Data collection and quality issues in relation to cancer staging and treatments for the Irish National Cancer Registry. Can information and communication technology access improve data capture?

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In partial fulfilment of the requirements for the degree of
Master of Science in Health Informatics.

MSc Health Informatics 2016

Declaration.

I declare that the work described in this dissertation is, except where otherwise stated, entirely my own work, and has not been submitted as an exercise for a degree at this or any other university. I further declare that this research has been carried out in full compliance with the ethical research requirements of the School of Computer Science and Statistics.

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Abstract.

The National Cancer Registry is responsible for collecting information on all cancers that occur in the Irish population. This information is used to produce figures on cancer incidence, prevalence and mortality. It was identified that in comparison to some of the United Kingdom cancer registries, in areas such as breast cancer hormone treatment and clinical rectal cancer staging, potentially not all information was being captured by the Irish cancer registry.

The research question was whether tumour registration officers employed by the National Cancer Registry captured more treatment if they had access to information and communication technology systems in hospitals, in comparison to those relying on paper records.

A literature review was performed assessing cancer registry performances in general, and in the context of breast hormone treatment capture and clinical staging for rectal cancers.

A quantitative research approach was used with purposeful sampling using a questionnaire for tumour registration officers in their base hospitals. In addition, oncology consultants in a private hospital were also furnished with a questionnaire, to assess breast hormone prescribing in the private hospital setting.

The questionnaires were then analysed to assess for statistical significance between hospitals with information and communication technology systems and those that had none or limited resources. Figures were obtained from the National Cancer Registry for both breast and rectal cancer patients in 2012. For both breast hormone treatment capture and clinical staging, tumour registration officers in hospitals with information and communication technology witnessed mainly higher capture rates. In the case of hormone capture it was identified that two sources of information and communication technology sources were more beneficial than one source. For rectal cancer clinical staging it was observed that access to any one system was better than none.

It would be recommended that where possible all information and communication technology sources should be accessed by the National Cancer Registry. In addition, following the literature review and questionnaire analysis, provision should be made on the

cancer database for recording hormone treatment that was refused, and when clinical staging was not performed. This would reflect more accurately on the National Cancer Registry, as it would show that in a certain percentage of cases that information was not lost, but rather the intervention had not been made. Overall, the research question was answered and the hypothesis that ICT access enhances data collection and quality confirmed.

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Abbreviations.

Abbreviation	Definition
CSO	Central Statistics Office
DOI	Date of Incidence
EHR	Electronic Health Record
EPR	Electronic Patient Record
ER+	Oestrogen Positive
ER-	Oestrogen Negative
IARC	International Agency for Research on Cancer
ICD	International Classification of Diseases
ICD-O	International Classification of Diseases- Oncology
ID	Identification
ICT	Information & Communication Technology
HIPE	Hospital Inpatient Enquiry
HSE	Health Service Executive
MRI	Magnetic Resonance Imaging
NCCP	National Cancer Control Programme
NCRI	National Cancer Registry Ireland
NICR	Northern Ireland Cancer Registry
NIMIS	National Integrated Medical Imaging System
PACS	Picture Archiving & Communication System
PCRS	Primary Care Reimbursement Scheme
ROI	Republic of Ireland
SEER	Surveillance, Epidemiological and End Results
TCD	Trinity College Dublin
TNM	Tumour, Node, Metastasis

TRO	Tumour Registration Officer
UK	United Kingdom
UKIACR	United Kingdom & Ireland Association of Cancer Registries
US	United States
WCISU	Welsh Cancer Intelligence & Surveillance Unit
WHO	World Health Organisation

Chapter 1: Introduction.

1.1 Introduction.

The National Cancer Registry, Ireland (NCRI) is a population based cancer registry responsible for identifying, collecting and recording information on all cancers in the Republic of Ireland (ROI). This information in turn produces figures on cancer incidence prevalence and mortality, and provides data for research (NCRI 2015a). The NCRI, along with the United Kingdom (UK) cancer registries produces performance indicator reports looking at timeliness and dataset completion (United Kingdom and Ireland Association of Cancer Registries (UKIACR) 2015a). The dataset for breast hormone treatments shows that potentially not all hormone treatment is captured by the NCRI. Another issue identified is the capture of clinical cancer staging for cancers such as rectal cancer. This is reflected in other registries also, but in some cases the NCRI appears to be performing below average. The purpose of this study is to assess what electronic systems are available to the NCRI Tumour Registration Officers (TRO) in Irish hospitals and whether the use of information and communication technology (ICT) enhances data capture for breast hormone treatments and clinical rectal cancer staging. In the ROI, the NCRI is in the unique position of being able to place TROs in hospitals in order to obtain patient cancer information under legislation (Health (Provision of Information Act) 1997).

1.2 Background.

The NCRI has approximately twenty TROs employed throughout the Republic of Ireland to record cancer information (NCRI 2016). Each TRO has responsibility for identifying and recording information on cancer in an outlined group of hospitals (O'Brien *et al.* 2013). Each TRO is assigned a "base" hospital, which is a hospital where the TRO is principally located and conducts the majority of their workload (O'Brien *et al.* 2013). All cancer centres have at least one TRO, and within that geographical location that TRO is also assigned hospitals with smaller cancer workloads. These hospitals include both public and private hospitals and their specialised cancer units such as day oncology units and radiation centres. Information is obtained from a variety of sources such as pathology reports, Hospital Inpatient Enquiry (HIPE) reports, paper records and electronic hospital systems (O'Brien *et al.* 2013). Information collected includes biographical details, smoking history, topography and morphology of the cancer, staging and treatments (NCRI 2014a, NCRI 2014b). Topography,

morphology, and treatment for each cancer are coded using International Classification of Diseases (ICD) codes. In relation to the NCRI database, treatment sites, for example the breast, are assigned an (International Classification of Diseases- Oncology) ICD-O code.

Currently in Ireland there are eight cancer centre hospitals, as recommended by the National Cancer Control Programme (NCCP) where the main surgical procedures for cancer such as breast and rectum are provided (Health Service Executive (HSE) 2016a). In addition, there are a further eighteen hospitals which provide chemotherapy administration. For the purpose of this dissertation, from this point on the eight designated cancer centres will be referred to as "cancer centres" and the other hospitals as "other hospitals".

1.3 Cancer and cancer registries.

Cancer is a generic title given to the abnormal spread of cells in the human body, which have the ability to invade other body structures and cause serious illness and death (American Cancer Society 2016). Figures from the World Health Organisation (WHO) (2015) state that in 2012 cancer was the main cause of morbidity and death worldwide. Internationally, the International Agency for Research on Cancer (IARC) provides statistics on cancer (incidence, causative factors, death rates and so on) from national cancer registries and provides the standards and guidelines for best practice (IARC 2016). Cancer registries play a vital role in cancer control through registering all cancers diagnosed within a distinct population (O'Brien et al. 2013). Further data is added to each diagnosis which allows health departments, researchers and others to analyse and interpret characteristics such as incidence, mortality and quality of care (Shanmugaratnam 1991). Population based cancer registries, such as the NCRI, link their information on each cancer case through means such as pathology reports, medical records, discharge reports and death certificates, both paper-based and electronic (Izquierdo & Schoenbach 2000). Health departments and other organisations or groups such as surveillance programmes can use this data for planning and assessing their service (Brewster *et al*. 2005). According to Goldstone (1983) what treatment a patient receives depends on statistical information. In terms of collecting data on cancer treatments, missing data on cancer and its treatments can lead to inaccurate analysis of tumour incidence and mortality (Creswell *et al.* 2013, O'Brien *et al.* 2013). Missing data on treatments can affect

the figures on cancer mortality and survivorship and hamper surveillance programmes due to inaccurate assumptions being made on the data provided (Creswell *et al.* 2013).

1.4 Problems identified.

As stated in section 1.1 problems identified included breast hormone treatment capture and incomplete staging for cancers such as rectal cancers. These issues will be outlined in more detail in the next sections of this chapter.

1.4.1 Breast hormone capture.

A UKIACR report (2015b) for breast hormone treatment for the Irish and UK registries showed a varying degree of capture. The figures are for the first six months post-date of incidence (DOI), and represent 2013 numbers for the UK registries and 2012 for the NCRI (See Tables 1.1 and 1.2). The Northern Ireland Cancer Registry (NICR) had documented 80.2% of all breast cancer patients as having received hormone treatment; the NCRI documented 40.2%. These percentages are measured against all breast cancers diagnosed and not just ER+ patients. As can be seen from Table 1.1 the lowest recording belonged to the Welsh Cancer Intelligence and Surveillance Unit (WCISU) which documented 10.3% as having commenced hormone treatment. As will be discussed in sections 1.4.2 and 2.2., it will be shown that these numbers do not adequately reflect the likely total percentage of women who received breast cancer hormone treatment. Breast cancer discussed in this dissertation refers to female breast cancer only and does not include male breast cancer.

Table 1.1 Breast hormone capture by UK and Irish registries.

Country:	England	Scotland	Wales	Northern Ireland	ROI 6 Months	ROI 12 Months
% Receiving hormones	36.35%	63.10%	10.3%	80.2%	40.2%	72%

Breast hormone capture by Irish & UK registries. (Percentages for UK registries reflect 2013; 2012 for the NCRI). UKIACR 2015b. NCRI figures obtained from the NCRI.

Table 1.2 Breast hormone capture by the NCRI in 2012.

Total Breast cancer numbers 2012	Total ER+	Received hormone treatment in first 12 months from DOI	ER status unknown
3035	2466 (81.3%)	1783 (72%)	137 (5.5%)

ROI Breast cancer figures for 2012. Figures obtained from NCRI 2015.

From Table 1.2 it appears that potentially 28% of breast hormone capture has being missed by the NCRI in 2012.

1.4.2 Breast cancers.

The most common female cancer worldwide is breast cancer, and the majority of these cancers are oestrogen positive (ER+) (Davies *et al.* 2011, NCRI 2012a). The NCRI (2012a) report states that in Ireland, breast cancer is the most common cancer for females and the second highest cause of death in females. Approximately 75- 80% of all female breast cancers are ER+ (Harrell *et al.* 2006, Djalalov *et al.* 2015). In breast cancer care, clinicians require information on the tumour's hormone receptivity, as this will affect prognosis and treatment (Chan *et al.* 2015). Use of hormone treatments, such as Tamoxifen, in ER+ cancers has shown an increase in survival and reduction in recurrence (Davies *et al.* 2011). The oestrogen receptor positivity is recorded on the pathology report, be it the biopsy or the main surgical specimen, for example a mastectomy (Marco *et al.* 2014). Generally older or elderly women tend to be ER+ compared to very young women with breast cancer who tend to be oestrogen negative (ER-) (Diab *et al.* 2000). Furthermore, hormone treatment is nearly always prescribed by an oncologist, as an adjuvant, with the patient having been referred to them by the breast surgeon (Siminoff *et al.* 2000). In Ireland, a patient will usually be referred to one of the eight cancer centres for a biopsy if a breast cancer is suspected. These centres will then provide any subsequent surgery that is required (HSE 2016b). Other treatments, following surgery, such as chemotherapy, may then take place at either the cancer centres or other hospitals. When the TRO has the ER status available to them they enter the status in the tumour marker box on the NCRI cancer database (see Appendix A for a screenshot of a blank tumour marker box, and Appendix B for a screenshot of a tumour box with tumour status applied).

1.4.3 Rectal cancer staging.

A UKIACR report (2015c) also provided clinical staging figures for rectal cancers, again for the same time periods as the breast hormone treatment, outlined in section 1.4.1. NCRI figures for rectal cancers diagnosed in the ROI in 2012 showed that 14% were assigned no clinical staging. While the NCRI figures are in line with the English and Scottish registries (Table 1.3), Northern Ireland has a completeness level of 92%. The NCRI figures account for all of the TNM clinical staging being absent (clinical staging will be explained in detail in sections 1.4.4. and 1.4.5.).

As can be seen from Table 1.4, it appears that the NCRI is missing 14% of clinical rectal cancer staging. Missing 14% of rectal cancer staging information will be shown in section 2.7 to be a significant proportion which has adverse effects for cancer registries in providing accurate population cancer statistics.

Table 1.3 Clinical rectal cancer staging by UK registries in 2013.

Country	England	Scotland	Wales	Northern Ireland
Rectal cancer staging capture	86%	84%	79%	92%

UKIACR (2015c)

Table 1.4 Clinical rectal cancer staging capture by the NCRI in 2012.

Total rectal cancers diagnosed in 2012	TNM staging left blank	TNM "X" value used	Total cancers with no staging
746	9	93	102 (14%)

Figures obtained from the NCRI.

1.4.4 Rectal cancers.

Between 2011 and 2013, on average 683 people were diagnosed with rectal cancer in the Republic of Ireland (NCRI 2015b). 173 deaths occurred between 2011-2012 from rectal cancer (NCRI 2015b). At diagnosis the clinicians need to assess the stage of the cancer and this is done usually by performing an endoscopy exam, biopsy, and radiological assessment such as a magnetic resonance imaging (MRI) (Tudyka *et al.* 2014).

1.4.5 STAGING.

Cancer staging looks at the cancer at the point of diagnosis and this provides information on the cancer growth, size and its extent (Sobin *et al*. 2009). It is essential that cancer registries obtain this information, if they are to provide figures for further research into cancer care and survivorship (Gurney *et al.* 2013). Staging a cancer at diagnosis is essential for treatment and assessing response to treatment, in addition to observing mortality rates (Merrill *et al*. 2011, Gurney *et al*. 2013). Cancers are staged using the TNM classification- (T = Tumour, N = Node, M = Metastasis) (Ostenfeld *et al*. 2012). Klassen *et al.* (2006) identified staging as one of the two main areas of missing clinical information in cancer registries. Staging at diagnosis before main surgery (if any) is performed, is known as clinical staging, and is based on physical assessment, radiological imaging and biopsies (American Joint Committee on Cancer 2016). Staging based on the main surgical removal of a cancer is pathological staging (Ramos *et al.* 2015).

The NCRI database also has a screen for staging the cancer both clinically and when necessary pathologically. Appendix C is an example of where the TRO has clinically staged the cancer using clinical information from for example, radiology scans and provided a TNM stage. Appendix D is a screenshot where no staging has been applied to the case and "X" has been applied to the staging fields.

1.4.6 NEOADJUVANT TREATMENT.

Treatment given prior to surgery to reduce the size of the cancer is called neoadjuvant treatment (Trimble *et al.* 1993). In advanced rectal cancer where the cancer is a stage T3 or T4 or is N positive, neoadjuvant treatment such as chemotherapy and radiotherapy, singly or combined is necessary prior to surgery (Shrag 2013). The decision as to whether neoadjuvant treatment is required is based on clinical staging by use of radiology such as MRI and endoscopy (Shrag 2013). It is necessary for staging to be complete in order to assess a cancer's response to treatment, as this provides information to clinicians as to whether the cancer has reduced. In addition, cancer registries and researchers need this information overall to assess whether various neoadjuvant treatments are of benefit (Sogaard & Olsen 2012, Walker *et al.* 2014).

1.5 Information communication technology and electronic records.

ICT in healthcare is the ability to share and review patient information and management electronically with many health providers in a more timely and efficient manner, than would be the case if relying on paper medical records (Coiera 2006). Technology devices allow transfer of information to happen simultaneously and in real time, and eliminate issues surrounding illegible handwriting or use of too much free text as is the case with paper records (Hawley *et al*. 2014). Ambinder (2005) states that an electronic health record (EHR) is the combination of all the interactions, both clinical and administrative, between a patient and care providers, in an electronic format. The use of data by organisations such as the NCRI using data from resources such as EHRs and paper records, is known as secondary use of data (Safran *et al.* 2007).

1.6 Radiology systems.

Within a hospital or institution picture archiving and communication system (PACS) is the software that allows for the capture, storage, retrieval and presentation of radiological images in a suitable and timely format (HSE 2013a). The national integrated medical imaging service (NIMIS) is an integrated national network of PACS systems that allows an image on one hospital PACS system to be viewed on another hospital's system (St. Vincent's University Hospital 2016).

From 2010 the HSE began a phased roll out program of installing NIMIS in Irish hospitals (HSE 2013b). NIMIS allows for all radiology images from participating hospitals to be stored on a central database, which can then be retrieved electronically by approved healthcare staff either in the same location or in another, simultaneously (McKesson Ireland 2016). All reports are attached to the electronic image and to the patient's records (McKesson Ireland 2016). Therefore, in theory a TRO with access to NIMIS should be able to access the report and based on that be in a position to clinically stage a cancer, using the TNM system.

1.7 Rationale for the study.

The researcher has been a TRO for over eight years and has seen a lot of improvement in those years in the capture of cancer information. However, it has been observed that hormone treatments and clinical staging for certain cancers are still difficult to obtain. As

this information is vital in the NCRI in providing accurate information, the researcher wanted to assess whether these were issues comparable with other international registries, and whether ICT had helped in improving capture. According to the Central Statistics Office (CSO) (2015) there were 8,880 cancer deaths in the Republic of Ireland in 2014 (30.5%), second only to circulatory disease (30.6%). This shows that cancer in Ireland accounts for almost 1/3 of all deaths, so it is an illness that has a significant impact on the population. The researcher in their own base hospital has managed to obtain access to a lot of the hospital's electronic systems and has seen huge benefits not only in capture but also with timeliness in capture. Hence, the researcher would be interested in evaluating whether ICT sources enhance capture across the NCRI and therefore access to systems in other hospitals could be requested.

1.8 Research question.

The research question of the dissertation is to assess data collection and quality issues in relation to cancer staging and treatments for the Irish National Cancer Registry, and determine whether ICT access enhances capture. Hypothetically it is believed by the researcher that TROs with more ICT should have better data collection and quality in terms of capturing certain cancer treatments and clinical staging.

1.9 Overview of dissertation.

This 1st Chapter gives an outline to the background of the NRCI, and issues it has with collecting information and the quality of data in certain circumstances. The issues identified for this dissertation were the collection of breast cancer hormone treatments and clinical staging information for rectal cancers.

The 2nd Chapter contains a literature review that examines cancer registries in general and issues found with them. The literature review then looks more in depth at cancer registry performance in relation to the collection of breast cancer hormone treatments and the factors influencing capture or the inability to capture this information. Clinical staging for rectal cancers and the issues around that scenario are also assessed. A literature review was also performed to identify other factors that can generally improve the efficiency of a cancer registry in data collection and quality.

Chapter 3 involves the research methodology in obtaining the information necessary to prove whether TROs with more ICT access obtain the required information for the NCRI more effectively.

In the 4th Chapter the results and analysis of questionnaires sent to the TROs and three oncology consultants are discussed.

In the 5th Chapter the findings from Chapter 4 are explored and discussed.

In the 6th Chapter, recommendations and study limitations and flaws are addressed. A final conclusion is also provided.

1.10 Summary.

The NCRI provides a vital service in publishing incidence and mortality figures for cancer in the Irish population. Information is gathered from a variety of sources throughout the country by TROs, but TROs in their various locations may have different access to information systems, that in turn may affect their timeliness and level of capture. As seen from figures in comparison to other registries, some information is not as complete as it should be. The NICR, for example which receives all its information electronically achieved higher capture rates than the NCRI. TROs are based in different hospitals which provide differing levels of cancer care. For cancer information and statistics to be provided accurately and for the NCRI to be seen as a reliable source of cancer information in Ireland it is imperative that information is accurate and complete. The objective of this dissertation is firstly to see how other cancer registries perform, whether they have similar issues and how these issues can and have been overcome. Next, with the aid of questionnaires, the ICT access TROs have in their different hospitals is compared with the actual information they receive. The theory is that the TROs with the better ICT access provide more accurate and complete data.

Chapter 2: Literature review.

2.0 Introduction.

A literature review was performed to look at data quality and missing information for cancer registries. Specifically, for this literature review, searches were performed to assess information regarding missing treatments, especially breast hormones, and missing clinical staging, especially for rectal cancers. Information was also sought for the role cancer registries play in health, limitations of cancer registries and the detrimental effect on registries when data quality is poor and incomplete. A literature review essentially determines what is already known about a particular subject (Pickard 2013). Pickard (2013) further says that the literature review helps to refine the aims of the research, provides all possible information on the research topic, and helps form the framework for the research and how that research will be performed. Literature obtained identified the very important role cancer registries have in providing cancer figures in terms of identifying cases, assessing survival and mortality rates and quality of treatments. Reasons why data is lost were also looked at and how improvements can be made in some cases. Some of the articles did state however, that while this information was very important, not much research had been conducted in to the reliability of the information cancer registries provided (Cress *et al.* 2003, Malin *et al.* 2002). When completeness of cancer data is assessed, it is frequently from the point of view of cancer registration and identification that cancer has occurred, and not the quality of the treatment recorded (Warren & Harlan 2003). The majority of the research was from the US.

Searches for literature were performed using search terms and combinations of terms, such as “cancer registry”, “cancer registries”, “population registries”, “missing data”, “data quality” and so on. Sources consulted included PubMed, MESH, Stella, Google, Google Scholar, and reference lists in the articles found. In performing the literature review, care was taken in performing searches with both the UK and United States (US) versions of certain words such as “tumour” and “tumor” to increase search returns. Synonyms of certain relevant words such as “tumour” and “cancer”, “endocrine” and “hormone” were also factored in to the search criteria. Parkin (2013) states that an awareness of factors such as synonyms is important in conducting a literature review. Literature rejected from the review

was research that mentioned briefly that information from cancer registries was incomplete or inaccurate, but did not delve further in to that aspect for their research.

2.1 Cancer registries.

Benefits of population based cancer registries include providing figures on cancer incidence and mortality, trends in survival in a defined population, and to aid screening and surveillance programmes (Izquierdo & Schonbach 2000, Brewster *et al.* 2005, Li *et al.* 2014). Information on incidence, mortality and survival can be used to improve diagnosis, treatment and follow on care (Parkin 2008). A registry collects data systematically on specified illnesses and population for use in a particular health area (Solomon *et al.* 1991, Arts *et al.* 2002). Information provided by cancer registries allows for a more amalgamated picture of cancer in a population, as it combines surveillance data with clinical data (Klassen *et al.* 2006).

2.1.1 Issues with cancer registries.

However, despite the benefits as outlined above, some articles questioned the validity of cancer registries for a number of reasons. One issue is whether a country has a national cancer registry or not. For example, the US has no one national cancer registry, but rather a fragmented cohort of registries, with Surveillance, Epidemiology, and End Results (SEER) being the largest, covering 28% of the population (Brewster *et al.* 2005). The problem with this, as outlined by Izquierdo & Schonbach (2000) is cancer information from a limited portion of the population cannot be generalised to all the population as there are too many variables such as age, ethnicity and socio-economic factors.

Another issue identified in the literature is whether cancer registry data is complete and accurate. Both completeness and accuracy of the information provided are two benchmarks of quality for a cancer registry (Chiang *et al.* 2015). These issues will be discussed further in the sections on breast hormones (2.2.) and staging (2.6.). Other discussions included whether cancer registries were connected to databases (2.8.) or EHRs (2.11.). Having connected health databases is seen to be superior to relying on older methods of data abstraction from paper records; which will also be discussed further in this literature review (section 2.8).

As stated in sections 1.4.1 and 1.4.3., data capture for cancer hormone treatments and clinical cancer staging was not as complete as it should be, especially compared to some of the UK registries. For the purpose of this dissertation and literature review, breast hormone treatment and rectal cancer staging were chosen to assess data quality and collection issues.

As outlined in 1.4.1 and 1.4.3, the NICR has a much higher capture rate for breast hormone treatments and rectal cancer staging than the NCRI. The NICR (no date) employs tumour verification officers who attend hospitals to verify that all the electronic data sent to the registry from sources such as hospitals and GP surgeries are correct. All information is received electronically, and it is the job of the verification officer to double check for the exact DOI, and for the correct site of the cancer and so on. The Scottish Cancer Registry, while receiving some information such as pathology reports electronically, still needs to obtain information from paper records both in hospitals and primary care (Scottish Cancer Registry 2010). The WCISU (no date) receives all information electronically and has no registration officers based in hospitals; rather they travel to hospitals to verify information received.

2.2 Breast hormones.

As outlined in section 1.4.1., the NCRI captured 40% of breast hormones recorded in the first six months of breast cancer diagnosis in 2012 (UKIACR 2015b). This is measured against all breast cancers diagnosed from DOI rather than against all ER+ breast cancers. The lowest recording of breast hormones in the six months since date of diagnosis in the UKIACR is the WCISU with 10.3% (UKIACR 2015b). In an audit by the Cancer National Specialist Advisory Group (2014), in Wales it was found that only 57% of an expected 90% of eligible women had their breast hormone treatment captured in 2011 by the WCISU. The 57% of hormone capture in 2011 is still a higher proportion than the 10.3% capture rate in 2013. However, in a joint UKIACR and Cancer Research UK (2015) study, the WCISU stated that they had a change in registration practices in 2012, in addition to capturing lower levels of radiotherapy and prostate cancer hormone treatments. Part of the reason for lower levels of capture is thought to be linked to a percentage of patients attending hospitals in England for some of these treatments, therefore their treatments are not being administered in the WCISU jurisdiction.

In studies assessing cancer registries' capture of breast hormone treatment for ER+ cancers, it was found that capture by registries was not as complete as for other breast cancer treatments (Malin *et al.* 2002, Du *et al.* 2006, Ritzwoller *et al.* 2013, Mallin *et al.* 2013, Silva *et al.* 2014). Mallin *et al.* (2013) found that 63.6% of the cases they assessed had breast hormone treatments; 424 had no treatments recorded by the registry but had been prescribed hormones, and 116 were coded as having being prescribed hormone therapy, when they had not. However, this study does not state how many of the total number of breast cancer cases were ER+ and therefore eligible for hormone treatment. While this does not influence why the registry missed or incorrectly recorded treatments, it may not reflect the actual percentage of patients eligible for treatment. Similarly, Malin *et al.* (2002) in assessing the treatment capture of the Californian Cancer Registry found that the cancer registry recorded 36.2% of hormone treatments. This study also does not mention ER+ status and whether the 36.2% is of the total number of breast cancer patients, or of the ER+ patients. The study did show though that where the registry reported hormone treatment, this was shown to have an accuracy of 94.7% when compared with the medical paper records.

In assessing hormone capture by the New Mexico SEER cancer registry, Du *et al.* (2006) found that hormone capture was not as complete as other treatments such as chemotherapy. Comparing registry capture with a review of medical paper records, Du *et al.* (2006) found that a significant proportion of hormone treatments had been missed. This study likewise does not state how many out of the total breast cases were ER+, thus while reflecting missed cases, the true percentage of missed cases is not known. Ritzwoller *et al.* (2013) had similar findings when comparing data from cancer registries with their own audit. Chemotherapy and hormone treatment capture can be lost if a patient receives their treatment in another state from where they were diagnosed (New Mexico Tumor Registry (2004) cited in Du *et al* 2006). If the second state is not linked in with the first state through SEER or any other cancer registry, then the data is often lost. Another point is that as the majority of these studies are US based, their system of administering chemotherapy appears to be somewhat different from the administration set up in the ROI. Du *et al.* (2006) state that in the US chemotherapy is often administered in an oncologist's private consulting suite, which tumour registrars have no access to. No studies in the literature review appear

to find that biopsy, surgery and chemotherapy patients had a higher chance of their hormone treatment being captured compared with biopsy and surgery patients.

2.3 Use of health insurance claims to capture treatment.

Malin *et al.* (2002), Du *et al.* (2006) and Mallin *et al.* (2013) performed their research by comparing cancer registry information against health insurance claims. This was seen as a flaw by the researchers as it automatically limited the comparison sample. Those with health insurance were most likely to be older women from a more affluent socio-economic background. In addition, the sample was limited to hospitals which were covered by a particular health insurance company (Malin *et al.* 2002, Du *et al.* 2006, Silva *et al.* 2014). Thus, only patients with health insurance had a chance of their hormone treatment being subsequently captured by the researchers and added to the cancer registry. Without health insurance coverage researchers had no apparent method of identifying where breast hormone treatments were missed.

2.4 Outpatient prescribing of hormone treatment.

Studies identified hormone treatment as being prescribed mainly in the outpatient setting and this was identified as a reason why cancer registries so often missed capture (Cress *et al.* 2003, Du *et al.* 2006, Kiderlan *et al.* 2015). Generally, hormone treatment is the last treatment provided to a patient with breast cancer (after treatments such as surgery and radiotherapy) (Malin *et al.* 2002). Kahn *et al.* (2002) state that in a lot of US hospitals, a patient may have numerous different medical record charts in one hospital alone. Accordingly obtaining outpatient information can be difficult, as information is only documented in one paper record. Malin *et al.* (2002) did find that the Californian cancer registry performed more adequately with capturing breast cancer treatments that were inpatient based rather than outpatient based. In Ireland, HIPE does not record or measure outpatient activity, nor does it provide information in relation to private hospitals (Health Information & Quality Authority no date). Therefore, while HIPE is of assistance in providing information as already stated in section 1.2 it is of no benefit in obtaining breast hormone treatments by the NCRI.

2.5 Timing of hormone capture.

Another issue identified in the capture of hormone treatments is the time frame for registries to capture the information and timing of the treatment in the patient's overall treatment plan. SEER collects only the first six months of a patient's treatment from DOI (Warren *et al.* 2002, Du *et al.* 2006). When assessing hormone capture, Du *et al.* (2006) assessed capture based on the first six months from DOI. When they assessed for capture after six months they found another 421 cases. Some patients require chemotherapy either before or after surgery, which can take up to six months to complete. As it is then possibly followed by radiotherapy, having a six month cut off on recording treatments by a cancer registry potentially misses a substantial proportion of hormone treatments (Thompson & Moulder-Thompson 2012, BreastCancer.Org 2013). The time from DOI to the time a cancer registry is able to access the information on hormones may also be too long, and the information may be stored elsewhere (Malin *et al.* 2002). If a cancer registry attempts to access information too soon after DOI, then it is possible that the hormone treatment may not have been commenced. Conversely if the registry leaves it too long, the means of obtaining the information may be gone as the paper records may be gone off site (Bray & Parkin 2009).

Currently SEER does not provide information to the public on chemotherapy due to the fact that it believes its information is incomplete (Du *et al.* 2006). The studies outlined above such as Malin *et al.* (2002), Du *et al.* (2006), Ritzwoller *et al.* (2013), Mallin *et al.* (2013) and Silva *et al.* (2014) have all shown that chemotherapy capture is much higher than hormone treatment capture. It must be assumed therefore that any hormone information that SEER might provide be looked at with caution.

2.6 Staging.

To provide information on quality of cancer care and survival it is essential that cancer registries obtain clinical staging information (Merrill *et al.* 2011, Gurney *et al.* 2013). When there is not enough information to provide a TNM stage, the cancer is defined as an unstaged cancer (Worthington *et al.* 2008). In determining the expected outcome and available options in treating a cancer, staging is considered the most important influencing factor (Seneviratne *et al.* 2014). Studies have been performed as to why cancer staging may

be missing, in the context of why it is not performed in the first instance; however, there is very little literature discussing staging that is not recorded by cancer registries (Lengerich *et al.* 2005, Worthington *et al.* 2008). If a large proportion of staging is missing from a specific cancer within a cancer registry, it is very difficult to extrapolate inferences for the quality of treatment and screening programmes as the true picture is not apparent due to the missing data (Klassen *et al.* 2006*,* Sogaard & Olsen 2012).

2.7 Causes for not capturing staging information.

Reasons for cancers not being staged at diagnosis include age, co-morbidities, imminent death and patient refusal (Bradley *et al.* 2008, Merrill *et al.* 2011). From the point of view of cancer registries not being able to obtain staging that was performed, Gurney *et al.* (2013) states that some cancer registries require staging to be inputted at the time of case registration. However, frequently it is not possible to perform clinical staging or have results quickly due to the complex nature of some cancers (Gurney *et al.* 2013). Gurney *et al.* (2013) also highlight that in cases where cancer registries receive staging from hospital cancer databases there may be issues with access to the information or the quality of the information. Klassen *et al.* (2006) reported that some rectal cancers that were treated were not clinically staged adequately due to the lack of correct radiological equipment, or were simply unstaged. The Worthington *et al.* (2008) study found that in their sample 7.85% of rectal cancers were unstaged and that the "M" stage was absent most frequently. This study goes further though to say that while this might appear to be a low percentage overall, to miss this percentage in a population registry means it could be significant when drawing conclusions overall about rectal cancer treatment and survival. Worthington *et al.* (2008) concluded that it should also not be assumed that an unstaged cancer reflected a poorer prognosis; their study found that the five-year survival rate of unstaged cancers were distinctly higher than the survival of those with "M" stage positive at diagnosis. Patients treated with radiotherapy were more likely to have been staged (Worthington *et al.* 2008); therefore, the staging information should be documented somewhere. In examining TNM staging data, Klassen *et al.* (2006) could find no particular reason as to why documented staging was not captured by cancer registries. How staging is obtained by cancer registries world-wide also appears to affect capture. It appears that in some countries, the hospitals report the staging to the cancer registry, rather than the registry accessing the information

at the hospital (Seneviratne *et al.* (2014). In some instances, it appears that the staging is not always reported to the cancer registry.

2.8 Linkage with other databases.

The literature review indicated that researchers believe that there is an improvement in cancer registry performance when information can be linked with other databases (Warren *et al.* 2002, Houser *et al.* 2012, Creswell *et al.* 2013). In a US context some of the research articles advocate linkage to private health insurance companies where cross reference can be made with claims (Warren *et al.* 2002, Ritzwoller *et al.* 2013). However, as discussed already in section 2.3, this only covers the proportion of a population that has health insurance, thus it still potentially leaves the registry with data that cannot be generalised. In conducting the literature review no literature could be found from an Irish context where researchers had used private health insurance as a bench mark against the information the NCRI, or any other population registry had. However, anecdotally the researcher is aware of one attempt previously by the NCRI to match breast cancer patients with insurance data from one of the Irish health insurance companies. Unfortunately, the data provided could not be matched adequately with the NCRI database. In addition, as only one insurance company provided information there would still have been a gap in accurately obtaining private patients' hormone treatments as there are other health insurance providers in the ROI. Mallin *et al.* (2013) also highlights that in a US context hospital cancer registries had higher capture rates for treatments such as radiotherapy and chemotherapy than those identified through health insurance claims. Linkage to a hospital cancer registry therefore may be a benefit to a population based cancer registry. There was very little research available directly dealing with the linkage of cancer registries with hospital based cancer registries.

2.9 Prescribing linkage.

Currently, the primary care reimbursement scheme (PCRS) provides information and analysis to the HSE in relation to all medications dispensed to medical card holders (HSE 2013c). One Irish based study, Kiderlan *et al.* (2015), compared breast cancer treatment for older women in Ireland with the Netherlands. They used the PCRS as a means to try and identify prescription claims for breast hormones in Ireland. This linkage allowed for a further 21% of

patients to be identified from their medical card numbers as having received breast hormone treatment that the NCRI had not identified. Unfortunately, the researchers stated that potentially 15% of women eligible for this study were not included as no record of breast hormone treatment could be found either through the NCRI or the PCRS. The researcher is aware that at present the NCRI does not obtain hormone information routinely from the PCRS, due to interoperability issues.

Cancer registries accessing prescribing information from primary care EHRs is also worth considering, according to Majeed *et al.* (2008). This study states that as prescribing is a main function in all health care, accurate prescribing information is most likely to be present on the EHR for a cancer registry. Accessing e-prescribing information can provide details that may not have been otherwise available to researchers and can provide necessary information for population studies (Cooke *et al.* 2010). Neugut *et al.* (2011) also supports the idea of linking pharmacy databases with cancer registries to obtain breast hormone treatments.

2.10 Comparing figures with screening programmes.

Parkin (2008) advocates for the linkage of cancer registries with screening programmes. O'Brien *et al.* (2013) highlight that when NCRI breast cancer ascertainment was compared with Breast Check figures for 2009, the NCRI had missed only four cases overall. When these four cases were examined, it transpired that three were non registerable by NCRI criteria. This comparison tool showed that in terms of breast cancer ascertainment the NCRI were performing adequately at identifying breast cancer screening cases (O'Brien *et al.* (2013).

2.11 EHRs.

The use of EHRs is increasing among population registries due to the presence of potentially complete patient records, including clinician documentation, diagnostic results, treatments provided and medications (Lau *et al.* 2011). In comparing cancer information held in an oncology EHR against SEER data and health insurance claims, Lau *et al.* (2011) found that overall the capture of breast hormone treatment was superior to that of SEER and the health insurance claims. This was due to the fact that the EHR would record all information after the six-month capture cut off point that SEER have. The EHR also records all the patients with no health insurance, thus having more case ascertainment. However, it was observed

that while staging capture overall was superior to that of SEER (who stage at time of diagnosis) staging was still frequently incomplete. The study went further to say that this would affect any figures published on staging as they would not be complete or generalised to a population. Safran *et al.* (2007) highlighted that research and audits all benefited from secondary information from EHRs. However, as stated already, missing information means that results cannot be generalised to a population with as much certainty. The Ritzwoller *et al.* (2013) study comparing breast cancer chemotherapy and hormone treatment capture by a cancer registry through electronic data and paper records found that the capture was comparable if not enhanced when using the electronic data. Unfortunately, the patients identified for the study had private health insurance, so again it cannot be said with certainty that these results would be generalised across all breast cancer ages and socio-economic groups.

Mallin *et al.* (2013) proposes not only linking insurance details embedded in EHRs with cancer registries, but also attempting to share other administrative information and clinical notes. This is a concept also highlighted by Abernethy *et al.* (2010). One issue stressed by Mallin *et al.* (2013) though is that in the outpatient setting in the US, EHR use is not as prevalent as in the inpatient setting, thus breast hormone treatment capture may still be an issue. Abernethy *et al.* (2010) discusses the benefit that has been seen when EHRs are utilised by cancer registries. Benefits generally include gathering data in "real time", and access to prescription history, in addition to gathering all the information on procedures performed at different locations over a wider area of the health care system. This would allow for more informed information being made available on cancer treatment quality and survival. However, Kim (2014) reports that in a lot of cases where EHRs are being accessed by cancer registry registrars, information is still being manually abstracted and re-entered into the cancer registry database, due to interoperability issues.

2.12 Review of EHRs and cancer registrars.

Only one study was found that surveyed cancer registrars themselves and their use of EHRs. Houser *et al.* (2012) surveyed cancer registrars and other health professionals involved with cancer registries and research. This study assessed whether the registrars found EHRs to be of benefit to cancer registration and data gathering. Houser *et al.* (2012) acknowledged that

one major limitation in their study was that the survey forms were not labelled in a format that identified to the researchers the type and location of the hospital the registrar was based in. Furthermore, there may have been duplicate surveys submitted for certain hospitals. Regardless of this limitation, the results overwhelmingly showed that where EHRs were utilised by cancer registrars, there was an improvement not only in cancer identification but in the gathering and quality of information. Workflow procedures and timeliness were also reported to be significantly improved with the introduction of EHRs. No mention is made of whether capture for treatments and staging were improved with EHRs, but that was not the purpose of the study in this case. However, the results were encouraging.

2.13 Taiwanese Cancer Registry.

One national cancer registry that stands out in the literature review as having made successful improvements in overall performance is the Taiwanese cancer registry. In 2003 mandatory reporting of all cancer cases in hospitals to the cancer registry was introduced (Chiang *et al.* 2015). All residents in Taiwan also have a national identity number and a health insurance number which the cancer registry is able to link to hospitals and cancer treatments and medications provided. In addition, Chiang *et al.* (2015) also reports that EHRs are prevalent in the Taiwanese health system thus access to information by registrars is more timely and complete. Furthermore, the registry also has database linkage to programs such as the death certificate office, and screening programs such as breast and rectum. While this study does not specifically delve in to whether there have been improvements in staging capture, the implication by Chiang *et al.* (2015) is that overall the increased access to EHRs and other databases, coupled with mandatory reporting, has improved the functioning of the registry. Currently in the ROI there is no mandatory reporting of cancer (NCRI 2012b).

2.14 Conclusion.

Cancer registries provide information on cancer incidence, mortality and survival which is of huge potential benefit to populations. This information however, needs to be accurate and complete. A cancer registry that has missing information for a proportion of a population due to age or socio-economic factors means that the information is not generalisable to the

population as a whole. Information can be missing for a variety of factors, sometimes beyond the control of a cancer registry such as a patient's refusal to have staging tests performed. However, it is when the information is available and cannot be sourced that is the concern for cancer registries. Some of the information is missed due to registration practices such as not recording patients' treatments six months after a patient's diagnosis. But as has been shown, frequently a patient may not commence a particular aspect of their treatment until after the six month cut off point. Using ICT such as EHRs has been shown to be of increasing use, as it allows cancer registries and registrars to access information that would otherwise need to be sourced from hospital paper records which may be missing or not have the relevant information. Use of health insurance claims has been of some benefit in the US in identifying missing treatments, but again this is only applicable to certain subsections of the population. Overall it appears from the limited amount of research available, that where ICT in some format is available to cancer registries, it is of benefit.

Chapter 3: Methodology.

3.0 Introduction.

As outlined in Chapter 1, the research question of this study is to see whether data capture and quality is enhanced when TROs have good ICT available to them in their base hospitals. To ascertain whether this is the case or not, a paper-based questionnaire was sent to TROs to assess what ICT is available to them in their base hospitals. Polit *et al.* (2001) state that research is the use of methodical methods to further enhance and refine a body of knowledge by answering questions and solving problems in health. Research is essential to the enhancement of knowledge and improvement in health policies (Bloomrosen & Detmer 2010, McCusker & Gunaydin 2014). In this dissertation the hypothesis is that TROs with more ICT access to software such as EHRs and NIMIS achieve better data collection and quality.

3.1 Literature review.

On conducting the literature review, it was observed that missing treatment and staging data was not a unique problem to the NCRI, but one that was observed worldwide. This was especially the case where registries in a country were fragmented and when paper records were the main source for finding information. One cancer registry that stood out was the Taiwanese national cancer registry (section 2.13) which reported improvements in its overall performance with the increased use of EHRs and database linkage. This study is to see from an Irish point of view if linkage to ICT infrastructure such as EHRs and databases, within hospitals, is helping capture for TROs. As only one study was found that assessed cancer registrars themselves, there was little influence on what research method to use. As highlighted in Chapter 2, Houser *et al.* (2012) used a paper-based survey to assess cancer registrars' assessments as to whether EHRs enhanced their work or not. A convenience sample was used. The literature review however did influence the questions asked of both the TROs and the consultants. In particular, in the TRO questionnaire, hospital database linkage was questioned more.

3.2 Research methodology approaches.

In approaching this study, the Pickard and Dixon (2004) map of research hierarchy (Figure 3.1) was used as a guide as to how this research should be performed. Research paradigms

were assessed and on that basis the research methodology was picked and from there the types of appropriate research method and techniques.

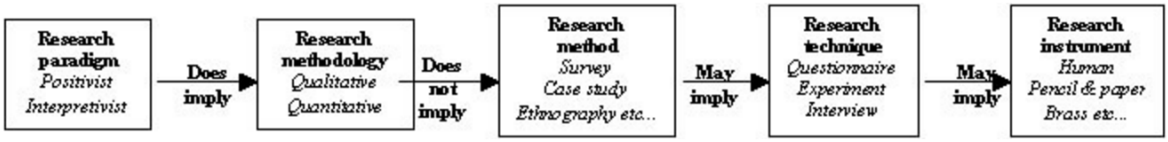

Figure 3.1 The Research Hierarchy (Pickard & Dixon 2014).

Two of the best known research methodology approaches are quantitative and qualitative research (Polit *et al.* 2001). Typically, quantitative research is viewed as a method where the researcher knows the question they wish to answer, deals with numbers and statistics, can be generalised, and is objective and quantifiable (McLafferty *et al.* 2010, Guetterman *et al.* 2015). This methodology comes from the positivist paradigm that believes that all reality can be examined as variables and test hypotheses (Pickard 2013). Alternatively, qualitative research deals with experiences and attitudes, is subjective and deals with words rather than numbers (Polit *et al.* 2001, McLafferty 2010). Increasingly, over the past number of years there has been a combining of these two methods to produce a more comprehensive understanding of a research problem or question and this is known as mixed method research (Plano Clark 2010, Covell *et al.* 2012). Steckler *et al.* (1992) see the mixed method approach as an advantage as there is no restriction in data collection to one method or the other, but rather a complementary effect by combining the two methods.

3.2.1 Quantitative approach.

The purpose of this study is to assess whether the TROs with more ICT have better capture of breast hormone treatment and clinical rectal cancer staging. As this requires gathering information on what ICT is available, a quantitative methodology was deemed most suitable. Quantitative research also is applicable to research where the researcher already has a defined objective and an idea of how they wish to achieve this objective (McCusker & Gunaydin 2015). Opinions were not being sought. As mentioned already, a quantitative methodology requires numerical data for analysis.

3.2.2 Research design.

The research design is the structure used by the researcher to plan out and implement the research in order to try and answer the research question or test a hypothesis (Polit *et al*

2001). In quantitative research the aim is to quantify a relationship between variables such as time and performance, and then express the relationship using statistics such as correlations and differences (Hopkins 2000). Two of the main methods of quantitative research design are descriptive and exploratory designs (Polit *et al.* 2001). Burns and Grove (2005) state that in a study, the research design picked must be the most appropriate to maximise validity and reliability.

3.2.3 Descriptive design.

A descriptive study is one in which the researcher collects the data without manipulation of the area being studied. The study can take place once (cross-sectional) or over a period of time (longitudinal), using techniques such as questionnaires to collect the data (Research Design, no date). Descriptive designs used in quantitative research can depict groups of information and then present this data in tables or numbers (Knupfer & McLellan 2001).

3.2.4 Exploratory design.

An exploratory approach as described by Polit et al. (2001) is when research does not just involve observing and describing a situation, but also fully investigates the factors and influences around the situation. Research Methodology (2016a) states that exploratory design does not look for the solution to a research question, but rather explores the question and determines the nature of the problem. For this dissertation the known problems include collection and quality issues in relation to breast hormone capture and clinical staging information. The objective is not to solve these issues but rather explore the hypothesis that a TRO with more ICT collects this information and collects it accurately. However, an exploratory design is usually not generalisable to a population nor does it allow for definitive conclusions to be drawn from the data gathered (Lynn University 2015). While the sample size of this study is small, it is generalisable to the particular population. On that basis, it was believed that an exploratory approach best suited this study. Using Pickard and Dixon's (2004) guide to research, in this case the research method was a survey using a questionnaire as the research technique.

3.2.5 Purposive sampling.

As stated in Chapter 1 the NCRI employs twenty TROs to collect cancer data from all Irish hospitals, both public and private. All eight cancer centres have at least one TRO. In hospitals

where there is more than one TRO, the questionnaire was sent to the full time person in that hospital. If both were full time, then it was sent to the person who was responsible for the breast and rectal cancers. Two TROs were based in private hospitals so they were also sent questionnaires as these hospitals formed the bulk of their work, and would also provide some insight to ICT in these locations. The rest of the TROs are based in other hospitals with oncologists and haematologists. Figure 3.2 gives a breakdown as to the type of hospitals the TROs are based in. As the study involves a particular group of people based on their unique characteristics (that is they are TROs) then purposive sampling is the appropriate approach to take (Enki Village, no date). Purposive sampling is of benefit when trying to research a small and unique group and gain insight to an area where not much research has been conducted previously (Research Methodology 2016b). Bryman (2012) also highlights that purposeful sampling does not rely on selecting participants randomly, but rather it samples the participants as they are relevant to the research question being addressed. It should be pointed out that three TROs have their base location at the NCRI head office. In this scenario, two of the TROs were provided with questionnaires based on the hospitals they provided cover for, as one of these hospitals was a cancer centre and the other a hospital with a full time oncology/ haematology service. In another case, a cancer centre was the base for three TROs. In this case a questionnaire was sent to the TRO responsible in this cancer centre for breast hormone capture. A questionnaire was sent to another TRO as they provided cover for a hospital with a full time oncology/ haematology service. The third TRO was responsible for rectal cancers; however, for the research it was desirable not to have duplication of answers for the one hospital.

The TRO responsible for breast cancers was picked over the TRO responsible for rectal cancer staging, as it appeared from the literature review to be more problematic capturing hormone information than clinical staging information, due to the timing and location of prescribing the hormones.

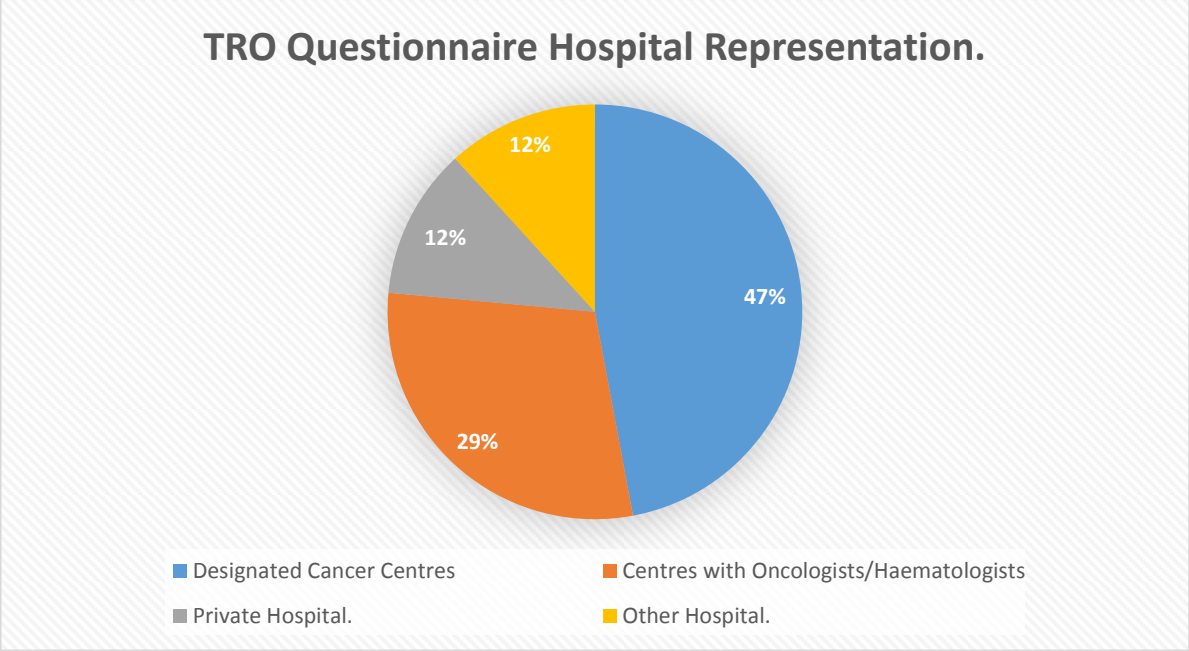

Figure 3.2 Percentage of hospitals covered by TRO questionnaires.

In relation to the questionnaire for the oncology consultants purposeful sampling was also used. Three oncology consultants had been identified as working in a private hospital and therefore could provide information on the prescribing of breast hormone treatment. They would be able to provide an insight in to this area that an oncology consultant working only in the public sector could not provide. However, the sample size was three. Polit *et al.* (2001) state that a sample size, the number of participants in the study, is more representative with a larger number. However, they say that it is not easy to identify in any one study what the best sample size is.

The oncologists were identified through a website for a private hospital which provides diagnosis and treatment for breast and rectal cancers. Their credentials and contact details were available on their hospital website. This private hospital is the base hospital for one TRO and therefore was believed to be of benefit in comparing and contrasting what ICT the TRO had available and how breast hormone treatments were prescribed. As stated previously only two TROs are based in a private hospital.

In terms of clinical staging information, no further group of participants were sent a questionnaire, as no one group would be able to provide any further information. As radiology is available either electronically or in a paper record, sending a questionnaire for

example to radiologists or gasto-intestinal consultants, was not going to elicit any further information. This issue would be dealt with by the TRO questionnaire and their ICT availability.

3.3 Data collection technique.

3.3.1 Questionnaire.

The best way of gathering the required information from the TROs was to ask closed questions regarding the ICT availability to them in their base hospitals. A questionnaire is a valuable technique in collecting objective and quantifiable data (Boynton & Greenhalgh 2004, Fanning 2005). Questionnaires are widely used to extract information (Rowley and Hartley 2008). Furthermore, Giesen *et al.* (2012) state that the use of a questionnaire allows for standardisation and anonymity. Bryman (2012) highlights that another advantage of questionnaires is that the participant can answer in their own time and at their own pace. A decision was taken to send the questionnaire in a paper format rather than via email or internet. Emailed questionnaires are beneficial from a cost and time point of view; however, there can be issues with formatting the text and resolution, and response rates (Schonlau *et al.* 2002, Wyse 2012). In addition, Schonlau *et al.* (2002) found that closed-ended questions in email questionnaires tended to have a higher rate of missed responses than paper-based questionnaires. As confidentiality was a factor, it was also believed that not requiring respondents to use their work based email accounts to respond would be beneficial in achieving higher response rates. For the same reason the online survey option was not used, as it would have required use of work email addresses. However, one advantage of using an online survey tool such as Survey Monkey would have been the more rapid distribution of the questionnaire, rather than posting it, thus saving time (Wright 2005, Wyse 2012). In addition, Wyse (2012) states using an online survey allows for more rapid analysis and assessing advancement of the questionnaire. Online survey questionnaires are also more cost efficient compared to posted questionnaires (Couper 2000). One identified disadvantage of online surveys is that they can be easily deleted by the recipient (Gingery 2011). Furthermore, sending online surveys can raise concerns about privacy and intrusiveness, and they may be routed to an email spam account (Web-based Survey Software, no date).

3.3.2 QUESTIONNAIRE PROCESS.

Figure 3.3 highlights the steps involved in the questionnaire process from start to finish. The literature review provided the information for defining the variables that needed to be assessed in the questionnaire. The design phase was the selection of the participants and deciding how best to distribute the questionnaire. The questionnaire was provided to a TRO for initial feedback at the first draft stage. At a later point, pre-testing of the TRO questionnaire was trialled with research staff at the NCRI and feedback obtained. Questions and formatting were amended as necessary and then resubmitted to the research staff for further evaluation. Pre-testing is vital according to van Teijlingen and Hundley (2002) as it highlights where a questionnaire might be problematic when provided to the participants. This pre-testing allows for feedback on all aspects of the questionnaire and gives the opportunity for questions to be formatted with more clarity.

This questionnaire was also provided to three nurses not in the NCRI who were not familiar with the workings of the NCRI or data collection. They assessed for readability, formatting and logical sequence of questions. Boynton & Greenhalgh (2004) write that it is important not just to get the questionnaire wording correct but also the format, such as text size, as this enhances response rates. Bryman (2012) also advocates that the questionnaire be easy to follow and the questions straightforward, especially as the researcher is not present to provide guidance. This pre-testing was felt to be important as the nurses would not have the same bias in terms of the type of question as the NCRI research staff may have, but would be attentive to the way the questions flowed. The oncology consultant questionnaire was also provided to the same research staff at the NCRI and two non-consultant hospital doctors familiar with oncology medicine for the same purpose.

The questionnaires once tested and revised were posted out to the relevant TROs and oncology consultants (Appendices E and F). From the start of formulating the questionnaire, it was important to take particular care not to let personal knowledge and bias influence the questionnaire or any other aspect of the research. Creswell (2013) states that for efficient and reliable research to take place, the researcher must remain objective. All TRO and consultant questionnaires were assigned a code for analysing results so cancer centres could be distinguished from the other hospitals.

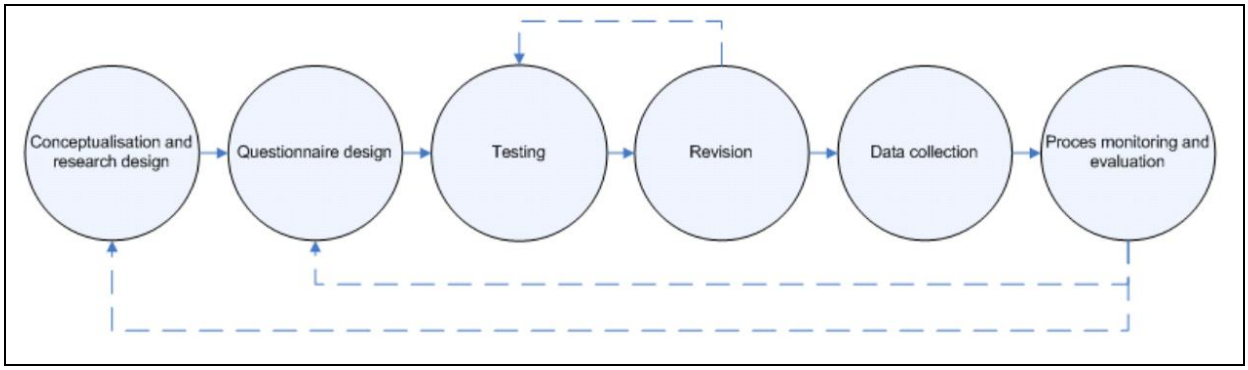

Figure 3.3 Questionnaire development as a process (Giesen *et al.* 2012).

A stamped addressed envelope was provided for the TROs and oncology consultants to return the questionnaire as this usually helps response rates (Boynton and Greenhalgh 2004). As the research question is to ascertain what ICT infrastructure TROs had access to, closed-ended questions were deemed appropriate. This is due to the fact that closed-ended questions provide response alternatives such as “yes” or “no” which was appropriate for questions regarding ICT access. This allows for comparability of responses and to enhance analysis (Polit *et al.* 2001).

Also included with the questionnaire pack was an information sheet outlining the rationale for the study, and contact details for the researcher (Appendices G and H). The consent form for the participants to grant permission for their inclusion in the study was also supplied (Appendices I and J). The consent made clear that any participation was voluntary and the participant could withdraw from the study at any stage. Bryman (2012) states that an advantage to signed consent forms is that it gives the participants the chance to be fully informed about the research from the start. In addition, should there be any issues of concern at a later date, the researcher has a record of the signed consent. It was also stated that no participant, consultant, TRO, or their place of work would be identifiable.

3.4 Ethical considerations.

Ethical approval was sought from Trinity College Dublin (TCD) to send questionnaires to the relevant TROs and oncology consultants in the private hospital. As the consultants were provided questionnaires in a private capacity, permission was not required from that particular private hospital. Permission was granted from TCD once minor amendments were made to both the information and consent forms for the TROs and the consultants. The

director of the NCRI was contacted regarding ethical approval for issuing questionnaires to the relevant TROS and it was deemed that TCD ethical approval would suffice.

3.5 Data analysis.

All answers from the completed questionnaires were inputted by question number in to an Excel sheet. As stated in section 3.1.2 all questionnaires were assigned a code for analysis purposes. Codes for the TROs ran from 1-17 and the hospital location and type were inputted beside it. Alongside this ran the question numbers and “yes” or “no” inputted depending on the answer type. The oncology consultant codes ran from 1-3.

3.6 Summary.

This chapter provided the framework as to how the research would be performed and the rationale behind adopting the specific methodology, design and techniques. An outline of the different methodologies was discussed and the reason behind adopting a quantitative methodology. Within that, the reasons behind using an exploratory design, purposive sampling and a close-ended questionnaire were also provided. While the sample sizes used in each questionnaire were small, the reasoning behind the valuable data that could be obtained from these two very distinct and unique groups validated their use and inclusion. The literature review from Chapter 2 helped to formulate the questions used in the two questionnaires. The following chapter will provide in detail the results and analysis of the questionnaires and how the answers can be measured against the information TROs obtain during the course of their work.

Chapter 4: Results.

4.0 Introduction.

This chapter involves the responses to questionnaires sent to TROs and oncology consultants to assess for ICT breast hormone capture and prescribing, and clinical rectal cancer staging. The chapter will provide in detail responses and analysis of the TRO and oncology consultant questionnaires.

Seventeen TROs were eligible for participation in the study, including the researcher. Sixteen responses were received, providing a response rate of 94%. Out of the sixteen responses, seven of the eight TROs representing the cancer centres replied.

Three TROs had to be contacted on receipt of the questionnaires, as they had not returned a signed consent form. The one response from a consultant also required contact for a signed consent form. In all four cases the signed consent form was forwarded on to the researcher. Contact was made by three TROs to the researcher to clarify if certain systems they had available to them in their hospitals were considered either an electronic patient record (EPR) or a cancer database. Clarification was given on both these issues. Again, as stated in section 1.2, hospitals will be identified as being either a cancer centre or other hospital.

4.1 Response level to questions.

All questions in the questionnaire apart from question 6 and its follow on questions received a 100% answer rate (see Table 4.1 for a breakdown in responses). Question 6, which had six components to it, included questions regarding base hospitals having NIMIS, PACS or another equivalent system and had various response rates ranging from 37.5% to 75%. A no response was where a TRO did not indicate an answer in either the “yes” or “no” box. Where TROs indicated their hospital had NIMIS, PACS or another system, there was a 100% response rate as to whether they had access to the system or not. It is not clear as to why this section had boxes left blank. At the start of the questionnaire the TROs were asked to “tick the appropriate box”; however, in hindsight it should have been requested that all questions were answered regardless. It may have been assumed that if the TRO’s base hospital did not for example have NIMIS, that leaving the box empty would indicate this. All response rates to the questionnaire can be seen in Table 4.1.

Table 4.1 Response level to questions in TRO questionnaire.

Question No	Topic	No. of required responses	No. of responses	Response rate
Question 1.	Percentage of information from paper records	16	16	100%
Question 2.	Does your hospital have an EPR?	16	16	100%
	Do you have access to the EPR?	10	10	100%
Question 3.	Does your hospital have a cancer database?	16	16	100%
	Do you have access to the database?	9	9	100%
Question 4.	Is breast hormone information on the database?	6	6	100%
Question 5.	Is clinical rectal cancer information on the database?	6	6	100%
Question 6.	Does your hospital have NIMIS?	16	12	75%
	Do you have access to NIMIS?	10	10	100%
	Does your hospital have PACS?	16	10	62.5%
	Do you have access to PACS?	9	9	100%
	Other radiology database?	16	6	37.5%
	Do you have access to the other database?	2	2	100%
Question 7.	If staging not available electronically, can you access information in paper record?	16	16	100%
Question 8.	Does your hospital have an e-prescribing system?	16	16	100%
	Do you have access to it?	2	2	100%
Question 9.	Does your hospital record medical card numbers?	16	16	100%

4.2 Questionnaire findings.

In Table 4.2 an account is given for each TRO's hospital that provided a response to the questionnaire. Hospitals A-G are cancer centres, I and J are private hospitals, and K- P are other hospitals. Hospital H is another hospital that unlike hospitals K-P does not provide cancer diagnosis or surgery. It is a TRO base hospital and thus was included in the questionnaire.

Table 4.2 Sources of information for TROs in their base hospitals.

HOSPITAL	PERCENTAGE PAPER RECORDS	EPR	DATABASE	NIMIS	PACS/ OTHER	E-PRESCRIBING	MEDICAL CARD NUMBER
A	0-24%	NO	NO	YES	YES	NO	YES
B	0-24%	YES	YES	NO	YES	NO	YES
C	0-24%	YES	YES	YES	YES	NO	YES
D	50-74%	YES	NO	NO	YES	NO	YES
E	50-74%	NO	YES	YES	NO	YES	YES
F	50-74%	YES	NO	NO	NO	NO	YES
G	75%+	YES	NO	NO	YES	YES	YES
H	25-49%	YES	YES	YES	NO	NO	YES
I	0-24%	NO	YES	NO	YES	NO	NO
J	50-74%	YES	NO	NO	YES	NO	NO
K	75+	NO	YES	YES	YES	NO	YES
L	50-74%	YES	NO	YES	NO	NO	YES
M	75%+	NO	NO	YES	NO	NO	YES
N	50-74%	NO	NO	NO	YES	NO	YES
O	25-49%	YES	NO	YES	NO	NO	YES
P	75%+	YES	NO	YES	NO	NO	NO

4.2.1 Paper records and electronic patient record systems.

As stated in section 4.1, questions 1 and 2 had response levels of 100%. Question 1 asked TROs about approximately what percentage of their information they obtained from hospital paper records.

As can be seen from the breakdown of numbers in Figure 4.1, six out of the sixteen TROs mainly get 50-74% of their information from hospital paper records. This is an even split between the cancer centres and the other hospitals. The hospitals with the least information taken from hospital records (0-24%) are the three of the cancer centres and one other hospital. The hospitals obtaining the most amount of their information from paper records are three other hospitals and one cancer centre. One cancer centre, where the TRO reported obtaining only 0-24% of their information from paper records, had no access to an EPR or a cancer database. It is not clear therefore, where the bulk of their information comes from. Clarification could not be sought on this as the TRO has since left the NCRI's employment. Overall the responses seem to show that ten out of the sixteen hospitals get more than 50% of their information from paper records.

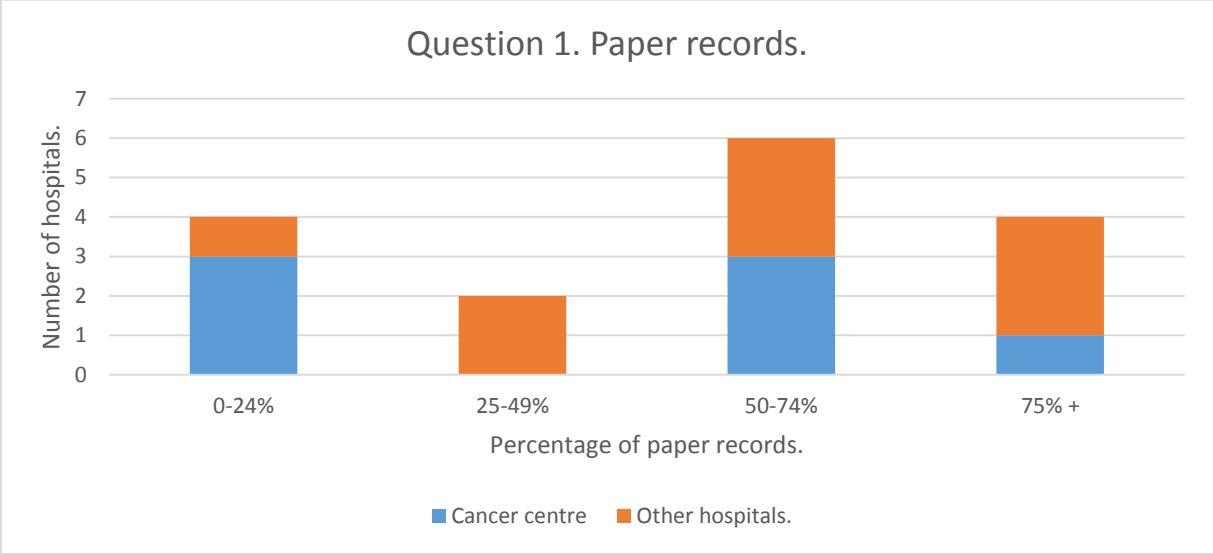

Figure 4.1 Percentage of paper records.

However, of the four hospitals who recorded 75% + of their information from paper records, two of the TROs recorded that they had access to an EPR. One of these hospitals is a cancer centre. This hospital, G, is assessed for breast hormone treatment capture in sections 4.4

and 4.5 and can then be assessed as to whether the EPR available to them perhaps has not has much functionality as other EPRs. In addition, hospital G is assessed to see whether its rectal cancer clinical staging is as adequate as the other designated cancer hospitals.

One of the hospitals, M, recorded 75% + of their information from paper records and had no access to either an EPR or a cancer database of any type. This hospital is not a cancer centre. In the hospitals with EPRs, all TROs had access to the systems. TROs had access in all hospitals to an EPR if present, regardless of it being a cancer centre or other hospital (Figure 4.2).

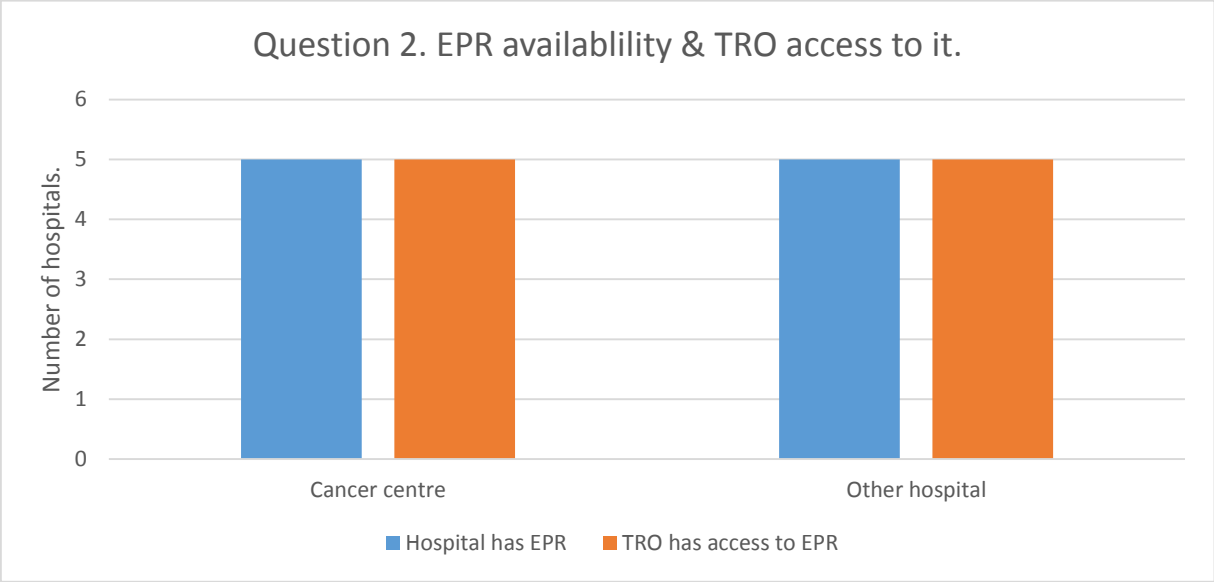

Figure 4.2 EPR availability in hospitals & TRO access to it.

4.2.2 Hospital cancer databases & obtaining information from same.

Out of the sixteen TRO responses, nine are based in hospitals that have a cancer database. Of these nine, four were in cancer centres and five in other hospitals. TROs had access to the database in six of the hospitals, and three did not. This is broken down to one in a cancer centre and two other hospitals. These figures are represented in Figure 4.3.

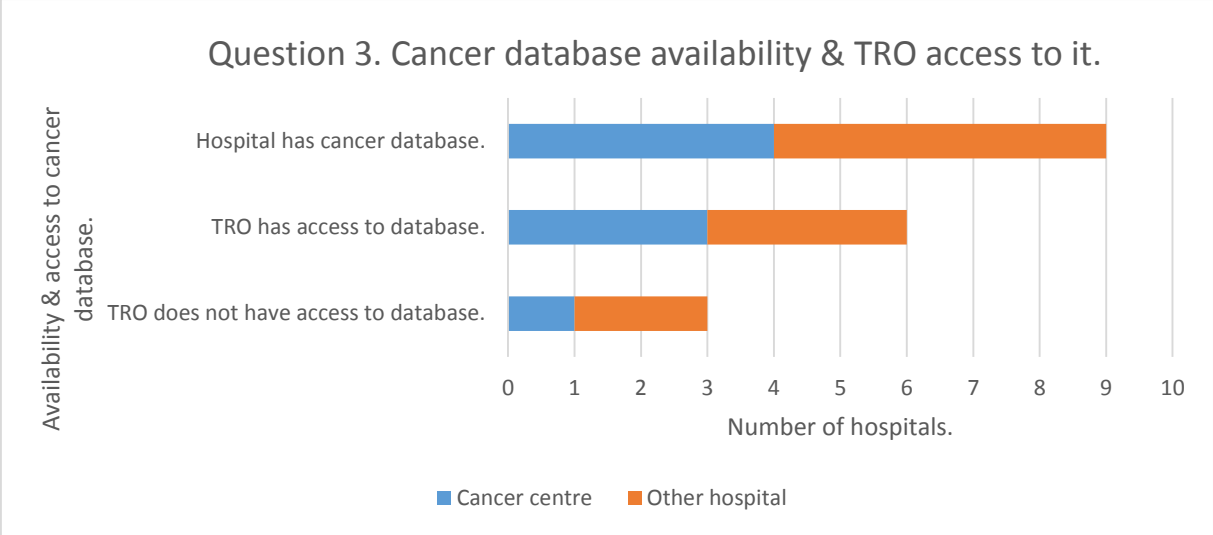

Figure 4.3 Cancer database availability & TRO access to it.

In relation to question 4 which was only relevant to the six TROs with access to the hospital cancer database, all said they could access breast hormone information. Two TROs added comments that while they could obtain the name of the hormone treatment, they could not access the date the treatment started. In this scenario, it is NCRI policy for the TRO to provide an approximate date of hormone treatment commencement. The TRO can approximate the date as being after the last chemotherapy or radiotherapy treatment the patient had, as hormone treatment is usually the last treatment in a breast cancer patient's care, as discussed in section 2.4.

The same six TROs with access to a hospital cancer database were asked in question 5 if they were able to obtain clinical rectal cancer information from the database, such as radiology reports. Four of the six stated they could, but two said they could not. One of the two TROs unable to obtain radiology information from the hospital cancer database, replied that they could access the relevant radiology information from NIMIS.

4.2.3 NIMIS, PACS, AND OTHER RADIOLOGY SYSTEMS.

Question 6 asked TROs if their base hospitals had NIMIS, PACS or another equivalent system and whether they had access to those systems if present in the hospital. In Figure 4.4 more than half of the TROs that responded have NIMIS in their base hospitals, and nine have PACS. The two other systems included by TROs were iSoft and IPIMS. These two hospitals were a private hospital and another hospital. Four hospitals had both NIMIS and PACS. Three of these hospitals are cancer centres. One other hospital has both PACS and another system.

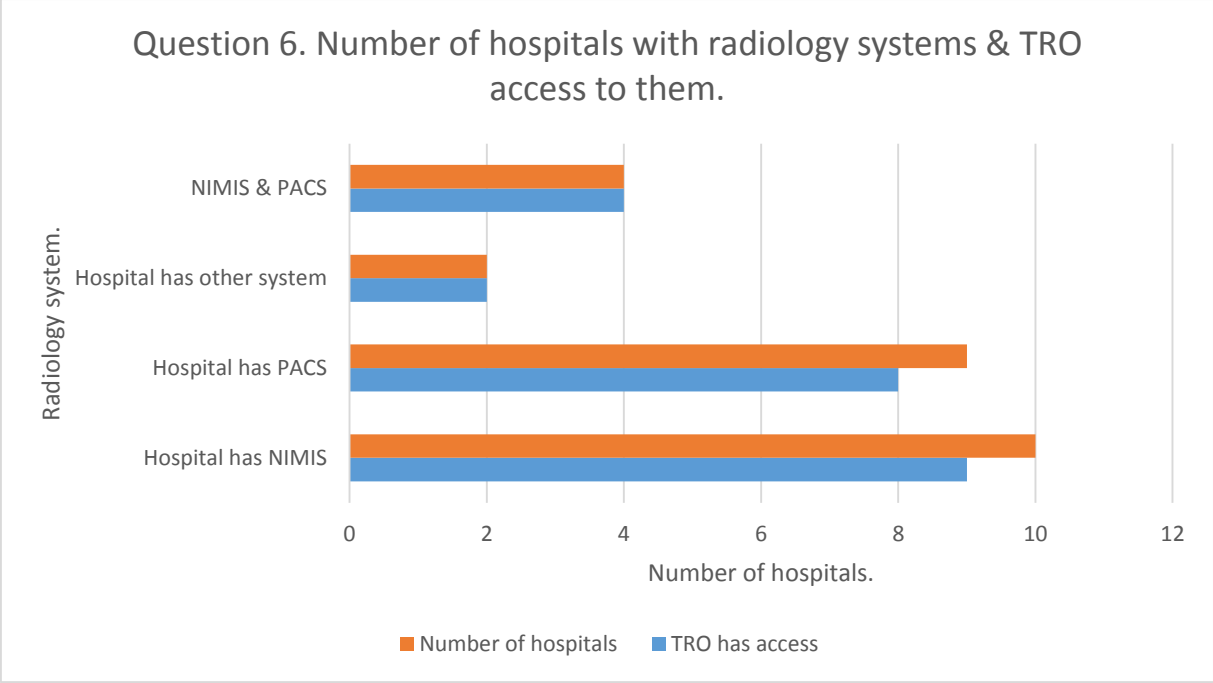

Figure 4.4 Number of hospitals with NIMIS, PACS or another radiology system.

4.2.4 Information available from paper records if not available electronically.

When asked in question 7 as to whether the TRO could access information not available electronically in a paper record, fourteen TROs (87.5%) replied that they could. One of the two TROs that replied "no", one added a comment stating that by the time they would look to access that information the paper record would be off-site (that is not available in the main hospital medical record department).

4.2.5 e-Prescribing systems in base hospital.

In reply to question 8, only two of the TROs said they have e-prescribing systems in their hospitals, and they both have access to the system. Both hospitals are cancer centres. One TRO commented that the e-prescribing system was for the oncology department only, and not otherwise available in the rest of the hospital.

4.2.6 Recording of medical card numbers.

Three of the sixteen hospitals do not record medical card numbers. Two of these hospitals are private hospitals, with the third being another hospital.

4.2.7 ICT SOURCES.

Of the seven cancer centres that a questionnaire was completed for, the most common ICT source of data that a TRO had access to were the EPR and PACS, with five TROs having access to both. The least common ICT source for a TRO in a cancer centre was an e-prescribing system, with only two TROs having access. These numbers are available in Figure 4.5.

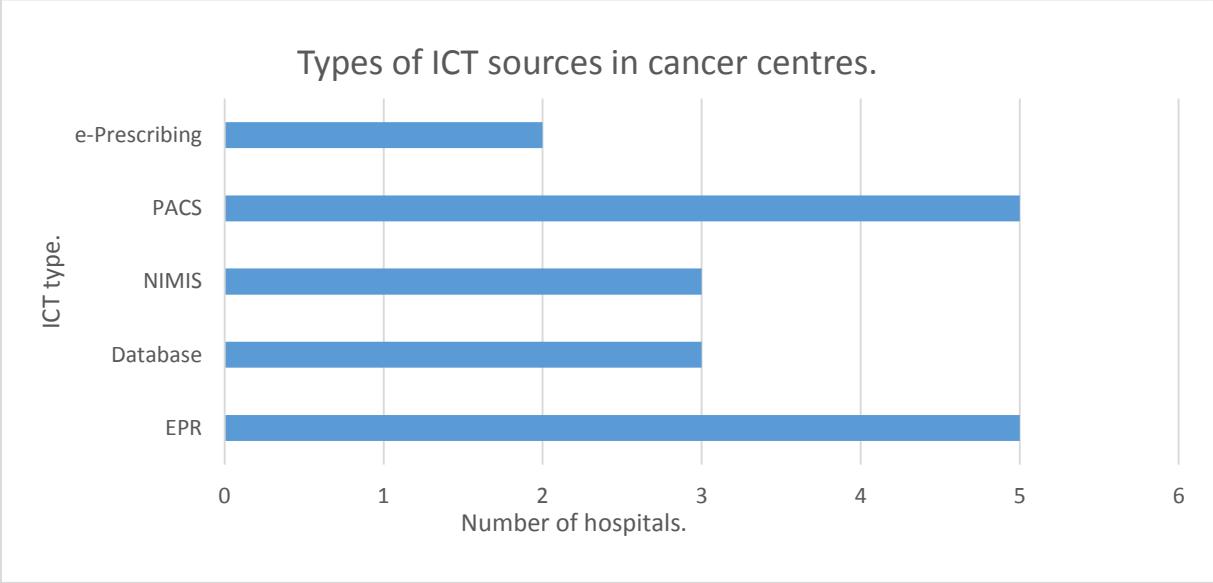

Figure 4.5 Types of ICT sources in cancer centres.

One cancer centre had only one ICT source available to it; the most ICT systems that any TRO had available to them was four. These figures can be seen in Figure 4.6. The figures are dependent on whether the TRO has access to the ICT source and not just its presence in a hospital. The figures also do not reflect the “no answer” responses. The mean value was 2.5 ICT sources per TRO in a cancer centre.

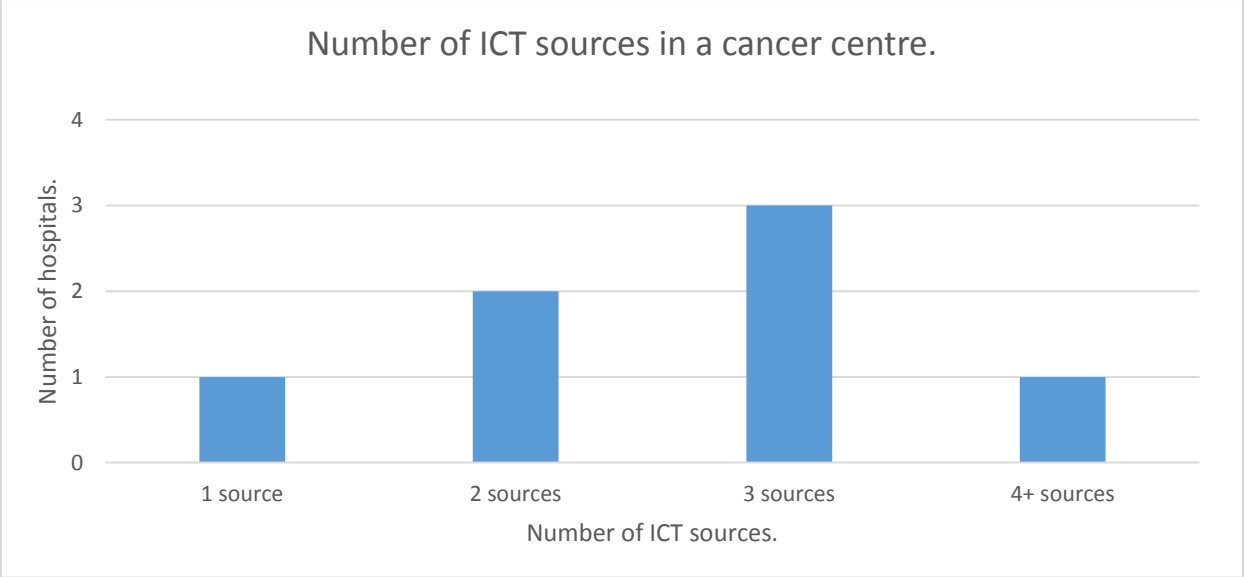

Figure 4.6 Number of ICT sources in a cancer centre.

In relation to the other hospitals, a breakdown of ICT sources available showed that NIMIS was the most common ICT source accessible to TROs. Again this was in relation to the TRO having access to the system and not it just being present in the hospital. None of the TROs in these hospitals has an e-prescribing system available to them. A breakdown of these figures is available in Figure 4.7. The mean value of electronic sources available in a hospital for all sixteen TROs was 2.1.

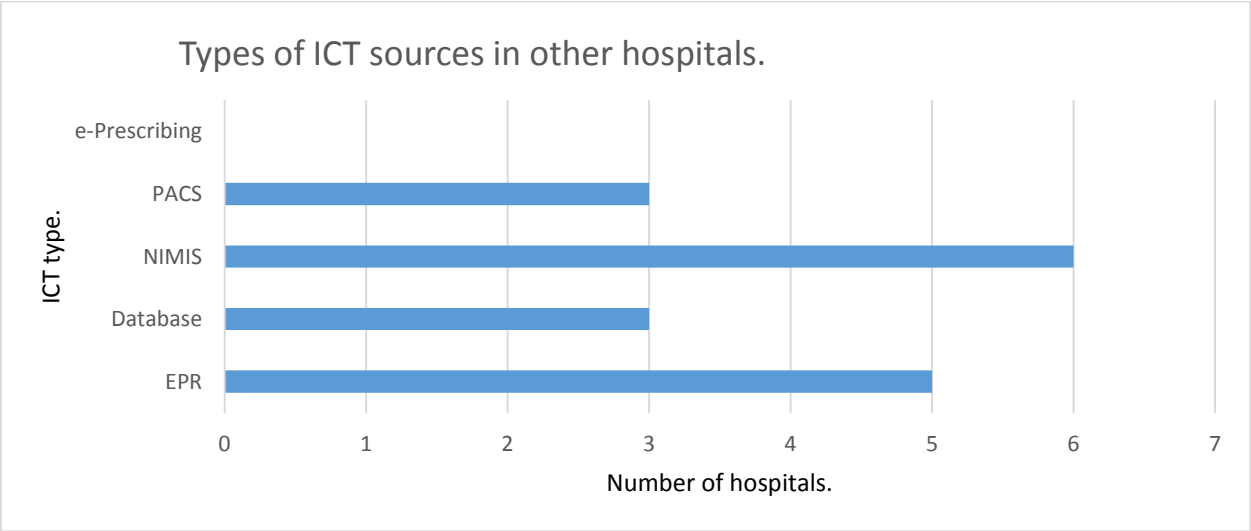

Figure 4.7 Types of ICT sources in other hospitals.

Figure 4.8 demonstrates the number of ICT sources available to TROs in other hospitals. Four hospitals have at least two sources, followed by three hospitals having at least one source.

None of these other hospitals had four sources of ICT available to them. Overall the breakdown of ICT sources available to TROs is provided in Table 4.2.

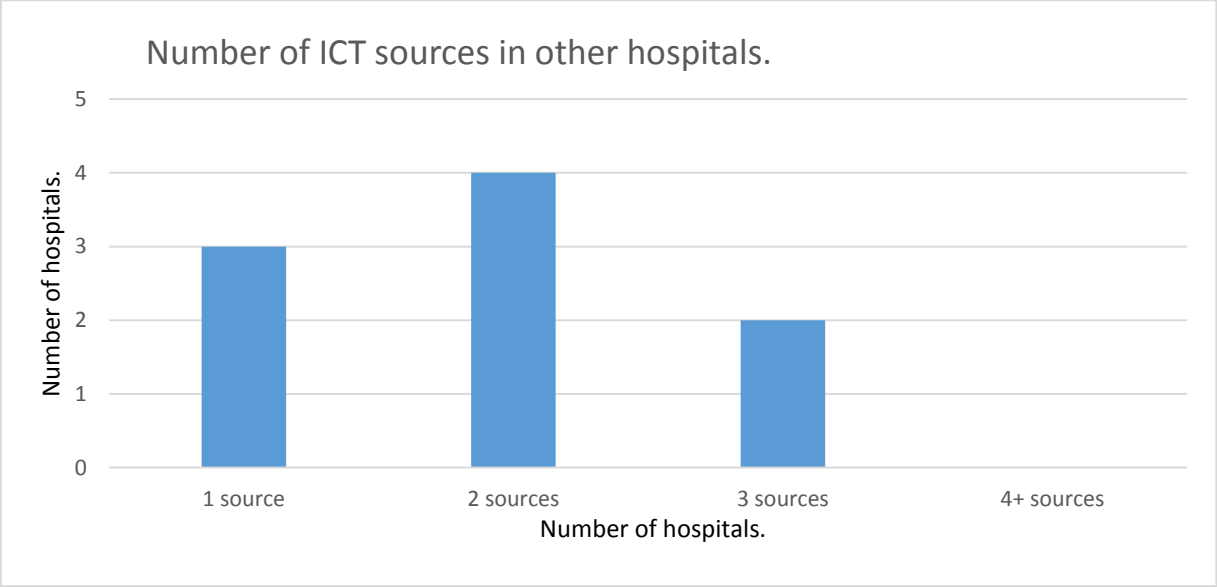

Figure 4.8 Number of ICT sources in other hospitals.

4.3 Oncology consultant questionnaire.

4.3.1 Response rate.

One response was received out of the three questionnaires posted out. As stated in section 3.2.5. purposive sampling was used for the oncology consultants, as they were a unique group; consequently, the risk was taken that there might be a low return for the questionnaire. This represents a response rate of 33%. All eight questions were answered. According to Mangione (1995) a response rate of less than 50% is not acceptable; however, Bryman (2012) suggests that if the researcher can prove that the participants who replied do not differ greatly from those who do not, then it possible to have relevant findings. It is possible that given the nature of their job and location that the replies may not have differed hugely but this cannot be proven conclusively.

4.3.2 TRO presence in the consultant's private hospital.

In relation to question 1 (Appendix F) the consultant said that "yes" they were aware that a TRO worked for the NCRI in their hospital. In relation to question 2, they stated that "yes" they knew that the TRO collected information on breast hormone treatments. The

consultant replied that they had never been contacted for information on breast hormone treatments.

4.3.3 Recording of breast hormones.

The consultant replied to question 4 that they recorded breast hormone treatment in a paper record in their private rooms. They did not duplicate this by recording the hormone prescription in an electronic format. They did not send a copy of the prescription to the hospital paper records, as per question 5. The second part of question 5 asked if they would consider sending a copy to the patient's hospital paper records and they answered "no" with a further comment of "lack of staff". In question 6, the consultant was asked if they would be prepared, with the appropriate security and data protection laws, to electronically provide breast hormone treatments to the TRO or the NCRI. They replied that if a system was in place, then "yes" they would consider this option.

4.3.4 Timing of breast hormone commencement.

In relation to the timing of commencing breast hormone treatment, the consultant was asked for the timeframe of commencement in questions 7 and 8. In question 7 the scenario was if a patient was to receive adjuvant radiotherapy, followed by hormone treatment, what would the approximate timeframe be. For this scenario the consultant ticked the 3-6 months option, representing the time from from DOI. In question eight the scenario was adjuvant chemotherapy, radiotherapy and then commencing hormone treatment. In this case, the consultant ticked the 6-12 months option. This seems to reflect what was shown in the literature review in section 2.5, that surgery followed by radiotherapy and then hormonal treatment would be in the 6-12-month timeframe. This same scenario where chemotherapy is administered prior to radiation moves the hormone treatment to the 6-12month time-frame.

4.4 Breast hormone capture analysis.

In this section a breakdown of figures for breast cancer hormones is outlined. The relevant hospitals are assessed to see if there is a statistical advantage in having ICT sources such as EPRs and cancer databases over paper records in obtaining breast hormone treatments.

4.4.1 Overall breakdown of hormone capture.

A breakdown of all results of ICT available to all the TROs in their base hospitals was outlined previously in Table 4.2. Hospitals A-G are cancer centres; hospitals I and J are private hospitals and the rest are other hospitals which provide some cancer surgery, and chemotherapy.

All breast and rectal cancer datum for 2012 was obtained from the NCRI for 2012. For clarification, both cancers had to have been histologically verified by biopsy in 2012; the hormone treatments may have been prescribed in 2013 or later. There was no cut off point in this study as to the date of hormone prescribing, so that no capture would be missed by the researcher and would reflect accurately where all capture by a TRO had taken place. The data provided information such as all treatments provided for each individual cancer, the hospital that provided each individual treatment and the dates of treatments. The information was provided by the NCRI in an Excel word sheet. All information was anonymised, and ICD codes used for topography, morphology and treatments. For the breast cancer cases, the data was sorted and filtered to the individual hospitals of diagnosis. As stated previously, in section 1.4.2, all breast cancer is managed through the eight cancer centres. Some of these centres also have Breast Check centres which provide breast cancer screening services.

Where applicable the Breast Check screening centre figures are included with the attached cancer centre. Breast Check is a screening service and provides biopsy only of the breast and/or a lymph node and no other treatment. A patient diagnosed at Breast check with cancer will be referred to a cancer centre (Breast Check, no date). The individual figures are not provided here as they would have no influence on whether a hormone treatment was provided by a hospital or capture of this information by a TRO. Thus for example hospital B has a Breast Check clinic co-located and accordingly the numbers were merged. This also explains why hospitals B, F and G in particular have higher numbers than other hospitals listed (see Table 4.3). Hospital N, while not a cancer centre, is allowed to diagnose and perform main surgery for breast cancer and is therefore included in the analysis. Hospitals I and J are both private hospitals; however, hospital I has a Breast Check clinic attached and this explains its higher breast cancer diagnosis figures in comparison to hospital J. Hospital J

has patients referred privately with breast lumps for biopsy and follow on treatment if required and was hence included in the study.

The total number of all breast cancers for 2012 was provided by the NCRI and was then filtered to include ER+ only patients. From this total only breast cancers where all treatments were provided by the diagnosing hospital were included. For example, if a breast biopsy was performed in hospital A and then the main surgery and/or chemotherapy was provided at another hospital, then the case was excluded from this study. If treatments were provided across an array of hospitals, then it would be more difficult to prove where missed hormone capture occurred than when all treatments were provided in the one hospital. Thus, out of 2133 ER+ cases eligible for the study, 1536 were included on the basis that all the breast cancer treatment took place in one hospital only (see Table 4.3). Radiotherapy location was not considered a factor as the hormone treatment would normally be prescribed by either the breast surgeon or the oncologist who prescribed the chemotherapy.

Table 4.3 Hormone capture per individual hospital in 2012. (Figures provided by the NCRI).

Hospital	Total number breast cancer cases	Total ER+	Total for inclusion	Hormones recorded	Hormones not recorded
A	245	189	145	109	36
B	497	414	257	220	37
C	247	214	199	173	26
D	245	213	130	104	26
E	177	138	129	119	10
F	436	333	215	178	37
G	353	291	208	154	54
I	262	233	157	66	91
J	85	58	50	6	50
N	68	50	40	30	10
Totals	**2615**	**2133**	**1536**	**1159**	**377**

For the analysis of the breast cancer cases it was observed that six out of the ten eligible hospitals had EPRs, four had access to a cancer database and two had access to an e-prescribing system. Two of the hospitals had a combination of EPR and cancer database access, two hospitals had combined EPR and e-prescribing access, and one had a cancer database and e-prescribing access.

Figure 4.9 provides an outline for all eligible hospitals and their percentage hormone treatment capture overall. Figure 4.9 then provides information for where biopsy and surgery were the main treatments prior to commencing hormone treatment; or where the patient had biopsy, surgery followed by chemotherapy. In both scenarios the patients may have had radiotherapy.

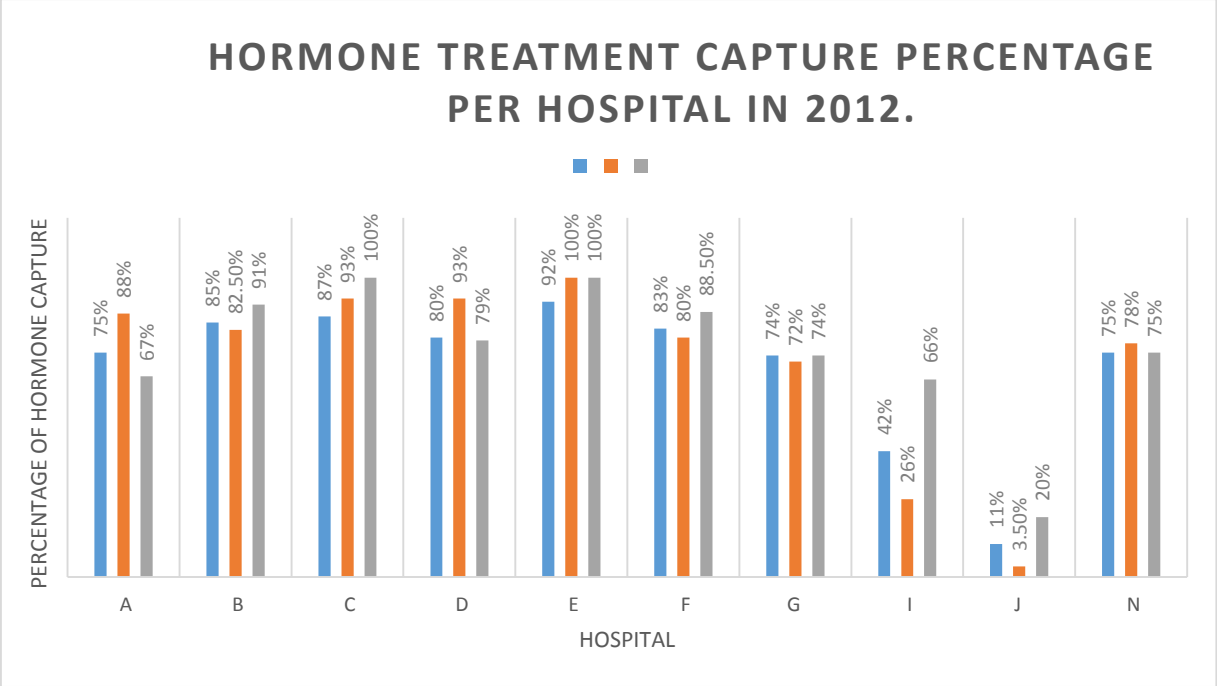

Figure 4.9 Hormone treatment capture percentage per hospital for 2012.

As can be seen from the percentages in Figure 4.9 private hospitals (I and J) in particular have a much lower rate of recording breast hormone treatments. In the case where chemotherapy is administered as an adjuvant, six out of ten hospitals showed an improvement in hormone capture, whereas three showed a decrease in capture and one hospital (E) maintained a 100% capture rate.

4.4.2 Overall hormone treatment capture comparison.

The ICT sources of interest in the context of assessing breast cancer hormone capture were EPRs, cancer databases and e-prescribing systems. To statistically assess whether there were any advantages in obtaining breast hormone treatment capture, Z-score testing was used to obtain p-values amongst the hospitals. Z-score testing was used because in testing for significance they allowed for the standardisation of results from the different hospitals (Study.com, no date). An online calculator was used to test for proportionality

(http://www.socscistatistics.com/tests/ztest/Default2.aspx). Z-score testing is appropriate when two different proportions are being measured against each other to test for significance capture (Social Science Statistics, no date). The significance level was set at 0.05 which is an acceptable level in research (Polit *et al.* 2001, Statistical Help, no date). Two tailed testing was used rather than one tailed as it was necessary to assess the hypothesis in both directions, as to whether it was accepted or rejected (Institute for digital research & design, no date).

In this section, hospitals A and N are compared with the other applicable hospitals to see if having no ICT source is significantly detrimental in obtaining breast hormone treatment information. Depending on the Z-score testing the hypothesis that hospitals with ICT systems are superior to paper records would either be accepted or rejected. Hospitals A and N have no EPR, cancer database or e-prescribing system. As observed in Table 4.2, hospitals B, C, E and G all have two ICT sources, the most common being an EPR. The results are outlined in Tables 4.4 and 4.5.

Table 4.4 Hospital A compared with other hospitals to assess for overall hormone treatment capture.

Hospital 1	Hospital 2	Z-score	p-value
A	B*	-2.6051	0.00906
A	C*	-2.8026	0.00512
A	D	-0.9565	0.33706
A	E*	-3.7747	0.00016
A	F	-1.7632	0.0784
A	G	0.2405	0.81034
A*	I	5.8276	0
A*	J	7.831	0

*Denotes the hospital with the p-value of statistical significance.

There was a statistical difference in the overall hormone capture comparing hospital A with hospitals B and C (EPR and database) and E (database and e-prescribing) with p-values of 0.00512 and 0.00016 respectively. Hospital A also shows a statistically significant p-value in breast hormone treatment capture compared to the two private hospitals, despite them

having some form of ICT. Three cancer centre hospitals showed a statistical advantage for overall hormone capture compared to Hospital A which has no ICT source of information.

Hospital N was then compared with the same group of hospitals to ascertain if there were any statistical differences in obtaining breast hormone treatments. The results of this analysis are provided in table 4.5.

Table 4.5 Hospital N compared with other hospitals to assess for for overall hormone treatment capture.

Hospital 1	Hospital 2	Z-score	p-value
N	B	-1.7092	0.08726
N	C	-1.9256	0.0536
N	D	-0.6769	0.4965
N	E*	-2.9505	0.00318
N	F	-1.1669	0.242
N	G	0.1273	0.89656
N*	I	3.7233	0.0002
N*	J	6.0622	0

*Denotes the hospital with the p-value of statistical significance.

Hospital N showed a poorer statistical difference compared with hospital E only, with a p-value of 0.00318. Despite hospitals B, C and G also having two databases each no statistical difference was shown overall in their breast hormone treatment capture against hospitals A and N. Hospitals I and J again showed a statistically lower recording of hormone treatment in comparison to hospital N, which has no ICT source. Thus, only one hospital (E) showed a statistical advantage of ICT capture of hormone treatment versus paper records.

Hospital E had shown the highest overall hormone treatment capture rate with 92%. Z-score testing was performed to compare hospital E with all the other hospitals to assess if its capture was statistically superior to the other hospitals. As can be seen in Table 4.6, hospital E showed a p-value of statistical significance compared with all hospitals, apart from hospitals B and C.

Table 4.6 Hospital E compared with other hospitals to assess for overall hormone treatment capture.

Hospital 1	Hospital 2	Z-score	p-value
E*	A	-3.7747	0.00016
E	B	1.8832	0.0601
E	C	1.5038	0.13362
E*	D	2.8489	0.00438
E*	F	2.4725	0.01352
E*	G	4.1426	0
E*	I	8.8404	0
E*	J	-10.0894	0
E*	N	-2.9505	0.00318

*Denotes p-value of statistical significance.

4.4.3 Comparisons for biopsy and surgery patients.

Figures for hormone treatment capture specifically for patients who had biopsy and surgery treatments and no chemotherapy, were tested for significant p-values using Z-score testing. The figures for this analysis are provided in Table 4.7. These figures provided by the NCRI for 2012 show a varying degree of capture by the eight hospitals involved in this study. As can be seen from this table, hospital E had a 100% capture rate. However, hospital J only managed to capture 1 out of 28 patients, representing the 3.5% capture rate seen in Figure 4.9. The other private hospital, I, also appears to have performed poorly, in capturing only 24 out of a possible 90 patients.

Table 4.7 Hormone treatment capture for biopsy & surgery only patients for all hospitals.

Hospital	Total number biopsy & surgery	Hormones recorded	No hormone recorded
A	53	46	7
B	132	109	23
C	79	74	5
D	45	39	6
E	67	67	0
F	141	113	28
G	99	72	27
I	90	24	66
J	28	1	27
N	18	14	4
Totals	**752**	**559**	**193**

Breakdown of figures for eligible hospitals in this study comparing cases that had biopsy, surgery and hormone treatment for 2012. Figures obtained from the NCRI.

In Table 4.8 hospital A was compared against the four hospitals with at least two sources of electronic data to test for significant p-values in obtaining information. Only hospital E showed a statistically superior breast hormone treatment capture rate with two ICT sources.

Table 4.8 Hospital A compared with hospitals with two ICT sources for hormone treatment capture in biopsy & surgery patients.

Hospital 1	Hospital 2	Z-score	p-value
A	B	0.7035	0.48392
A	C	-1.3476	0.17702
A	E*	-3.0655	0.00214
A	G	1.9831	0.0477

*Denotes the hospital with the p-value of statistical significance.

Table 4.9 shows the comparison between hospital A and hospitals with one ICT source. In this scenario hospital A, hospitals D and F showed no statistical advantage in having one ICT

source over paper records. In addition, hospital A showed a statistically significant p-value in obtaining information compared to the private hospitals, I and J.

Table 4.9 Hospital A compared with hospitals with one ICT source to assess for hormone treatment capture in biopsy & surgery patients.

Hospital 1	Hospital 2	Z-score	p-value
A	D	0.01383	0.98404
A	F	1.0734	0.28462
A*	I	6.9467	0
A*	J	7.2178	0

*Denotes the hospital with the p-value of statistical significance.

Table 4.10 shows the comparison between hospital N and hospitals with two ICT sources. As can be seen, hospitals C and E both show a statistical advantage in two ICT sources compared to none with Hospital A for capturing breast hormone treatments; hospitals B and G show no statistical advantage over paper records.

Table 4.10 Hospital N compared with hospitals with two ICT sources to assess for hormone treatment capture in biopsy & surgery patients.

Hospital 1	Hospital 2	Z-score	p-value
N	B	0.497	0.61708
N	C*	-2.0974	0.03572
N	E*	-3.9527	8E-05
N	G	0.4466	0.65272

*Denotes the hospital with the p-value of statistical significance.

Similarly, to hospital A, hospital N showed no statistical disadvantage in using paper records as a source of obtaining breast hormone treatments compared to hospitals with one ICT source. Likewise, hospital N showed statistical p-value results compared with hospitals I and J, the two private hospitals.

Table 4.11 Hospital N compared with hospitals with one ICT source for hormone treatment capture in biopsy & surgery patients.

Hospital 1	Hospital 2	Z-score	p-values
N	D	0.8722	0.3843
N	F	0.2356	0.81034
N*	I	4.1452	0
N*	J	5.2397	0

*Denotes p-value of statistical significance.

In comparing hospital E with all other hospitals, due to its overall high capture rate of 92%, it showed a significant p-value with all hospitals for all biopsy and surgery patients in capturing hormone treatment (Table 4.12).

Table 4.12 Hospital E compared with all hospitals to assess for hormone treatment capture in biopsy & surgery patients.

Hospital 1	Hospital 2	Z-score	p-value
E*	A	3.0655	0.00214
E*	B	3.6332	0.00028
E*	C	2.0954	0.03572
E*	D	3.0723	0.00214
E*	F	2.696	0.00694
E*	G	3.6153	0.0003
E*	I	9.207	0
E*	J	9.5005	0
E*	N	2.0944	0.03572

*Denotes p-value of statistical significance.

4.4.4 Comparisons for biopsy, surgery and chemotherapy patients.

For this comparison of breast hormone treatment capture chemotherapy was included alongside biopsy and surgery. In Table 4.13 it can be seen that two hospitals, C and E, both had a 100% capture rate. Additionally, as was seen previously in Figure 4.10 five hospitals (B, C, F, I and J) showed their highest percentage capture rates in both overall capture rates and in comparison to patients who only had biopsy and surgery. Hospitals G and N showed a

higher capture rate than compared to biopsy and surgery, and equalled their overall capture rates.

Table 4.13 Figures for hospitals showing hormone treatment capture for patients with biopsy, surgery & chemotherapy.

Hospital	Total number biopsy, surgery & chemotherapy	Hormones recorded	No hormone recorded
A	46	31	15
B	73	67	6
C	45	45	0
D	43	34	9
E	67	67	0
F	35	31	4
G	62	46	16
I	59	39	20
J	25	5	20
N	8	6	2
Totals	463	371	92

Breakdown of numbers for eligible hospitals showing cases that had biopsy, surgery and adjuvant chemotherapy. Figures obtained from the NCRI.

As with the comparisons for overall and biopsy and surgery capture, hospitals A and N were again compared with all other hospitals to assess whether there is an advantage or not in ICT systems for capturing breast hormone treatments. Table 4.14 outlines hospital A in comparison to the hospitals with two ICT sources. Here hospitals B, C and E all show that statistically two ICT sources are superior to relying on paper records for hormone capture.

Table 4.14 Hospital A compared with hospitals with two ICT sources to assess for hormone treatment capture in biopsy, surgery & chemotherapy.

Hospital 1	Hospital 2	Z-score	p-value
A	B*	-5.0192	0
A	C*	-4.1917	0
A	E*	-5.0192	0
A	G	-0.7727	0.4413

*Denotes the hospital with the p-value of statistical significance.

In Table 4.15, hospital A for the first time is shown to be at a disadvantage statistically in obtaining breast hormone capture in comparison to a hospital with one ICT source, as hospital F has a p-value of 0.02574. In addition, for the first time a private hospital does not have a statistically poorer breast hormone capture rate compared to another hospital.

Table 4.15 Hospital A compared with hospitals with one ICT source to assess for hormone treatment capture in biopsy. Surgery & chemotherapy patients.

Hospital 1	Hospital 2	Z-score	p-value
A	D	-1.2406	0.21498
A	F*	-2.2285	0.02574
A	I	0.1391	0.88866
A*	J	3.815	0.00014

*Denotes the hospital with the p-value of statistical significance.

In Table 4.16 hospital N again shows a statistical disadvantage in comparison with hospitals C and E.

Table 4.16 Hospital N compared with hospitals with two ICT sources to assess for hormone treatment capture in biopsy, surgery & chemotherapy patients.

Hospital 1	Hospital 2	Z-score	p-values
N	B	-1.5103	0.13104
N	C*	-3.4192	0.00062
N	E*	-4.1484	0
N	G	0.0491	0.96012

*Denotes the hospital with the p-value of statistical significance.

Similar to Table 4.15, in relation to the private hospitals, again for chemotherapy patients, hospital I is shown to fare favourably with hospital N. Again, hospital I, the other private hospital is statistically poorer in capture, despite having an ICT source. None of the other hospitals have any statistical benefit in having one source of ICT in comparison to hospital N.

Table 4.17 Hospital N compared with hospitals with one ICT source to assess for hormone treatment capture in biopsy, surgery & chemotherapy patients.

Hospital 1	Hospital 2	Z-score	p-values
N	D	-0.257	0.7986
N	F	-0.9995	0.31732
N	I	0.52029	0.61708
N*	J	2.8723	0.0041

*Denotes p-value of statistical significance.

Finally, Table 4.18 demonstrates again that hospital E is statistically superior to all other hospitals in breast hormone data capture for patients with biopsy, surgery and chemotherapy.

Table 4.18 Hospital E compared with all other hospitals to assess for hormone treatment capture in biopsy, surgery & chemotherapy patients.

Hospital 1	Hospital 2	Z-score	p-values
E*	A	5.0192	0
E*	B	2.3986	0.0164
E*	C	NaN	0
E*	D	3.908	0.0001
E*	F	2.8231	0.0048
E*	G	4.4428	0
E*	I	5.1959	0
E*	J	8.2758	0
E*	N	4.1484	0

*Denotes the hospital with the p-value of statistical significance.

Overall it appears that hospitals with two ICT sources of information may be of more benefit compared to hospitals with no ICT source or with one ICT source. This is especially the case, when it comes to obtaining breast hormone information for patients who have a biopsy followed by surgery and chemotherapy. Hospital E which has an EPR and e-prescribing system fared best against all other hospitals in terms of capture. However, hospital G also has an EPR and e-prescribing system and never showed any advantage over another

hospital. Possible reasons for this are discussed in Chapter 5. Furthermore, statistically private hospitals performed poorly in their hormone treatment capture. This was despite having at least one ICT source each, in comparison with hospitals with no ICT source. Potential explanations for this will be addressed in Chapter 5.

4.5 Rectal cancer analysis.

In this section hospitals are compared for their radiological capture of clinical rectal cancer staging using the TNM system. The ICT sources of main interest are NIMIS and PACS. Cancer database access is also observed to see if it is an advantage in obtaining clinical staging. As in section 4.4 the study intends to show that the hypothesis stating that hospitals with ICT sources capture more complete and accurate data.

Outlined in Table 4.19 are the figures obtained directly from the NCRI for rectal cancer diagnosis in 2012. Similarly, to the breast cancer cases, raw data was provided in an anonymised Excel spreadsheet and the data was sorted and filtered to obtain figures for the relevant hospitals in this study. Out of a possible 318 cases for the fifteen hospitals, 275 cases had clinical TNM staging entered for the case, and 43 did not. All the rectal cancer had to be histologically verified by biopsy in 2012. Hospital H was not included as per section 4.2.7 as it does not diagnose or surgically treat any cancers. This represented a total of 13.5% of rectal cancers that had no TNM clinical staging applied. For the purpose of this study cases were deemed to have no staging if all the clinical TNM staging was missing. If partial staging was present it was not included in this analysis, as it was possible that the radiology report did not provide sufficient information for the TRO to clinically stage the cancer accurately. In this case, as per NCRI policy the TRO would have to clinically code a section “X”.

Table 4.19 Outline of rectal cancer cases per hospital for 2012. (Figures provided by the NCRI).

Hospital	Total Rectal cancer cases	Total with TNM staging	Total with no TNM staging
A	29	24	5
B	18	18	0
C	34	33	1

Hospital	Total Rectal cancer cases	Total with TNM staging	Total with no TNM staging
D	25	21	4
E	16	16	0
F	25	13	12
G	18	12	6
H	N/A		
I	29	25	4
J	13	10	3
K	17	17	0
L	11	10	1
M	21	19	2
N	29	27	2
O	11	11	0
P	22	19	3
Totals	**318**	**275**	**43**

Figure 4.10 provides a percentage breakdown of numbers per hospital where clinical TNM staging was applied to rectal cancers. As can be seen the range varies from 52% to four hospitals obtaining 100% of TNM clinical staging. As highlighted, 13.5% of the clinical staging was completely missing from the above cases applicable to this study. This was the case in registrations even when patients had their main surgery performed on their cancer, frequently in the diagnosing hospital. The pathological staging was almost always complete. In other cases, the patient had neoadjuvant treatment performed prior to their surgery and clinical TNM staging was absent. As stated in Chapter 1, clinical staging would be necessary to decide whether a patient proceeded to surgery or to have neo-adjuvant treatment.

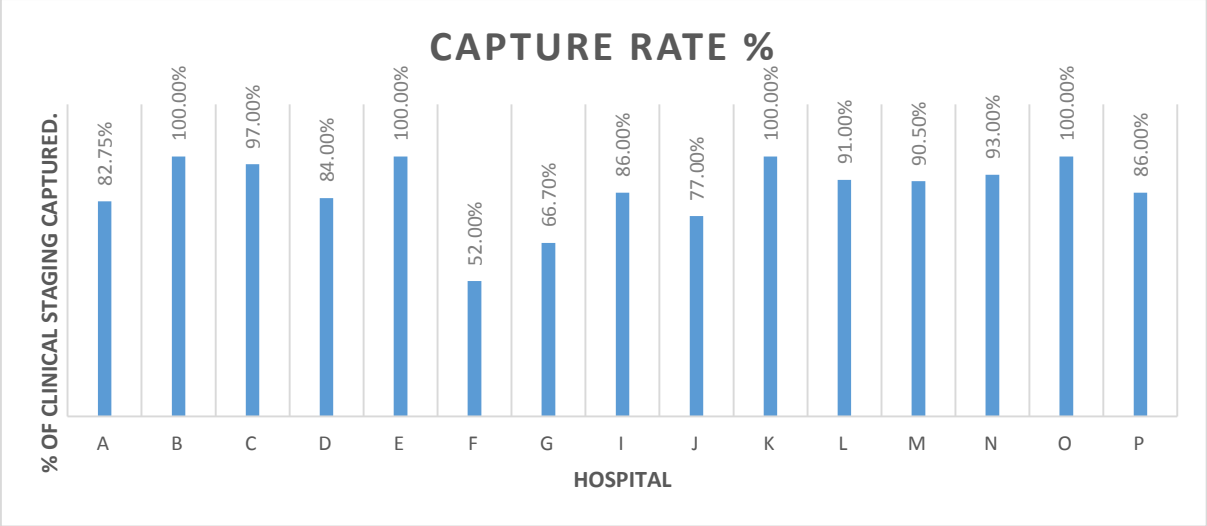

Figure 4.10 Percentage capture per hospital for rectal cancer clinical staging in 2012.

As can be seen from Table 4.2, only hospital F had no access to an electronic radiology system such as NIMIS, PACS or an equivalent radiology system. Hospital K was the only hospital to have access to both NIMIS and PACS, and a hospital cancer database. Table 4.2 displays that eleven hospitals had access to one ICT form of radiology, with three hospitals (A, C and K) having access to both NIMIS and PACS. Hospitals E, H, L, M, O and P have access to NIMIS only. Figure 4.11 provides a graph representation of percentage capture per hospital depending on the radiology system used. From this chart it appears that if a TRO is to have access to one radiology system alone, that NIMIS provides better clinical staging information than PACS. This is assessed for statistical significance, in addition to evaluating if having access to both NIMIS and PACS is better than one system alone (section 4.5.2.).

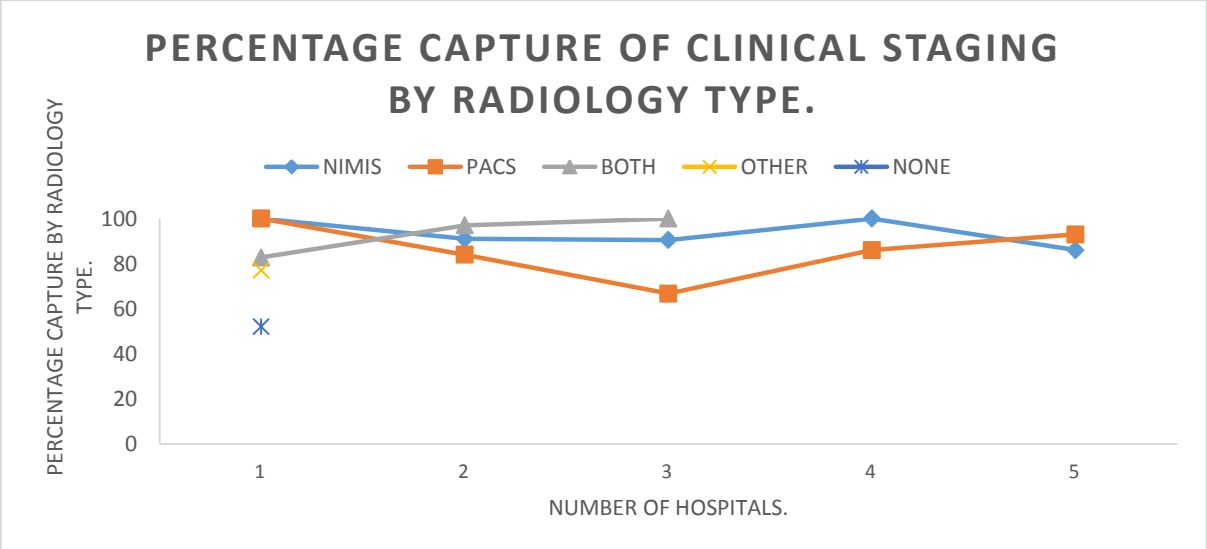

Figure 4.11 Percentage of clinical rectal cancer staging by radiology type for hospitals in 2012.

4.5.1 Comparing hospitals for statistical significance.

Using the same online proportionality website, Z-score two tailed testing was conducted, based on the figures from Table 4.19.. In comparing hospital F with all other hospitals, all hospitals showed statistical significance compared to hospital F, apart from hospitals G (cancer centre) and J (private hospital) (Table 4.20). Hospital F missed 48% of its clinical staging, which was the biggest missing percentage of all the hospitals. Hospitals B, E, K and O all had 100% capture. Of these hospitals B has PACS only and no NIMIS, while the other three have NIMIS.

Table 4.20 Hospital F compared with all other hospitals for clinical rectal cancer staging.

Hospital 1	Hospital 2	Z-score	p-value
F	A*	-2.4267	0.0151
F	B*	-3.4619	0.00054
F	C*	-4.1263	0
F	D*	-2.4254	0.0151
F	E*	-3.2951	0.00096
F	G	-0.9618	0.33706
F	I*	-2.7449	0.00614
F	J	-1.4912	0.13622
F	K*	-3.3799	0.00072
F	L*	-2.2389	0.0251
F	M*	-2.825	0.0048
F	N*	-3.4368	0.00058
F	O*	-2.8142	0.00496
F	P*	-2.5218	0.01174

*Denotes the hospital with the p-value of statistical significance.

While the overall numbers in each hospital for rectal cancer are not on the scale of breast cancer numbers it would appear that having at least one ICT source of radiology is beneficial in obtaining clinical staging for rectal cancers.

As was witnessed with the breast cancer data, hospital G as a cancer centre appears to perform poorly compared with other hospitals in terms of rectal cancer clinical staging with a 66.7% capture rate. Thus it was compared with all other hospitals to see if this was a fair reflection or not, given that it has an EPR and PACS. However, the questionnaire did state that the TRO received 75%+ of their information from paper records. The results are outlined below in Table 4.21. As can be seen, seven hospitals showed significant levels of clinical staging capture compared with hospital G. Three of these hospitals were cancer centres and the other four were other hospitals.

Table 4.21 Hospital G compared with all other hospitals for clinical rectal cancer staging.

Hospital 1	Hospital 2	Z-score	p- value
G	A	-1.1326	0.25848
G	B*	-2.6312	0.00854
G	C*	-2.908	0.00362
G	D	-1.1989	0.23014
G	E*	-2.4944	0.01278
G	F	0.843	0.4009
G	I	-1.4365	0.14986
G	J	-0.5706	0.56868
G	K*	-2.5639	0.01046
G	L	-1.408	0.15854
G	M*	-1.7059	0.08726
G	N*	-2.1791	0.02926
G	O*	-2.1068	0.03486
G	P	-1.3574	0.17384

*Denotes the hospital with the p-value of statistical significance.

As hospital K had both NIMIS, PACS and a cancer database it was also compared to all other hospitals (Table 4.22). As can be seen, it had a statistical advantage over all other hospitals only on three occasions.

Table 4.22 Hospital K compared with all other hospitals for clinical rectal cancer staging.

Hospital 1	Hospital 2	Z- score	p-value
K	A	1.8.134	0.0703
K	B	NaN	0
K	C	0.7141	0.4777
K	D	1.7339	0.8364
K	E	NaN	0
K*	F	3.3799	0.00072
K*	G	2.6152	0.0088
K	I	1.6025	0.1096
K*	J	2.0878	0.03662
K	L	1.266	0.20408
K	M	1.3073	0.1902
K	N	1.1071	0.267
K	O	NaN	0
K	P	1.5847	0.1141

*Denotes the hospital with the p-value of statistical significance.

4.5.2. Comparing NIMIS and PACS for statistical significance.

A comparison was made to see if there was any statistical significance between having NIMIS, PACS or both. As can be seen from the graph in Figure 4.11 it would appear that NIMIS has a higher clinical staging capture rate than PACS. The combined total of rectal cancer patients in NIMIS only hospitals was 81, and 75 of those patients had clinical staging on their NCRI registration. The combined total of rectal cancer patients in PACS only hospitals was 119, with 103 of those patients having clinical staging on their registration. No statistical difference was found in comparing the two different radiology systems.

Table 4.23 Comparison of NIMIS with PACS for statistical difference in clinical staging capture.

NIMIS	PACS	Z-score	p-value
75 out of 81 patients	103 out of 119 patients	1.3397	0.18024

4.5.3 Comparing two radiology systems with one system.

A comparison was then made to see if there was a benefit in having both NIMIS and PACS against PACS alone. For hospitals with both NIMIS and PACS ,74 out of 80 patients had clinical staging applied to their rectal cancer on the NCRI database. For the PACS only hospital the same figures of 103 out of 119 were applied. As can be seen from Table 4.24, no statistical difference was observed.

Table 4.24 Comparison of NIMIS & PACS with PACS only for clinical staging capture.

NIMIS & PACS	PACS	Z-score	p-value
74 out of 80 patients	103 out of 199 patients	1.5925	0.11184

NIMIS and PACs were then compared against hospitals with only NIMIS. As can be seen from Table 4.25, again no statistical difference was identified.

Table 4.25 Comparison of NIMIS & PACS with NIMIS only for clinical staging capture.

NIMIS & PACS	NIMIS	Z-score	p-value
74 out of 80 patients	75 out of 82 patients	1.3114	0.1902

4.6 Conclusion.

In terms of response levels for the TRO questionnaire achieving a very high response rate was invaluable in being able to assess the level of ICT availability to TROs in their base hospitals. It allowed for analysis of the base hospitals with varying degrees of ICT access to ascertain whether ICT is of value or not in breast hormone treatment capture and clinical rectal staging. The results were somewhat mixed, perhaps more so for the breast hormone capture than the rectal cancer clinical staging. While hospitals with two ICT sources appear to achieve in the main a higher percentage of hormone treatment capture, the results were not as significantly overwhelming as may have been expected. It appears that patients who received chemotherapy as an adjuvant had a statistically higher rate of their hormone treatment being captured by a TRO than those who did not have chemotherapy. Potential reasons for this are addressed in Chapter 5. Other possible reasons as to why the hospitals with no ICT did not perform quite as badly as expected to are also explored. Private hospital

capture was also observed to be a major topic in the hormone capture. Possible reasons behind this is also addressed in Chapter 5.

For the assessment of rectal cancer clinical staging capture, it appears that overall any ICT radiological source is better than none, and having two or more sources is not statistically superior to having only one source. It appears that having access to a hospital cancer database was not of major advantage.

Limitations and flaws in the questionnaire that were observed in the analysis are also addressed in Chapter 6 and discussed as to how they could have been addressed differently in hindsight.

Chapter 5: Findings & discussions.

5.0 Introduction.

In this chapter some of the findings from sections 4.4 and 4.5 are explored and discussed. The research question as to whether ICT in TRO base hospitals enhances capture of information needs to be decided. Firstly, breast hormone treatment capture is addressed, followed by the clinical rectal cancer staging.

5.1 Breast hormone treatment capture results.

In this section, the results comparing hospitals with no ICT with hospitals with ICT is discussed, along with the results of private hospitals and the results indicating that recording patients with chemotherapy treatment seems to enhance hormone treatment capture.

As observed in sections 4.4, hospitals A and N had no ICT sources, specifically EPRs, hospital cancer databases and e-prescribing systems for capturing breast hormone treatment. Surprisingly their capture overall was not hugely inferior; in fact, it appears comparable in certain circumstances especially with hospitals with only one ICT source. It was only in the comparison of biopsy, surgery and chemotherapy patients that a hospital with one ICT source (F) showed a statistical advantage over hospitals A and N (Table 4.15). At no other stage did a hospital with one ICT source show a statistical advantage over hospitals A and N. In fact, when compared with the two private hospitals, A and N compared statistically better in almost all scenarios. For hospitals with two ICT sources only hospital E was statistically superior with both hospitals, in all scenarios.

Looking at hospital A first, in relation to overall capture of breast hormone treatment capture, hospitals B, C and E all showed statistical significance over hospital A. When the cases were categorised to biopsy and surgery, hospital A was only statistically inferior to hospital E. When chemotherapy became a factor then hospitals B, C and E were statistically superior in their hormone treatment capture compared with hospital A. However, overall the main finding to take from this situation is that in the case of hospital A, three out of the four cancer centres with two ICT sources showed a statistically superior capture of treatments.

In relation to hospital N, again hospital E was superior compared to hospital N in overall hormone capture in all scenarios. In biopsy and surgery, and biopsy, surgery and chemotherapy, only hospital C and hospital E were superior in hormone capture compared with hospital N. Chemotherapy did not appear in this instance to improve statistically for hospitals B and G in the capture of hormone treatments (Table 4.16). As was observed in section 2.2, it appears from US studies that chemotherapy administration makes no difference in hormone treatment capture. However, statistically in the ROI it appears that the NCRI overall captures more hormone treatments if chemotherapy has been administered to a patient, than to non- chemotherapy patients.

5.1.1 TRO WORKLOAD.

The issue of why hospital N may not be at a disadvantage in using paper records needs to be examined. The average number of all breast cancer cases for the hospitals, regardless of ER status was 262. Hospital N had a total number of 68, which suggests a much smaller breast cancer workload for the TRO. This smaller number may allow a quicker timeframe for the TRO to access paper records and thus obtain the information, before paper records go off site. So, while other hospitals also have to rely on a substantial portion of their information coming from paper records, they may not have the same timeframe to access the information in the paper records, thus perhaps not achieving the same hormone treatment capture.

As to why hospital A is not overtly at a major disadvantage for overall capture or for biopsy and surgery patients, this cannot be explained so easily. Perhaps it is a question that that particular hospital has a longer timeframe before paper records are removed off site compared to other hospitals, but no explanation can be given with certainty. The 0-24% of paper record usage by hospital A is discussed in section 5.1.5. again. However, as already mentioned, overall hospital A's capture was statistically poorer than hospitals with two ICT capture sources.

5.1.2 PRIVATE HOSPITAL CAPTURE.

From Tables 4.4, 4.5, 4.9, 4.11, 4.15 and 4.17 it can be seen that the two private hospitals, I and J, despite both having one ICT source, had significantly poorer capture rates than hospitals hospitals with no ICT. The only scenarios when hospital I was not statistically

poorer was in the cases were chemotherapy was a factor (Tables 4.15 and 4.17). As seen in Table 4.2 hospital I has access to a hospital cancer database, while hospital J has access to an EPR. There is a difference in the percentage of paper records in use also, with hospital I having 0-24% paper records compared with hospital J's 50-75%.

Both hospitals show a substantial rise in obtaining breast hormone treatment in patients who have chemotherapy. Hospital I's capture rate rises from 26% for biopsy and surgery patients to 66% for chemotherapy patients (Figure 4.9). For biopsy and surgery patients, hospital I identified 24 out of 90 patients as having received hormone treatment compared to 39 out of 59 for biopsy, surgery and chemotherapy patients (Tables 4.7 and 4.13). Using the same online calculator as in sections 4.4 and 4.5, a Z-score analysis of these results provided a z-score of -4.7654 and a p-value of 0. This shows that chemotherapy patients had a statistically higher rate of their hormone treatment being captured by the TRO in hospital I.

Similarly, hospital J showed an increase in hormone capture from 3.5% for biopsy and surgery patients to 20% for biopsy, surgery and chemotherapy patients (Figure 4.9). Tables 4.7 and 4.13 show numbers increased from 1 out of 28 having captured hormone treatment, to 5 out of 25 patients for biopsy, surgery and chemotherapy. Z-score calculator analysis provided a Z-score of -1.8844 and a p-value of 0.0601. This p-value was not statistically significant, however it does show that again the patients who receive chemotherapy are somewhat more likely to have their hormone treatment captured.

Reasons for this may be varied. Firstly, patients who have biopsy and surgery only, might see the oncologist in the oncologist's private rooms. Unfortunately, the TROs have no access to these private consultation notes. As per the oncologist's reply in the questionnaire, section 4.3.3, a copy of the hormone prescription is not sent to the patient's paper record or recorded on any ICT system. Accordingly, it is virtually impossible for the TRO to obtain this information. Chemotherapy patients' hormone capture might be due to them leaving a larger "footprint" in the hospital. The TRO possibly has some way of identifying chemotherapy patients and then knows to attempt and locate the breast hormone information on either the ICT system or in the paper record. In addition, when the TRO goes to complete the registration for a breast patient, it may be flagged on their ICT system (EPR

or database) that the patient is receiving chemotherapy, and thus the TRO may know to attempt and obtain the possible hormone treatment. Historically a patient's private consultation with an oncology consultant is not recorded on a hospital system or in the paper record. Therefore, once the TRO has recorded all other information for the registration there is nowhere else to attempt to locate the information.

Unfortunately, as stated in section 4.2.6, neither of these two hospitals record medical card details. Therefore, even if the NCRI was able to obtain a regular linkage with the PCRS (section 2.9) it seems unlikely that these patients would be identified as being on breast hormone treatment.

Overall, at present the researcher does not foresee any resolution to this problem in recording information from consultants' private rooms. Until such time that this information can be gathered, there is going to be an absence in complete hormone figures for the NCRI for breast cancer patients.

5.1.3 EPR AND CANCER DATABASES.

Overall it appears that hospitals with two ICT sources were at an advantage in obtaining breast hormone treatment capture. This advantage was not only over hospitals with no ICT sources, but over hospitals with one ICT source. In conducting the analysis in Chapter 4 it did appear that perhaps hospitals in which only one ICT source was available, a cancer database was more beneficial than an EPR. For example, in the case of the two private hospitals, for hormone treatment capture with the biopsy and surgery patients, hospital I had a significant capture over hospital J (Figure 4.9, Tables 4.7 and Table 4.13). Hospital I has 24 out of 90 patients recorded as receiving hormone treatment compared with 1 out of 28 patients for hospital J. Using the Z-score analysis, this provided a Z-score of 2.6119 and a significant p-value of 0.00906. This is a statistically significant result.

When considering the same two hospitals in relation to biopsy, surgery and chemotherapy patients, hospital I again had a significant capture rate over hospital J (Figure 4.9, Tables 4.7 and 4.13). The Z-score calculated was 3.8681 with a p-value of 0.0001. Therefore, it may be concluded that in the scenario of private hospitals in this study, a hospital cancer database is of more value than an EPR.

For the four hospitals with two sources of ICT, hospital E which had the best capture in all scenarios, has access to a cancer database and e-prescribing system. Hospital G also has an e-prescribing system but access to an EPR and not a cancer database. In all comparisons with hospitals A and N, hospital G had no statistical advantage over them. Consequently, it may be reasonable to assume that hospitals E and I having access to a cancer database is more advantageous than an EPR. Hospital E as stated had the best overall capture in all scenarios but has no access to an EPR. In addition, hospitals B and C have access to both an EPR and cancer database. Both these hospitals showed a statistically significant result in overall breast hormone treatment capture compared with hospital A. A potential reason for these same two hospitals not providing as many statistically superior results to hospital N has already been discussed in section 5.1.2.

5.1.4 Percentage of paper records capture.

Of all the hospitals involved in the assessment of breast hormone treatment only hospital G replied 75%+ for information from paper records, as per the questionnaire (Table 4.2).

Despite Hospital E having the best capture rate of all hospitals for hormone treatment, the questionnaire response showed it gathers 50-74% of its information from paper records. Hospital B, while showing overall significance compared with hospital A, rarely showed any statistical benefit over hospital N. Hospital B states it receives 0-24% of its information from paper records. Yet hospital C also has the same two ICT sources as hospital B and also has 0-24% paper records. Hospital C performed statistically better against hospitals A and N. Hospital G, despite having two sources of ICT has already been shown to have no real benefit in having access to an EPR and e-prescribing system. Therefore, is it possible that two sources of ICT work best with some paper record intervention. Question 1 in the TRO questionnaire (Appendix E) asked for overall paper record use by the TRO. It is possible that breast cancer cases require less paper record use. Therefore, the researcher is of the opinion that it cannot be conclusively stated that overall the percentage of information taken from paper records directly influences breast hormone capture. Reasons for this also include, as previously stated, the apparent discrepancy in the response from hospital A in that it receives 0-24% of its information only from paper records, despite not having any ICT source of information. Thus, perhaps the answers to question 1 need to be taken with caution. The

types of EPR and cancer databases may differ between hospitals and have different functionality.

5.1.5 Other aspects of hormone treatment.

The NCRI has no method of recording on the database if a patient refused to commence hormone treatment. In the researcher's experience this is a very rare occurrence, yet one that does happen from time to time. There is a comment box where a TRO can make a note that the patient refused treatment but there is no actual way for the NCRI to pull figures for this. In addition, on occasion it has been noted that despite being eligible for hormone treatment, the oncologist decides due to hormone treatment side-effects, not to commence hormone treatment. Again, there is no consistent and accurate method of recording this on the NCRI database. Therefore, it is possible that in a certain percentage of cases hormone treatment was not there to be recorded, but this cannot be quantified at present.

5.2 Rectal cancer clinical staging.

In this section, the findings from Chapter 4 in relation to clinical rectal cancer staging capture are discussed. As stated in section 4.5, only one hospital had no access to an ICT source of radiology. In addition, this hospital had no cancer database. This hospital, F, only obtained 52% of clinical staging for rectal cancer patients in 2012. All other hospitals had at least one source of radiology ICT such as NIMIS. The four hospitals that achieved a 100% capture rate were a hospital with PACS, two hospitals with NIMIS and one hospital with both NIMIS and PACS. Therefore, it appears that in three out of four cases of TROs achieving 100% capture, NIMIS was one of the radiology types, either on its own or in combination.

5.2.1 Radiology combined with a cancer database.

For clarification, it is NCRI policy that if TNM staging is documented on radiology or a hospital database for example, that the TRO not take this TNM staging and input it directly to the NCRI database. This is due to the fact that the TNM clinical staging on a report on radiology or a hospital database might contain a typo or be inaccurate. The clinical staging on the report, however, will indicate the extent of the tumour and guide the TRO in their TNM staging. Hospital C also has access to a cancer database for clinical staging and with its access to NIMIS and PACS had a capture rate of 97%. As was seen in Table 4.22 hospital K

only had a statistically higher capture rate than hospitals F, G and J. Therefore, it cannot be said with any certainty that in capturing rectal cancer clinical staging that having it available on a hospital cancer database is definitely of benefit, but it does appear to be somewhat helpful. In the case of the hospitals, E and I, both have a hospital cancer database but cannot get staging on it. However, hospital E had access to NIMIS and achieves 100% capture, whereas hospital I has access to PACS and achieves 86% capture.

5.2.2. Comparison of the radiology systems.

Tables 4.23, 4.24 and 4.25 showed that there was no statistical difference in the type of radiology system used by a TRO overall. Even with the combination of two systems there was no overall difference in the capture of rectal cancer clinical staging. However, the mean scores for clinical staging capture were 97% for having both systems, 86% for PACS and 91% for NIMIS.

5.2.3. Radiology system compared with no radiology system.

The real statistical differences in obtaining rectal cancer clinical staging were found when comparing a hospital with no radiology system with all other hospitals. As per Table 4.20 it can be clearly seen that hospital F having no radiology system for the TRO is detrimental to clinical capture. The hospital does have PACS but the TRO responded that they have no access to it.

5.2.4 Registration of clinical rectal cancer staging.

Similarly, to section 5.1.6 the NCRI has no method of recording on a registration when complete clinical staging is not available due to the fact it was not actually performed. These can be for the reasons as outlined in section 2.7. As this is not recorded it is impossible to say with certainty what the true overall percentage of missed staging is. If such a method were provided, then at least it would reflect more accurately for the NCRI in terms of clinical staging capture. Based on the figures of the NICR in Table 1.3 in achieving 92% clinical capture, the NCRI at 86.5% would seem to have room to improve. Providing figures on non-staged cancers may prove to be beneficial to overall figures going forward.

5.3 Conclusion.

In conclusion, this chapter has shown that overall having access to any ICT in a base hospital is of benefit to a TRO in trying to obtain breast cancer hormone treatment and clinical rectal

cancer staging. In the case of breast hormone treatment capture, it has been seen that overall two sources of ICT are required to show a statistically significant capture rate over a hospital with no ICT source. It appears that if one of the two ICT sources is a hospital cancer database, there may be a higher chance of obtaining hormone capture. Only in the case of biopsy, surgery and chemotherapy patients did a hospital with one ICT source show a statistical advantage over a hospital with no ICT. The analysis also showed that hormone capture in private hospitals is problematic. In addition, it also appears that in an Irish context patients who have chemotherapy along with biopsy and surgery are more likely to have their treatment captured, than those without chemotherapy. Unfortunately, only two hospitals had e-prescribing. It would have been interesting if other TROs had access to an e-prescribing system to see if this would enhance capture. Logically it would appear that it should, but as seen in the case of hospital G, it did not enhance capture.

From a clinical rectal cancer staging perspective it would seem that any radiological source is sufficient in assisting a TRO in staging a rectal cancer in their base hospital. In fact, hospital K, which can access both radiology systems and a hospital database for information, was not statistically superior to those with only one system to access. The analysis showed that no one ICT system was more effective in clinical staging. Certainly, not having access to a radiology ICT system is a huge disadvantage. It is encouraging however, that four out of fifteen hospitals achieved 100% clinical capture.

Chapter 6: Conclusions.

6.0 Introduction.

In this chapter recommendations, limitations, and flaws identified are discussed and a final conclusion provided.

6.1 Limitations and flaws.

As stated in section 3.0 a questionnaire was sent to TROs with a base hospital. Included in this was hospital H, as this is a base hospital. However, given the services the hospital provides it may have in hindsight been more prudent to send that TRO a questionnaire for one of their other hospitals. Hospital H as stated in section 4.5 provides no breast biopsies or surgical treatments, nor rectal biopsies or clinical staging, so its inclusion provided no insight in to either hormone capture or clinical staging.

While question 1 in the TRO questionnaire (Appendix E) asked for a quantitative value as to the percentage of paper records used by a TRO, perhaps the replies were from a subjective point of view. In addition, as previously stated it is possible that some cancers require more paper record usage that breast or rectal cancers. Perhaps the questionnaire could have asked in the circumstances of breast and rectal cancers specifically what percentage of paper records are required.

Question 6 (Table 4.2) of the TRO questionnaire had a reduced response rate to parts of the question. Even though at the very start of the questionnaire, TROs were asked to tick the appropriate box, it should have been specified that they answer every option.

Originally, the TRO questionnaire was intended to contain questions regarding TROs whose hospitals did have ICT solutions, but the TRO did not have access to them. The TROs would have been asked if they had ever sought access but had been denied by their hospital. This perhaps would have shown that data was missing due to external factors outside the TRO and NCRI's control. The questions were omitted as the researcher thought that including them would have been of no benefit to the study. In hindsight, it would probably have been wise to have included them.

Ideally comparisons between the NCRI and the UK registries would have been a direct comparison from the same year. The UK registries had completed their information for

2013, however, for the performance figures on the UKIACR website the NCRI only had completed figures for 2012. Overall this possibly did not matter too much as it was identified that information was not being captured and the research question was to assess if ICT influenced capture on the whole or not.

6.2 Recommendations.

Firstly, it is advocated that where possible all TROs should have the maximum available ICT sources in a hospital made available to them. This may not always be possible due to the resources a hospital has, but when possible it should be accessed. Access to TROs depends on the individual hospitals, so access is partly out of the control of the NCRI. Perhaps on a national level the NCRI could work to have ICT access granted for all its TROs in their various hospitals. Given that the NCRI under legislation has the permission to obtain patient information through TROs, perhaps legislation or other frameworks need to be addressed to ensure mandatory access to ICT sources in hospitals.

Secondly, while it may not hugely affect hormone treatment figures overall, perhaps the NCRI should consider an inbuilt database option for non-prescription of hormone treatment. This would address those who refuse treatment, or when treatment cannot be prescribed due to side-effects.

In addition, in a similar fashion it would be worth considering recording when clinical staging is not actually performed. This would at least justify the reason as to why clinical staging appears to be missing in a percentage of rectal cancer cases.

Any possible methods of pinpointing patients who receive hormone treatment from an oncologist in a private setting should be explored. How this can be achieved is unclear, however it is recommended as a substantial proportion of treatments appear to be missing. Not every patient attending a private hospital has a medical card, so even if the private hospitals did record this information there could still be a significant gap in capture.

6.3 Conclusion.

In conclusion, the researcher believes that the research question as to whether ICT enhances data collection and quality for the NCRI, from the point of view of hormone capture and clinical staging, has been answered. It has been proved overall that where the TRO has some

ICT in a base hospital, that capture generally is higher than those with no ICT source. There were some instances when this was not the case, and possible reasons for this have been outlined, such as TRO workload. On a national level the NCRI appears to be able to achieve overall a much higher rate of hormone capture than as seen in the fragmented US system. Where ICT radiology systems are available to TROs in base hospitals, clinical rectal cancer staging is high overall and in some cases 100% complete.

Given that breast hormone treatment has been shown to improve breast cancer patients' survival and mortality rates, it remains essential that the NCRI endeavours to obtain as much hormone treatment information as possible. Equally, for rectal cancer patients, especially those who receive neoadjuvant treatment, it is essential that all clinical staging, once performed, can be obtained so existing and newer neoadjuvant treatments can be assessed for effectiveness. In conclusion, it is firmly believed that where an ICT source is available it does enhance NCRI data collection and quality.

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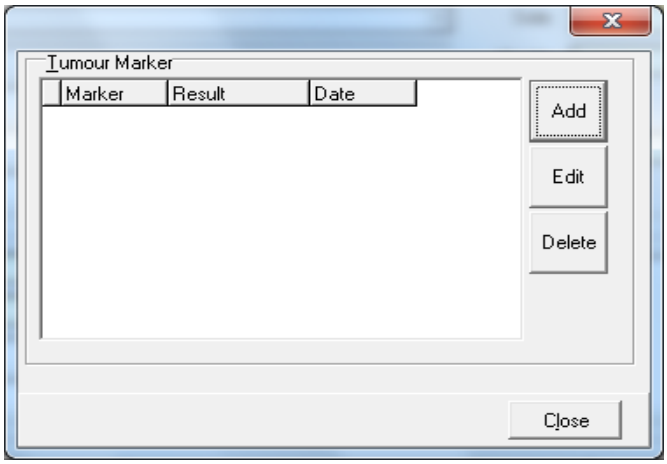
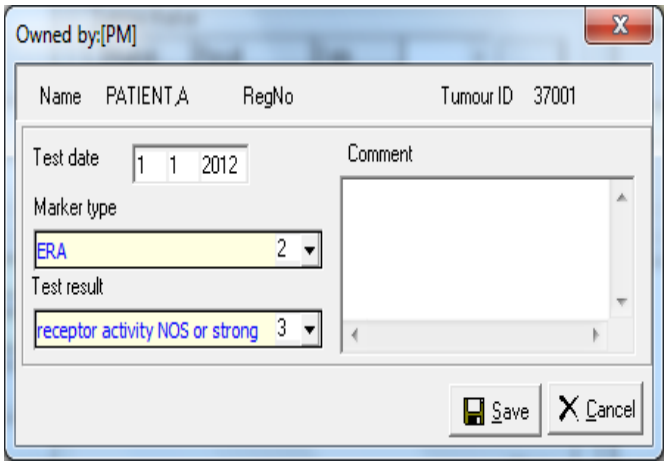
Appendices.

Appendix A. NCRI blank tumour marker box.



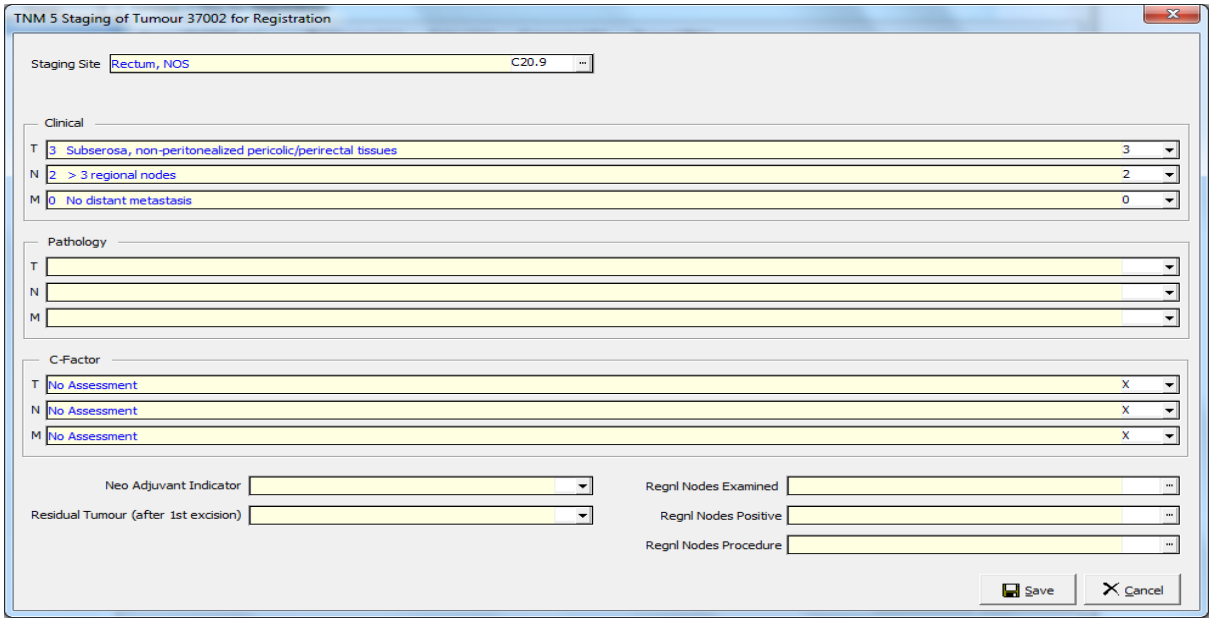
(Source NCRI).

Appendix B. NCRI tumour marker box with ER+ marker.



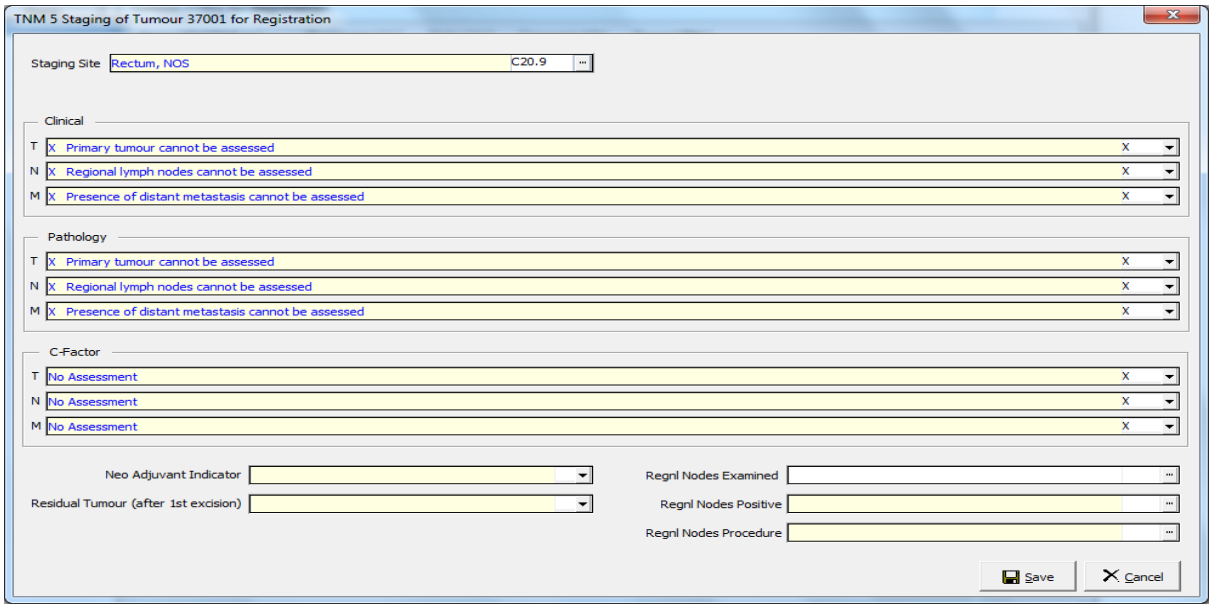
(Source NCRI).

Appendix C. NCRI TNM staging box with clinical rectal staging applied.



(Source NCRI).

Appendix D. NCRI TNM staging box with no staging applied.



(Source NCRI).

Appendix E. Questionnaire for TROs.

Please tick appropriate box to answer questions.

1. Approximately what percentage of information in your hospital comes from paper records?

☐0-24% ☐25-49% ☐50-74% ☐75% +

---

2. Does your hospital have an electronic patient record system?

☐YES ☐NO

If "YES" do you have access to the record system?

☐YES ☐NO

---

3. Does your hospital have their own cancer database?

☐YES ☐NO (If "NO" please go to question 6).

If "YES" do you have access to the database?

☐YES ☐NO (If "NO" please go to question 6).

4. Is information about hormone treatments for breast cancer patients, such as Tamoxifen and date first prescribed, present on the database?

☐YES ☐NO ☐DON'T KNOW

5. Is clinical rectal cancer staging information such as, radiology reports, usually available on the database?

☐YES ☐NO

Please go to page 2.

6. Radiology systems:
Does your hospital have a radiology information system such as (tick as appropriate)?

NIMIS: Access to system:
☐YES ☐NO…….☐YES ☐NO

PACS (Picture Archiving & Communication System):
☐YES ☐NO…….☐YES ☐NO

Other:
☐YES ☐NO……..☐YES ☐NO

Please provide name of other system: _____

---

7. If the information is not available electronically are you usually able to access the relevant staging information from the paper record?

☐YES ☐NO

---

8. Does your hospital have an e-prescribing system?

☐YES ☐NO

Do you have access to it?

☐YES ☐NO

---

9. Does your hospital record patient medical card numbers?

☐YES ☐NO

Any comments: _____

_____

The questionnaire is now complete. Thank you for completing it.

Appendix F. Questionnaire for oncology consultants.

Please answer the questions by ticking the appropriate box.

1. Do you know if there are any National Cancer Registry Tumour Registration Officers (TRO) in your hospital?

   ☐YES ☐NO

---

2. Do you know if they record the treatment of oestrogen positive breast cancer hormone treatments?

   ☐YES ☐NO

---

3. Have you ever been contacted for information on breast hormone treatments?

   ☐YES ☐NO

---

4. When reviewing a patient in your private rooms, do you document hormone treatment on (please tick as appropriate):

   Paper record:
   ☐YES ☐NO

   Electronic system:
   ☐YES ☐NO

   Both:
   ☐YES ☐NO

---

5. Do you send a copy of the prescription to the paper record in the hospital?

   ☐YES ☐NO

   If NO, is this something you would consider doing?

   ☐YES ☐NO

---

6. Would you be prepared, subject to appropriate security and data protection laws, to provide breast hormone treatment information to the TRO or NCRI directly via electronic means?
   ☐YES ☐NO

---

7. From date of incidence, where the patient is to receive adjuvant radiotherapy and breast hormone treatment, would the time frame for hormone commencement be within:

   ☐ 1-3 months ☐3-6 months ☐6-12 months ☐12 months+

8. From date of incidence, where the patient is to receive adjuvant chemotherapy, radiotherapy and hormone treatment, would the time frame for hormone treatment commencement be within:

   ☐ 1-3 months ☐ 3-6 months ☐ 6-12 months ☐ 12 months+

   Any comments: _____
   _____
   _____
   _____

Thank you for completing the questionnaire.

Appendix G. Questionnaire information sheet for TROs.

TRINITY COLLEGE DUBLIN

INFORMATION SHEET FOR TUMOUR REGISTRATION OFFICERS.

- I am Phil Gallagher, and I am a tumour registration officer (TRO) with the National Cancer Registry, Ireland (NCRI). I am carrying out this research as part of my dissertation to obtain a MSc in Health Informatics in Trinity College Dublin.

- I have previously worked as a staff nurse on two oncology wards.

- The motivation for this study is in relation to data collection and quality issues in obtaining rectal cancer staging and breast hormone treatment by the NCRI.

- You were selected for this study as you are a TRO in a hospital, that is involved in the management of rectal and/ or breast cancers. I identified you through your role as a TRO with the NCRI, and your contact details were available to me through the NCRI online staff list.

- As you know me, please do not let that influence the way you reply to the questionnaire.

- I intend to provide you with a questionnaire to assess what Information and Communication Technology (ICT) systems you have available to you in your hospital. This is the first study to be undertaken to assess how TROs access their information.

- As some TROs are based at more than one cancer centre, it is possible that you may receive more than one questionnaire. Where two TROs are based in the same location, one questionnaire will be provided to the full time TRO.

- You have the right to withdraw and to omit individual response without penalty.

- The questionnaire should take no more than 30 minutes.

- There will be no risks/ benefits to you the participant as neither you nor your hospital

will be identifiable.

- I can be contacted at any stage for clarification of questions. Following the study, you may contact me to see a copy of the results.

- Your anonymity of participant and third-party information in analysis, publication and presentation of resulting data and findings will be preserved.

- Any inadvertent discovery of illicit activities will be reported to the relevant authorities.

- Clarification for verifying direct quotations and their contextual appropriateness will be sought if necessary.

- Thank you for taking the time to participate.

- My contact details are: gallagp9@tcd.ie 087 9063794.

Appendix H. Questionnaire information sheet for consultants.

TRINITY COLLEGE DUBLIN

INFORMATION SHEET FOR ONCOLOGY CONSULTANTS.

- I am Phil Gallagher, and I am a tumour registration officer (TRO) with the National Cancer Registry, Ireland (NCRI). I am carrying out this research as part of my dissertation to obtain a MSc in Health Informatics in Trinity College Dublin.

- I have previously worked as a staff nurse on two oncology wards.

- The motivation for this study is in relation to data collection and quality issues in obtaining rectal tumour staging and breast hormone treatment by TROs for the the NCRI.

- You were selected for this study as you are a consultant in a private hospital, that is involved in the management of breast tumours.

- As you may know me, please do not let that influence the way you reply to the questionnaire.

- I intend to provide you with a questionnaire to assess how breast hormone treatments are prescribed for patients and how they may differ from being prescribed in a public hospital.

- I wish to assess what Information and Communication Technology (ICT) systems you have available to you in your hospital, that may assist in the capture of breast hormone treatments by the NCRI. This is the first study to be undertaken to assess how TROs access their information.

- You have the right to withdraw and to omit individual response without penalty.

- The questionnaire should take no more than 15 minutes.

- There will be no risks/ benefits to you the participant as neither you nor your hospital will be identifiable.

- I can be contacted at any stage for clarification of questions. Following the study, you may contact me to see a copy of the results.

- Your anonymity of participant and third-party information in analysis, publication and presentation of resulting data and findings will be preserved.

- Any inadvertent discovery of illicit activities will be reported to the relevant authorities.

- Clarification for verifying direct quotations and their contextual appropriateness will be sought if necessary.

- Thank you for taking the time to participate.

- My contact details are: gallagp9@tcd.ie and 087 9063794.

Appendix I. Questionnaire consent for TROs.

TRINITY COLLEGE DUBLIN

INFORMED CONSENT FORM FOR TUMOUR REGISTRATION OFFICERS.

LEAD RESEARCHER: PHILOMENA GALLAGHER.

Background of research: I wish to examine data collection and quality issues in relation to cancer staging and treatment with the national cancer registry, Ireland (NCRI). The areas in particular that I wish to focus on are:

- The staging of rectal cancers
- The treatment of breast cancer with hormones.

It has been identified that staging for rectal cancers is not as complete as other cancer registries and I wish to find out what reasons there may be for this, and what information and communication technology (ICT) facilities there are for tumour registration officers (TROs). Where ICT is available is there more complete staging of rectal cancers, or is there no difference between ICT and paper records.

Recording of hormone treatments for breast cancer is not as complete as some registries in the UK and I wish to see if there is an advantage for TROs with more ICT facilities over those with paper records. If ICT access were improved in some hospitals would it enhance a TROs management pickup?
It is hoped that this study will identify that where available ICT does help with the capture of staging and treatments for the cancers mentioned above, and that this in turn can help to obtain access to relevant ICT systems in hospitals.

Procedures of this study: in this study, I will provide all TROs eligible for the study with a questionnaire to complete and return to me for analysis. For the purpose of this study no TRO or hospital will be identified in any form in the dissertation.

PUBLICATION: The information obtained will be published as part of my dissertation for a MSc Health Informatics in Trinity College Dublin. In addition, the results may be published in scientific journals or at scientific meetings. If so then individual results will be aggregated anonymously and research reported on aggregate results.

DECLARATION:

- I am 18 years or older and am competent to provide consent.
- I have read, or had read to me, a document providing information about this research and this consent form. I have had the opportunity to ask questions and all my questions have been answered to my satisfaction and understand the description of the research that is being provided to me.
- I agree that my data is used for scientific purposes and I have no objection that my data is published in scientific publications in a way that does not reveal my identity.

- I understand that if I make illicit activities known, these will be reported to appropriate authorities.
- I freely and voluntarily agree to be part of this research study, though without prejudice to my legal and ethical rights.
- I understand that I may refuse to answer any question and that I may withdraw at any time without penalty.
- I understand that my participation is fully anonymous and that no personal details about me will be recorded.
- I have received a copy of this agreement.

PARTICIPANT'S NAME:

SIGNATURE:

Date:

Statement of investigator's responsibility: I have explained the nature and purpose of this research study, the procedures to be undertaken and any risks that may be involved. I have offered to answer any questions and fully answered such questions. I believe that the participant understands my explanation and has freely given informed consent.

RESEARCHERS CONTACT DETAILS: GALLAGP9@TCD.IE 087 9063794

INVESTIGATOR'S SIGNATURE:

Date:

Appendix J. Consent sheet for oncology consultants.

TRINITY COLLEGE DUBLIN

INFORMATION SHEET FOR ONCOLOGY CONSULTANTS.

- I am Phil Gallagher, and I am a tumour registration officer (TRO) with the National Cancer Registry, Ireland (NCRI). I am carrying out this research as part of my dissertation to obtain a MSc in Health Informatics in Trinity College Dublin.

- I have previously worked as a staff nurse on two oncology wards.

- The motivation for this study is in relation to data collection and quality issues in obtaining rectal cancer staging and breast hormone treatment by TROs for the NCRI.

- You were selected for this study as you are a consultant in a private hospital that is involved in the management of breast cancers. You were identified as your hospital is one that I am liaise with through my job as a TRO, and your contact details were available on your hospital's website.

- As you may know me, please do not let that influence the way you reply to the questionnaire.

- I intend to provide you with a questionnaire to assess how breast hormone treatments are prescribed for patients and how they may differ from being prescribed in a public hospital.

- I wish to assess what Information and Communication Technology (ICT) systems you have available to you in your hospital, that may assist in the capture of breast hormone treatments by the NCRI. This is the first study to be undertaken to assess how TROs access their information.

- You have the right to withdraw and to omit individual response without penalty.

- The questionnaire should take no more than 20 minutes.

- There will be no risks/ benefits to you the participant as neither you nor your hospital will be identifiable.

- I can be contacted at any stage for clarification of questions. Following the study, you may contact me to see a copy of the results.

- Your anonymity of participant and third-party information in analysis, publication and presentation of resulting data and findings will be preserved.

- Any inadvertent discovery of illicit activities will be reported to the relevant authorities.

- Clarification for verifying direct quotations and their contextual appropriateness will be sought if necessary.

- Thank you for taking the time to participate.

- My contact details are: gallagp9@tcd.ie and 087 9063794.