cancer don’t know.” (Male, age 56).



- ▶ Participants cited a **number of sources of information about Cancer Care West** including nurses in their local hospital, nurses in BreastCheck, nurses in the Radiotherapy department and local radio. A substantial number of participants said that their main source of information was from previous residents of Inis Aoibhinn that lived in their local area. One man said *"I heard about Inis Aoibhinn from a neighbour of mine. He attended it and he explained it to me. I knew different people who had stayed there before and I had a chat with them"* (Male, age 64).
- ▶ In relation to their overall understanding of the organisation, participants agreed that they **viewed the charity as two distinct elements – Inis Aoibhinn and Cancer Care West (Cancer Support Centre)**. One participant explained that she wouldn't consider them part of the same group. *"Well, I'd say that Cancer Care West and The Lodge (Inis Aoibhinn) don't seem to fit together at all. For me, Cancer Care West is some kind of vague idea, I don't really know what it involves and if you were to ask me what Cancer Care West means to me I would say it doesn't mean very much"* (Female, age 58).

## Theme 2: Preconceptions

- ▶ Many of the participants described being **unsure about what to expect** in the lead-up to their stay in Inis Aoibhinn and having several preconceptions about the facility. Although it had been explained to some degree, it transpired that significant elements of ambiguity about the service remained. One participant described her assumptions on first arriving at Inis Aoibhinn: *"I don't think people realise what Inis Aoibhinn is, I think people have this illusion that it is a hostel or a room that there are a few people in. Your mind is all over the place before you arrive"* (Female, age 46).
- ▶ This lack of clarity and understanding about Cancer Care West and its function, resulted in **anxiety** on the part of many prospective residents. Some participants spoke about needing to make a decision about whether to stay or not. Other participants suggested that speaking to someone in greater detail about Inis Aoibhinn and the service provided may have been beneficial. One woman explained this **uncertainty**, saying *"I was terrified going down, absolutely petrified. I think if I had spoken to someone who had been there before and heard about their experience, I would have felt a lot more at ease"* (Female, age 46).
- ▶ Participants also expressed **concerns about the limited space** at Inis Aoibhinn and how difficult it might be to get an opportunity to stay. One participant noted *"A neighbour of mine explained Inis Aoibhinn to me, the only trouble he said was to get into it as there was a waiting list"* (Male, age 64). Many of the participants also spoke about their initial assumptions that they would have to stay in bed and breakfast while waiting to get a place in the facility.

## Theme 3: Atmosphere and Facilities

- ▶ The participants had **overwhelmingly positive things to say about both the atmosphere in Cancer Care West and the facilities it provides**. There were recurring comments about cosiness and kind heartedness, which were often attributed to the staff there. Inis Aoibhinn was regularly likened to a 5 star hotel. For example, one person said *"it (Inis Aoibhinn) has a hotel look about it, but it also has cosiness and warmth which I think has a lot to do to with the staff"* (Female, age 46).
- ▶ All of the participants **attributed the inviting atmosphere of the service to the charming and welcoming demeanour of the staff**. One man summed it up, saying *"In my experience it takes a special person to work in Inis Aoibhinn. All those people who work there were so caring, they are just amazing people"* (Male, age 74).
- ▶ Another integral element mentioned by many participants was the **social aspect of Cancer Care West**. In each of the focus groups, a number of the participants spoke about the friendships and bonds they formed with the other residents and the importance of being surrounded by people who were experiencing similar things to them. The companionship of other Residents at Inis Aoibhinn was a source of support for those who stayed there. Accordingly, the facility became much more than a place to stay as one participant said *"There is a lot of support you get from the atmosphere at Inis Aoibhinn. You get support from the people that are around you and the people that are staying there"* (Male, age 56).

## Theme 4: Support

- ▶ Participants spoke about accessing different types of support. Following on from the supportive atmosphere which is encompassed in the Cancer Care West setting, participants also talked about **the supportive network** that it provides. Frequently, people mentioned the importance of meeting people who were also experiencing cancer and the ways in which they shared their own personal stories with each other. The participants agreed that Cancer Care West afforded a comforting environment in which to talk, with one saying *"There was security in having friends and the staff around you. Everyone there had cancer, there was no beating around the bush and you felt safe enough talking about it"* (Male, 58).
- ▶ Although some of the participants did mention **wanting space to be alone** during their time in Inis Aoibhinn, the majority of participants found that the support garnered from the staff and each other helped to relieve some of the psychological strain that accompanied their cancer diagnosis. For example, one woman said *"The support that was there, it just took the pressure away and it made my journey a lot easier"* (Female, age 55).

- ▶ Alongside this emotional support, it was felt that Cancer Care West also provided a **a tangible source of support to participants through the Cancer Support Centre** and its many facilities. One participant noted *"I started doing art there and that was great, that made a big difference"* (Female, age 46). In general, those participants who had engaged with the Cancer Support Centre felt that it enhanced their stay at Inis Aoibhinn.

## Theme 5: Making the Cancer Experience Easier

- ▶ Participants described features of Cancer Care West which they found **helped in easing some of the pressures associated with their cancer experience**. In particular, participants appreciated **having one's own personal space** while staying at Inis Aoibhinn. Not only did this space allow participants the autonomy to deal with their cancer journey on their own terms, it also enabled their family members to continue on with their own lives with minimal disruption. One woman said *"That to me was the best part of it – my family were allowed to get on with their own lives. They were quite prepared to stay and they did come down but they didn't have to stay in Inis Aoibhinn"* (Female, age 55).
- ▶ Participants were also **grateful for the facility of having friends and family stay overnight**. One participant said *"I had my niece and my husband stay, anybody that had free time would come down and stay. It was great to have somebody there when you were going to your room at night, you could have someone to talk to"* (Female, age 63).
- ▶ **Relieving the burden of having to travel daily for treatment** was another commonly cited advantage of being resident in Inis Aoibhinn. Several of the participants agreed that they would not have coped well with a daily journey to the hospital. At least 10 of the participants travelled each day for the first few weeks of their treatment as Inis Aoibhinn was at capacity. Of those who travelled initially, almost all mentioned how tiring it became as the weeks continued and as their treatment progressed.
- ▶ Staying at Inis Aoibhinn allowed individuals to **rest and recharge away from their familial responsibilities**. One woman explained *"I also think that giving people time to heal is huge for the recovery of the patient. In Inis Aoibhinn you have all the support you need, and yet you have time to rest. I am a busy person and I know that if I was at home I would be doing a whole load of jobs and I may not have recovered as well as I did because I allowed time to rest between treatments when I was at Inis Aoibhinn. I do think that stands to you a lot"* (Female, age 60)

- ▶ In addition, Cancer Care West provided a **comfortable backdrop** for people to undergo their Radiotherapy treatment. Many participants mentioned enjoying activities to pass the day during their time in Inis Aoibhinn. They spoke about how **accessible Galway and all of its amenities** were to the facility. People who had been resident during the summer months especially remembered how nice the weather had been and being able to walk to the beach in Salthill after their treatment. The facilities provided by the Cancer Support Centre were also mentioned as valuable distractions during their time with the service.

## Theme 6: Making the Choice

- ▶ Participants spoke about **various factors which led to their decision to stay** at Inis Aoibhinn. Some participants discussed having reservations about the decision and considered other options. One stated *"I could have stayed in a hotel or bed and breakfast and I thought long and hard about it...and I talked to a few who said "No, don't stay on your own in a hotel just be part of it", and I'm glad I made that decision because it would have been a long four weeks if I had not stayed there"* (Female, age 55).
- ▶ Participants who had not stayed in Inis Aoibhinn from the beginning spoke of the **regret at the decision and at having missed out on the supportive resources** which were available there. One man described his experience saying *"If I had the choice again I would stay the full term because the atmosphere is very uplifting"* (Male, age 56).



- ▶ As well as the financial aspect, participants also spoke about wanting to relieve their families of the burden of having to drive to Galway as an important factor in deciding to stay. The majority of participants mentioned **'not wanting to travel' as one of the core reasons for staying at Inis Aoibhinn**. As one participant stated, *"the difference between staying and travelling on a bus from Sligo every day – there is just no comparison, you couldn't put them in the same league"* (Male, age 64).

## Theme 7: Life after Inis Aoibhinn

- ▶ Participants spoke about **feeling mixed emotions upon leaving** Inis Aoibhinn. While many of the participants were happy to leave and did not experience readjustment difficulties, others found the process quite difficult. Those who had difficulty readjusting described **a sense of disconnect or loss**. One man talked about his struggle returning home; *"It was a wrench, I think it was 12 weeks but it became a home away from home....and going home was very different, very cold, very calculated and cut off. Suddenly there wasn't any keeping in touch with staff...."* (Male, age 56).
- ▶ Participants agreed that the sense of support and the friendships they forged in Inis Aoibhinn were what they missed most. A proportion of people did keep in contact with their fellow residents once they had returned home and often visited each other in their respective counties. Others, however, had not, and several people mentioned their **wish to reconnect with their Inis Aoibhinn companions at some stage**. As many people are dispersed across a range of counties, the potential to meet up together is limited. One woman said *"I was just thinking of all the people that were there when I was there, you know from Mayo and Galway....I may never get a chance to meet them"* (Female, age 63).



- ▶ Participants also varied on their **take up of follow up services** once they returned home. A small proportion felt that they did not require any after-care supports. On the whole however, many **expressed an interest in maintaining supports after finishing treatment**. People listed a number of support options which they would like to see in their area, such as support groups, a contact number for a counsellor, phone support, or contact with fellow ex-residents. One of the barriers mentioned in accessing assistance was **a lack of availability**. This may be due in part to the fact that many people were unaware that they could access services once their stay at Inis Aoibhinn was finished. One said that he *“would honestly think that staff at Inis Aoibhinn should explain about the Cancer Support Centre more to people, particularly the week they are leaving so that you are not thrown out feeling that’s the end of you. I thought when you left Inis Aoibhinn that you were finished with the services”* (Male, 58). Overall, participants stated that they would like to see more follow on supports in place post treatment in order to alleviate potential readjustment difficulties.





## 6 GENERAL SUMMARY

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**IT IS CLEAR** from the responses and discussions that participants felt positively about their stay at Inis Aoibhinn. In general, their stay was comfortable and participants were satisfied with the standard of care provided. The staff were found to be welcoming and warm, and overall were considered an asset to the organisation. Participants noted pragmatic features that added to their stay, including the central location of the residence in Galway city. Simple touches were appreciated, with many individuals pointing out details such as freely available tea and coffee, as well as a supply of books and DVDs. The welcome extended to family members and friends was also frequently mentioned as a positive feature of Inis Aoibhinn.

However, some less positive aspects of the experience were also highlighted. These included feelings of uncertainty or anxiety relating to both the periods leading up to, and leaving the residence. Individuals reported not knowing what to expect, or presuming a more clinical hospital-like setting when they initially heard about the service. These assumptions were maintained until the individuals saw the facilities for the first time, either after taking it upon themselves to visit in advance or upon arriving for their first day as a resident. Participants highlighted worries concerning the limited capacity of Inis Aoibhinn, with many identifying this as a concern in advance of their stay. Some reported worrying that there may be other people in need of comparatively more care, and so were concerned about taking up a place in the residence at the expense of someone else. Settling in was quite challenging for many participants, with some struggling to adapt to their new surroundings and having difficulties finding their way to the Radiotherapy department or the Cancer Support Centre. Leaving Inis Aoibhinn after the completion of treatment was a trying transition for many individuals, as they sometimes felt less supported than they had been during their stay. Returning home resulted in a loss of contact with other cancer patients and a return to 'normality' which was not always a positive experience, especially for those who had established a newfound support network in the staff and fellow residents during their stay.



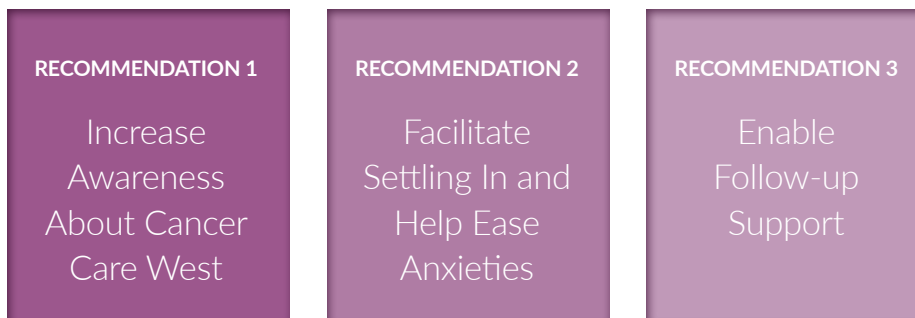
In terms of the wider remit of Cancer Care West, the Cancer Support Centre was considered to be a useful service for individuals. Participants appreciated the facility, but many indicated that they chose not to avail of the services available. However, each of these participants emphasised that they appreciated how useful the service would be to those who needed it. Again, the issue of limited resources was mentioned. Some participants noted that the waiting lists were a barrier to engaging with the activities available, and highlighted concerns about taking the place of someone more in need of the service. Those who used the Cancer Support Centre spoke highly of the staff and services and said they would recommend it to others.

A common issue that arose during these conversations related to the relationship between Cancer Care West, Inis Aoibhinn (or “*The Lodge*” as it was familiarly known), the Cancer Support Centre and University Hospital Galway. Participants were not always aware that Cancer Care West encompassed *both* Inis Aoibhinn and the Cancer Support Centre. Some participants did not distinguish between the charity, Cancer Care West, and the Hospital, leading to questions regarding the funding of the services.

In light of these findings, the research team developed a list of minor recommendations that may serve to enhance the service provided.

## 7 RECOMMENDED CHANGES

Recommended changes fall into 3 major categories and are described below.



### RECOMMENDATION 1

#### Increase Awareness about Cancer Care West

- ▶ Strengthen association between Inis Aoibhinn and the Cancer Support Centre as part of Cancer Care West.
- ▶ Make distinction between Cancer Care West and University Hospital Galway more explicit in communications about the organisation.
- ▶ Highlight the fact that Cancer Care West is a **charity**.

### RECOMMENDATION 2

#### Facilitate Settling In and Help Ease Anxieties

- ▶ Make more information about services available in advance of stay. Invite potential future residents to Inis Aoibhinn to see the facilities.
- ▶ Liaise with staff in the Radiotherapy Department to help provide more detailed information about the facilities at Cancer Care West.
- ▶ Make information more readily available on the Cancer Care West website (pictures, testimonies from past residents about what to expect, etc.).



- ▶ Provide a welcome pack with information about services and local amenities, as well as general information about the locality (maps, areas of interest, etc.) and upcoming events.
- ▶ Develop a standard welcome protocol that requires staff to show the new resident around while also introducing them to other residents.
- ▶ The addition of a weekly social activity may prove useful in providing a social platform for residents who are staying on their own.
- ▶ Include a detailed description of the Cancer Support Centre online; in the welcome-pack; and upon orientation to the facilities.

### RECOMMENDATION 3

#### Enable Follow-up support

- ▶ Provide contact number for Inis Aoibhinn for participants to contact if in need of support.
- ▶ Refer participants to services in their own local area prior to returning home. Provide booklets, pamphlets, and contact details, etc.
- ▶ Inform residents that they are welcome to visit when returning for check ups and let them know that the Cancer Support Centre will continue to be available for their use.



## 8 CONCLUSION

**OVERALL**, this was deemed to be a worthwhile exercise that enabled the research team to gain an insight into the experience of individuals staying at Inis Aoibhinn. Feedback was overwhelmingly positive, with participants emphasising their appreciation of the service. In particular, they felt that they had avoided many difficulties associated with travelling during their treatment. Further, the tangible and emotional support offered by staff and fellow residents was considered invaluable. The report emphasized that individuals were happy with the care that they received, and thus did not call for any major structural changes. However, through the study, potential minor changes were identified that could help the patient across the cancer trajectory. Coming to terms with the novelty of the diagnosis, settling into Inis Aoibhinn and coping during treatment were all addressed. Further, the study afforded a novel insight into life after the patients' stay at Inis Aoibhinn. This highlighted gaps in the transition from cancer patient to the return to 'normality' after cancer. The research has pointed to simple recommendations that could help during this often neglected period on the cancer trajectory. Finally, those who participated in both the focus groups and the individual interviews consistently referred to Inis Aoibhinn as a "*home away from home*", signifying that the organisation has achieved its primary goal of providing individuals with a comfortable residence during this challenging time.



## 9 APPENDIX Demographic Information about Participants

Table 1. Individual Interview Participant Information

Information about participants who took part in the individual interviews during their stay at Inis Aoibhinn.

GENDER	AGE	CANCER DIAGNOSIS	CANCER TREATMENT	DURATION OF STAY (DAYS)	YEAR	COUNTY
Female	69	Breast	RT	27	2014	Mayo
Female	59	Breast	RT	25	2014	Donegal
Male	65	Prostate	RT	56	2014	Mayo
Male	76	Prostate	RT	52	2014	Sligo
Male	66	Glottis	RT	37	2014	Mayo
Male	78	Prostate	RT	55	2014	Donegal
Female	48	Breast	RT	29	2014	Mayo
Male	68	Prostate	RT	53	2014	Donegal
Female	52	Breast	RT	46	2014	Leitrim
Male	66	Prostate	RT	21	2015	Mayo
Female	69	Breast	RT	27	2015	Mayo
Male	67	Prostate	RT	56	2014	Roscommon
Male	59	Neck	RT	50	2014	Donegal
Male	51	Kidney	RT	7	2015	Donegal
Female	48	Breast	RT	39	2015	Galway
Female	48	Breast	RT	12	2015	Offaly
Male	75	Prostate	RT	42	2014	Galway
Male	79	Oesophagus	RT	14	2015	Mayo
Female	53	Breast	RT	19	2015	Mayo
Male	67	Prostate	RT	35	2015	Donegal
Male	59	Brain	RT	27	2015	Offaly
Male	70	Prostate	RT	37	2015	Donegal
Male	64	Lung	RT	25	2015	Donegal
Male	70	Prostate	RT	37	2015	Leitrim
Male	49	Nasopharynx	RT	16	2015	Sligo
Female	51	Breast	RT	29	2015	Roscommon
Female	58	Breast	RT	13	2015	Galway

Table 2. Focus Group Interview Participant Information

Information about participants who took part in the focus groups interviews after their stay at Inis Aoibhinn.

FOCUS GROUP ATTENDED	GENDER	AGE	CANCER DIAGNOSIS	CANCER TREATMENT	DURATION OF STAY (DAYS)
Castlebar	Female	46	Breast	RT	42
Castlebar	Male	54	Prostate	RT	37
Castlebar	Male	64	Prostate	RT	45
Castlebar	Male	66	Prostate	Brachy	9
Castlebar	Female	60	Breast	RT	30
Castlebar	Female	68	Breast	RT	43
Castlebar	Male	63	Prostate	RT	31
Donegal	Female	46	Breast	RT	35
Donegal	Male	77	Prostate	RT	5
Donegal	Female	56	Larynx	RT	3
Donegal	Female	55	Breast	RT	32
Donegal	Male	74	Prostate	RT	37
Donegal	Female	63	Breast	RT	28
Sligo	Female	62	Breast	RT	5
Sligo	Female	58	Breast	RT	43
Sligo	Female	72	Rectal	RT	34
Sligo	Male	56	Lip	RT	10
Sligo	Female	70	Breast	RT	49
Sligo	Male	73	Prostate	RT	52
Sligo	Female	68	Breast	RT	4
Sligo	Male	64	Prostate	RT	27
Sligo	Male	71	Prostate	RT	44
Sligo	Female	55	Breast	RT	24
Sligo	Male	58	Prostate	RT	25
Sligo	Male	54	Gastric	RT	25

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